# Allogeneic Stem Cell Transplantation

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### Welcome!

Welcome to Memorial Sloan-Kettering Cancer Center and the Adult Bone Marrow Transplant (ABMT) Service. This booklet was written to help you learn more about an allogeneic stem cell transplant, why you will need special care, and what you and your family can do. Please read it carefully. The doctors and nurses will review this with you and answer your questions. All of your questions are important.

# The Allogeneic Transplant Team

Our Allogeneic Transplant Service works as a team. The doctor that you see in the clinic may not be the one who will take care of you while you are in the hospital. Transplant doctors rotate on and off the inpatient unit. They are often on for two weeks, but not always. During that time, they manage all of the allogeneic transplant patients 24 hours a day. At the end of the two weeks, another attending doctor takes over. While you are an inpatient, the inpatient attending will be in charge of your day-to-day care. However, if any major problems come up while you are in the hospital, the inpatient attending doctor will discuss them with your primary transplant doctor. Once a week, all of the attendings meet to discuss your progress.

Many people will be involved in your care on the inpatient unit. You will have a primary team of nurses. A nurse practitioner and a clinical nurse specialist may see you from time to time. You will see many doctors. Some will have finished their medical resident training and are doing specialized training in hematology. These are called fellows. You will also see doctors who are still in training. These are called interns and residents. The attending doctor supervises them. A case manager will help to plan for anything you need when you go home. A social worker will help you with everything from feelings of sadness or loneliness to financial concerns. Nursing assistants will help you bathe and dress. They will also check your weight and vital signs each day.

Once you are discharged from the hospital after your transplant, you will be followed closely in our outpatient department by your primary attending, nurse practitioners, and ambulatory care nurses. They will monitor your recovery and administer medications, transfusions or fluids as you need them. At first, you will be seen frequently. Over time the visits will be spaced farther apart. Your doctors and nurses are available by phone to help with any questions or problems that occur between visits.

Ongoing follow up care after transplant is very important to make sure you achieve the best possible health. At some point after your transplant, you may be referred to our survivorship nurse practitioner. The aim of this nurse practitioner is to assist your general recovery and manage the effects of cancer treatment and transplant. The survivorship nurse practitioner is part of the transplant team and works closely with your attending and nurses to ensure your recovery.

### What Stem Cells Are

Blood-forming stem cells are cells that will grow or mature into different blood cells. They make all of your red blood cells, white blood cells, and platelets. Red blood cells carry oxygen throughout your body, white blood cells fight infection, and platelets help your blood to clot and control bleeding. Stem cells are also known as pluripotent or progenitor cells.

### Where Stem Cells Are Found

The cells used in stem cell transplants come from one of three sources:

- bone marrow
- your blood stream these are called peripheral blood stem cells
- the umbilical cord and placenta of newborn babies

#### **Bone Marrow Stem Cells**

Bone marrow is a spongy substance found inside larger bones. It resembles blood and is a rich source of stem cells. Stem cells can be taken from a donor's bone marrow. This is called a bone marrow harvest. It is done with general anesthesia in the operating room. The donor usually goes home the same day of the procedure.

# Peripheral Blood Stem Cells

Stem cells may also be found in the bloodstream. Before stem cells are collected from the bloodstream, the donor is given a growth factor to stimulate the bone marrow to make more stem cells. Usually, this drug is G-CSF. Other names for G-CSF are Neupogen® and filgrastim. The donor takes this medicine by injection. Some of the new stem cells will leave the bone marrow and move into the bloodstream. The nurse will teach the donor how to give the injection and tell him or her how often it must be done. After a scheduled number of doses of G-CSF, the donor has the stem cell collection.

The stem cell collection process is similar to donating blood. The donor has an intravenous (IV) line in each arm. Blood is removed from one arm, put through a blood filtering machine, which removes the stem cells, and then returned to the donor through the IV in the other arm. This is called pheresis.

### **Umbilical Cord Blood Stem Cells**

Umbilical cord blood is another source of stem cells. At birth, the cord blood is collected from the umbilical cord and placenta and taken to a cord blood bank. It is tissue-typed, processed, and stored frozen until needed for a transplant.

Cord blood from one infant provides a limited amount of blood stem cells. It is sometimes not enough for adult or larger patients, who may need more stem cells. In this situation, we will frequently use two cord blood units from two different babies. Both cord blood collections will be infused on transplant day.

# What An Allogeneic Stem Cell Transplant Is

An allogeneic stem cell transplant replaces your stem cells with new, healthy ones from a donor. "Allogeneic" means that the stem cells come from a donor other than yourself. You will have chemotherapy, radiation therapy, or both, to kill your cancer and suppress your immune system. This will damage your normal bone marrow. You will then receive the transplant of the donor stem cells. They are given into a vein, usually through your central venous intravenous (IV) catheter. They may be infused from a bag, like a blood transfusion, or from a large syringe attached to your catheter. This will take place in your hospital room.

Stem cell transplants are used to treat many diseases. These include leukemia, lymphoma, myeloma, aplastic anemia, other tumors, and immune deficiencies that are present from birth. The care you need before a transplant depends on your disease. Your doctor will tell you why a transplant is used, why you cannot use your own stem cells, and what treatment plan is best for you.

### The Donor

Not everyone can be your donor. The right donor is someone whose tissue type most closely matches yours. Tissue typing is based on your human leukocyte antigens (HLA). These are found on the surface of your white blood cells. They are important for immunity because they help your body recognize your own cells so they do not attack them. If foreign cells enter your body, your white blood cells will see them as foreign and will mount an attack to get rid of them.

A person with a close HLA match is most often a brother or sister. Family members will have a blood test to see what tissue type they have. The person whose tissue type is most like yours is chosen to be the donor. If no one is a close match, your doctor will help you start a search with a donor registry, cord blood banks, or both. The donor gives stem cells for the transplant and may also be needed to donate platelets after the transplant.

People who are not related can have a close match by chance. If you do not have a family member with a matching tissue type, we look for an unrelated adult volunteer donor or cord blood units. The National Marrow Donor Program® has millions of people registered who have had their blood typed for this purpose. However, the search for a donor may take weeks or even months to complete. Sometimes cord blood will be used if the transplant is urgent, as this is available more quickly. If you will need stem cells from someone who is not related to you, your doctor will give you a more detailed explanation.

# Myeloablative Transplant versus Non-Myeloablative Transplant

There are two approaches to treatment before an allogeneic transplant. One is called myeloablative. In this approach you receive high doses of chemotherapy with or without radiation. These treatments aim to kill your cancer but also kill (myeloablate) all stem cells in your bone marrow. The donor stem cells will then replace the ones killed by the treatment. This form of treatment is very intense and it may not be suitable for all patients.

Another approach involves a less intense treatment. It uses lower doses of chemotherapy with or without low doses of radiation. It also includes drugs that suppress your immune system. This type of transplant is called a non-myeloablative. It aims to keep your immune system and stem cells in check rather than destroying them. This will still allow the donor stem cells to "engraft" in most cases.

Your doctor will consider many factors when choosing which type of transplant is best for you. These include your disease, other treatments you have received, and your general health status. Your doctor will discuss these factors in detail with you.

### **Before Your Treatment Starts**

#### Diet

There is no special diet preparation before a stem cell transplant. You do not have to take a lot of vitamins. If you are under- or overweight, try to get to your normal weight before you come into the hospital. Your doctor can guide you with this effort.

# **Preserving Fertility**

Many cancer treatments can affect fertility, the ability to have children. You may be infertile from the treatment you have already received. If not, you will most likely be infertile after your transplant treatment. This will have no effect on your ability to have sex. However, some patients report that they have a decrease in their sex drive.

There may be options for you to preserve your fertility before your transplant treatment begins. This must be done before you come into the hospital.

Men can preserve their fertility by sperm banking. This involves collecting, freezing, and storing sperm. Generally, three collections are needed. There are sperm banks throughout the U.S. where you can do this. To get more information about sperm banking, ask your doctor or nurse for our book "Fertility and Cancer Treatment: Information for Men," and for our list of local sperm banks.

There are also options for women to preserve their fertility. This involves taking hormones for about 10-14 days and collecting eggs. The eggs may be fertilized with sperm to create embryos. The embryos or eggs are then frozen and stored. Because of the extra time this takes, you must discuss this with your doctor. To learn more about egg or embryo freezing, ask your doctor or nurse for our book "Fertility and Cancer Treatment: Information for Women," and for our list of local fertility specialists.

For more information, you can go to the MSKCC Fertility and Parenthood web page at http://www.mskcc.org/mskcc/html/92039.cfm. You can also ask your doctor for a referral to the fertility specialist for the Survivorship program.

#### **Radiation Simulation**

If you are going to have radiation as part of your treatment, you will meet with the radiation therapy team before you are admitted. You may also have a CT scan or PET scan or both to plan your treatment. You will also have a planning session called simulation. During this session, several x-rays are taken along with measurements of your chest. These are used to make lead shields. Your lungs are very sensitive to radiation and the shields will be used to protect them during some of the treatments.

### **Dental Exam**

You will have a dental exam. Decayed teeth and gums can cause serious infections in patients being treated with high doses of chemo or radiation. If possible, we would like you to see a dentist at MSKCC. We must be sure that anything that could cause an infection in your mouth is fixed before your transplant. For example, you may need cavities filled, loose fillings replaced, or gum disease treated. Mouth care will be very important for the entire time you are in the hospital. (See **Oral Hygiene**, p. 14.)

### A Central Venous IV Catheter

A central venous IV catheter is an intravenous (IV) line that can stay in place for many months. Hickman<sup>®</sup>, Broviac<sup>®</sup>, and Hohn<sup>®</sup> catheters are examples of central venous IV catheters. You will need to have one of these because fluids, medicines, blood products, and stem cells are given through it. Most, but not all, blood samples can also be drawn from the catheter. Central venous catheters are usually placed the day of admission or several days before. Some are removed before discharge. However, some patients go home with the catheter in place. If you go home with it, your nurse will teach you or a family member, or both, how to care for it.

#### **Tests**

Before your treatment starts, you will have some tests done. These will tell us how your body is functioning and what the status of your cancer or bone marrow disease is. We will use the test results to watch for any changes during treatment. You will have some, or possibly all of the following tests.

- Chest x-ray
- Blood tests
- Urine test
- A pregnancy test, if appropriate
- Electrocardiogram (EKG), echocardiogram (ECHO), MUGA scan These tests tell us how your heart is functioning.
- Pulmonary function tests (PFTs) These are breathing tests to see how well your lungs work.
- CT or PET scan These scans may be used to see where tumors are in your body, to plan your radiation treatments, or both.
- Bone marrow biopsy This gives us a sample of your bone marrow. It will tell us about the state of your blood cells. It is done before your transplant, three to four weeks after your transplant, and then every three months for the first year. The timing may vary.
- Lumbar puncture (spinal tap) This lets us check for abnormal cells in your spinal fluid. A small needle is inserted through your back and a small amount of fluid is withdrawn. A lumbar puncture is only done for certain types of leukemia.

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

# **Admission Day**

# If You Have Already Had Your Central Venous Catheter Placed

Go to the Admission Center. It is just inside the 1275 York Avenue entrance. After the admission process, an escort will take you to the transplant unit. When you get there, you will meet members of your transplant team. The team has doctors, nurses, nurse practitioners, and clinical nurse specialists. Other members of the team that you will meet are the social worker, the psychiatrists, dietitian, chaplain, nursing assistants, and unit secretaries.

# If You Are Having the Central Venous Catheter Placed on Admission Day

Go to the PreSurgical Center or the Pediatric Day Hospital. You will be taken to the transplant unit from the recovery room after the catheter is placed.

# **Radiation Therapy (RT)**

Radiation therapy may be part of the preparation for your transplant. Small doses of radiation will be delivered to your whole body (TBI) or to the parts of your body that have lymph nodes (TLI). These doses are given two to three times a day over several days. They are called "fractionated" treatments because the whole dose is divided up. Each treatment takes from 10 to 30 minutes. If you are male and have leukemia or lymphoma, you may have a boost to the testes. This is done to destroy cancer cells that might be hidden there.

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

Having a radiation treatment is something like having an x-ray. The treatment does not hurt. Do **not** wear any jewelry during treatments. The metal may change the radiation dose to that area. You and your clothes do not become radioactive during or after the treatments. You cannot pass the radiation to other people.

Stop using any creams, lotions, deodorants, or oils (even Chapstick® or lip balm) two days before you start radiation treatments. Do not use them at all while you are getting radiation. You may use Aquaphor® at night.

Family members may go with you when you have your treatments. They must wait outside the treatment room, but they can see you on a video screen and talk to you. The nurse will tell you more about how the radiation treatment is given and what you will do during the treatments.

# Chemotherapy

Chemotherapy alone or combined with radiation therapy does two things:

- It helps treat your disease.
- It prevents your body from rejecting the transplanted stem cells.

Some people receive several chemotherapy drugs instead of chemotherapy and radiation. Your doctor will tell you which drugs you will get. Your nurse will give you a fact card on each drug. The fact card describes the short- and long-term side effects. It also tells you when to call your doctor.

# **Side Effects of Radiation and Chemotherapy**

There are side effects to radiation therapy and chemotherapy. Possible side effects of this therapy include the following:

# **Bone Marrow Suppression**

Radiation and chemotherapy treatments kill both leukemia cells and normal cells in your bone marrow. Because

the bone marrow produces your blood cells, your blood counts will be very low until the donor's marrow begins to work. While your blood counts are low, special measures will be used to protect you from infection and bleeding. (See **Infection**, p. 11 and **Bleeding**, p. 11)

# **Gastrointestinal Tract Symptoms**

Radiation and chemotherapy can make you feel sick when they are given. They also destroy normal cells lining the mouth and intestines. This may cause nausea, vomiting, and diarrhea during and after the treatments. You may also develop painful sores in your mouth and mild to severe pain in your throat and lower esophagus. These are temporary. You will be given anti-nausea and pain medicine when you need it. As your white blood cell count starts to increase, your mouth and throat will start to heal.

#### Hair Loss

You will temporarily lose hair on your body and scalp. This begins about seven to ten days after you have finished your treatment. Until your hair grows back, it may help to wear a scarf, wig, or hat. Your hair will start to grow back beginning about three months after the transplant. The color or texture of your hair may change when it grows back. The "Look Good…Feel Better" program has specially trained people to teach you how to use make-up to cover sallow skin and hide the loss of eyebrows. The program is given twice a week. Call (212) 639-5665 to sign up.

# Sexual Function/Sterility

Sterility is a side effect of both TBI and high-dose chemotherapy. It is highly likely that you will not be able to have children after your transplant. You will be able to have sexual relations. If you have any problems, tell your doctor. There are many causes and most problems can be helped. Your feelings about a cancer diagnosis and treatment can make you less interested in sex. Fatigue is also common after transplant. You may not have the energy to have sex when you are tired. Sometimes, physical problems interfere. Ask about Memorial's Sexual Medicine Program. Your doctor can tell you more about it.

### Women

Your periods may become irregular or stop. While you are in the hospital, you will take medicine to stop your periods. This is because your platelet count will be low and you will bleed very easily. The medicine will be stopped when your platelets are high enough so that it is safe for you to have periods again. You may need hormone replacement after treatment.

Some women want to bank a fertilized ovum. However, most women having transplants cannot do this. You can discuss this with your doctor.

#### Men

After treatment, your sperm count may be much lower or you may not produce any sperm. If you want to bank your sperm, you must do it before radiation and chemotherapy. Ask your doctor, nurse, or social worker for details before your admission. Some male patients develop erectile dysfunction (impotence). If this happens, please tell your doctor. Our Sexual Medicine Program has doctors who specialize in this area. They can help you select a treatment that best meets your needs.

### Difficulty with Concentration

Some people tell us they have trouble concentrating after transplant. They complain that their attention span is short. Math may become difficult. This often improves over time, but some patients will not return to the same level they had before transplant. Children may require testing every year or so after the transplant. The results will help your doctor make suggestions to the child's school.

# **Specific Side Effects from Radiation**

Radiation has some additional side effects.

#### **Skin Reaction**

You may have a skin reaction that looks like a sunburn. Your skin will later become slightly darker than normal. This side effect can be greater if you are also getting certain chemotherapy drugs. It usually fades over several months. Your skin may also be dry after treatment. Use alcohol-free lotions, creams, or oils to help relieve the dryness. The radiation therapy nurses will tell you what to use during radiation. After your transplant, stay out of the sun as much as possible. When you are outside, protect your skin with a sunblock of SPF 30 or higher at all times.

# **Salivary Gland Symptoms**

The salivary glands are found on both sides of your neck and under your chin. These glands may become tender and swollen and you may have less saliva. The swelling will go down a few days after your radiation therapy. The decrease in saliva is usually temporary. In most cases, it improves after several months.

### **Cataracts**

Some patients develop cataracts months to years after TBI. These are often mild and do not need to be removed. If you develop dense cataracts, they can be removed surgically.

### **Decreased Childhood Growth**

TBI may reduce a child's growth. Ask the pediatric transplant doctor to discuss this side effect with you.

# **Secondary Cancers**

Some patients who have a transplant get another cancer later. Some of the treatments for your cancer can cause other types of cancer. Your risk depends on your age, your health, your family history of cancer, and other treatments you have had. Your transplant doctor can tell you more about your risk for getting a second cancer. Ask what regular screening checks you should have in the future.

### Hypothyroidism

Some patients have low thyroid function after TBI. You will have blood tests to check for this side effect. If you develop it, you will be given thyroid hormone. You will need to take this pill once a day for the rest of your life.

# **Specific Side Effects from Chemotherapy**

# Hemorrhagic Cystitis

Certain drugs, such as Cytoxan<sup>®</sup>, can irritate the lining of the bladder. This may cause blood in the urine and painful urination. To help prevent this, you will receive large amounts of IV fluids, which will make you urinate often. Try to urinate at least every one to two hours on the days you receive Cytoxan. Your urine will be measured and checked for blood.

# **Coping With Side Effects**

We cannot predict which of the above side effects you will have or how severe they will be. You may feel some of them just a little, or you may feel some of them a lot. Because of your treatments, there may be days when you feel very sick. We can give you medicine to try to help you feel better, so it is important to tell us how you are feeling. We need to work together to assure that you receive the best possible care. The Integrative Medicine staff is available to teach you relaxation methods. Some patients have found this helpful. You can call 646-888-0800 to get more information.

### While You Are In Isolation

You will be placed on protective **isolation precautions** to protect you from germs when you are admitted. A card telling visitors about the type of isolation will be placed on the door to your room. The door to your room must remain closed. All staff and visitors who go into your room must wear a mask, wash their hands, and put on gloves. The mask and gloves will be in a box near the sink. You may have visitors every day while you are in the hospital, but they can not have a cold or **any** signs of illness. No more than two people should visit at any one time. Your visitors should not eat in your room or use your bathroom. These precautions are in place until you go home from the hospital.

It is not necessary to sterilize things before they are brought into your room. You may bring photos, frames, or a pillow from home to make the room more comfortable. However, space may be limited and you do not want to have clutter in the room. The nurse can help you choose things best suited for isolation.

You may wear a hospital gown, but if you prefer, you may wear your own nightclothes or casual clothing. You may also have stuffed animals that can be laundered and new packaged games. You may **not** have fresh flowers or plants.

# Weight and Vital Signs

You will be weighed each day around 6 am. Most weight changes during transplant hospitalization are due to fluid retention or loss. The inpatient team needs this information by the time they make rounds to make important treatment decisions. Your blood pressure, temperature, pulse, respirations, and blood oxygen level will be checked every four hours around-the-clock. No one likes being awakened at night, but these measurements are important. Any change may require a treatment change.

# **Exercise and Activity**

Once isolation begins, you may not leave your room unless you are going for treatment. However, activity is very important. Get out of bed at least twice a day and try to walk in your room every day to maintain your muscle tone and strength. Sit up in a chair as often as possible. You can also ask for a restorator bike that has pedals that can connect to a chair. It can help you keep active.

Your nurse will assist you with your daily activities if you need help. You may bring a laptop, books, games, etc. to help occupy your time. If you are a student, bring your books and assignments to keep up with schoolwork. In pediatrics, the hospital teacher will come to your room and help you with your lessons.

# **Eating Well**

Because chemotherapy and radiation therapy damage the lining of your stomach, you may not feel well enough to eat anything during part of your hospital stay. To maintain your weight, you may need to receive nutrition through your IV. This is called TPN (total parenteral nutrition). The TPN mixture provides all the nutrients your body needs. Your progress will be checked daily, and changes will be made in the TPN mixture as needed.

Even if you are receiving TPN, you may try to eat and drink if you feel like it. Do not force yourself if you do not feel well. The dietitian and nurse will talk more with you about which foods are best when you are having your treatments.

After your gastrointestinal tract heals, the dietitian can plan a diet for you. It will be based on the Low Microbial Diet booklet that will be given to you before your discharge. Your dietitian will review it with you. Well-cooked, easily digestible foods make eating easier. Do not share your food or drinks with anyone. You should not have any take-out foods while you are in the hospital unless they are cooked at home. Ask your nurse, dietitian, or doctor about what kinds of foods your family and friends can bring you.

#### **Mouth Care**

Mouth care is an important part of your care in which you can also participate. It must be done at least four times a day or more often if mouth sores appear. You can continue to brush your teeth with an **ultrasoft** toothbrush. Your nurse will show you how to do mouth care to help keep your mouth clean.

# **Stem Cell Transplant Day**

Once the chemotherapy and radiation treatments are completed, you will receive the donor's stem cells. They are given through your central venous catheter. They will travel through your bloodstream and into your bone marrow spaces where they begin to grow, making healthy blood cells in your body. The nurse will check your temperature, blood pressure, pulse, and oxygen level while you are receiving the stem cells. You will be in the hospital until your new stem cells start to work reasonably well. This takes about four to six weeks from the day of transplant.

# **Unmodified Stem Cell Transplant**

Allogeneic stem cell transplants can be unmodified or T cell depleted. In unmodified transplants, the stem cells are given without first taking out the T cells. Red cells or plasma may need to be removed before you receive the stem cells if you and your donor are not the same blood type.

The stem cells are given to you through your IV over several hours. This process is like a blood transfusion. The stem cells are in a bag. They look like a bag of blood. There are rarely any side effects from the infusion of unmodified stem cell transplants.

# T Cell Depleted Stem Cell Transplant

A T cell depleted stem cell transplant is one in which certain lymphocytes, known as T cells, are removed. Your doctor may decide that this type of transplant is best for you. If you are to have a T cell depleted stem cell transplant, you will receive it once the process of removing the T cells is complete. This takes 12-24 hours, so you may receive the transplant either late at night or sometimes, the day after your donor has given the stem cells. The doctor will inject them directly into your central venous IV catheter from a large syringe. There are rarely any side effects.

### **Unrelated Stem Cell Transplant**

After the stem cells are obtained from an unrelated donor, they are immediately brought to Memorial Sloan-Kettering. Here they are processed for an unmodified or a T cell depleted transplant.

### **Umbilical Cord Blood Transplant**

The cord blood cells are stored frozen. On transplant day, they will be thawed in the laboratory and brought to your room in a bag. They will be given through your catheter. Sometimes patients can feel sick to their stomach or get high blood pressure during the cord blood infusion.

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

# **Possible Complications After Your Transplant**

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

### Infection

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

Fever is one important sign of infection. If you develop a fever, a chest x-ray will be obtained and urine and blood cultures will be done. You will be given IV antibiotics to help your body fight the infection. Nearly all patients develop fever during the first two weeks after transplantation. Most infections are treated successfully with antibiotics.

Your doctors and nurses will try to prevent you from getting infections. You will likely be given drugs that are used to treat infections. For the transplant patient, they are also used to prevent them. You will receive anti-viral medicines. These help prevent any viral infection you had in the past from coming back after the transplant. Viral infections can include:

- cold sores
- recurrence of genital herpes
- shingles
- cytomegalovirus
- other infections affecting the lungs or gut

Patients whose immune systems are not working well can get infections that would not occur in healthy people. These are called opportunistic infections. You may need medicine to help protect you from these infections. You will be at risk for them until your white blood cell count and immune system return to normal.

# Bleeding

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

#### Anemia

When your red blood cell count is low, you may experience weakness and fatigue. Your nurse will assist you with your daily activities if you need help. You will be given red blood cell transfusions as necessary. These and all other blood products will be irradiated to prevent harmful side effects.

### **Organ Complications**

You may have complications in your kidneys, liver, lungs, or heart. These are not common, but they can be serious. You are at higher risk if you already have a medical condition in any of these organs. This is why we carefully evaluate your organ functions before the transplant.

### Kidneys:

Your kidneys filter your blood and make urine to send waste products out of the body. The chemotherapy you get before transplant can affect how well your kidneys work. This is temporary, but waste products may remain in your blood until your kidney function improves. It also means that your kidneys will have more trouble getting rid of any drugs you are given. Your nurses will keep records of the amount of fluid you get. This includes what you drink and what you get through your IV line. They will also write down how much urine you make. This will help the doctors to know if you are beginning to have problems with your kidneys. You will also have blood tests every day to tell your doctors how your kidneys are working. If necessary, the doctors will adjust the doses of any drugs you are getting to decrease the risk to your kidneys.

#### Liver:

Your liver removes harmful substances from your body fluids, absorbs nutrients, and produces bile. Bile helps you digest your food. Side effects on your liver include problems with digestion. A more serious problem is that the liver may no longer remove breakdown products of your body and you will become jaundiced. In some patients, small blood vessels in the liver are injured. This is called veno-occlusive disease or VOD. These vessels can then become blocked so that blood cannot flow. This can cause the liver to become enlarged and may damage liver cells. Fluid may fill the abdomen. Liver problems of this sort usually begin within the first three weeks after transplant. With rare exception, all patients receive a drug that helps to prevent clot formation in the liver. This drug is called heparin, and it is given through your venous catheter. If you have side effects in your liver, your doctor will discuss the treatment options with you in more detail.

### Lungs:

Your lungs control breathing. Infections that affect the lungs may cause problems with breathing. Two problems that can occur during transplant are:

- an infection of the lungs causing pneumonia and
- damage of your lungs from chemo and radiation

This most commonly occurs in the first few weeks after transplant and can be serious. You will have regular chest x-rays while you are in the hospital. Your doctors and nurses will watch you closely for any sign of pneumonia. Tell them if you notice any change in your breathing. Do not ignore a cough or shortness of breath. Treatment depends on what causes the pneumonia.

Exercise your lungs. This may help to keep them clear. Your nurse will show you how to do deep breathing. You may also use an incentive spirometer. For this, you inhale deeply through a small tube to force a tiny ball to rise. You will receive different kinds of medicines to prevent or treat lung infections. Your nurse will review your routine with you.

#### Heart:

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

### Graft versus Host Disease (GVHD)

T cells are white blood cells whose function is to attack foreign cells. They are responsible for starting GVHD. GVHD is an immune response of the T cells in the donor transplant (graft) against the patient's (host's) body. There is a chance that GVHD will develop when the new stem cells begin to "engraft" or grow. A close match of HLA or tissue type between you and your donor helps lower the risk, but does not eliminate it. Other factors in GVHD are your age and the gender of your donor. Anyone whose donor is not an identical twin receives some type of prevention for GVHD. This prevention would include either removal of the T cells from the transplant that cause GVHD, or drugs 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 admission.

There are two kinds of GVHD, acute (early) and chronic (late and longer lasting). Acute and chronic GVHD were defined in the past in large part by their timing relative to the transplant. Now, acute GVHD no longer occurs only within the first three months. That is because we have many treatments for transplant and many sources do donors. It can develop later than that, but usually within the first year. Chronic GVHD usually occurs within the first year, but rarely before the first three months after transplant. It may not occur at all. The symptoms of either may be mild to severe. You may develop acute, but not chronic GVHD. You may develop chronic GVHD without

having had acute. You may develop both. You may or may not be free of symptoms between acute and chronic. Most patients develop neither or at least milder forms that do not require ongoing treatment beyond two years.

Symptoms of *acute GVHD* can affect the skin, gastrointestinal tract, liver, or all of these organs. A skin rash may appear on parts or all of your body. You may have a yellow skin color (jaundice) and an enlarged liver. You may also have nausea, vomiting, and mild to severe diarrhea.

*Chronic GVHD* often develops after the first 100 days, and usually within the first year after transplant. Symptoms may include skin rash or dry or thickened skin, loss of appetite and weight, diarrhea, dry mouth and sores in the mouth, dry eyes, hair loss, inflammation of the liver, loss of energy, or increased risk for infections.

GVHD can be mild or severe. It may slow the growth of the bone marrow. This means it will take longer for your immune system to function. It may affect one or more parts of the body. If you have it, your doctor will discuss the treatment plan with you. Mild cases of GVHD may be helpful for patients with active leukemia and lymphoma going into transplant. Return of these diseases is lower in transplant survivors who had mild GVHD. That is because the donor T cells may attack any remaining cancer cells. Doctors are doing more research to learn how to maximize this anti-cancer effect. If your disease was in complete remission before transplant, you do not need the beneficial effect of GVHD.

# **Graft Failure or Rejection**

The transplanted cells sometimes do not grow up successfully inside your body. Graft rejection means your immune system rejects the new stem cells. The treatments you get before the transplant are aimed at preventing graft rejection. The risk of graft rejection lasts about two to four weeks after transplant. Occasionally, graft failure can be at a later time after your transplant. If it occurs, one option may be to get more stem cells from your donor if they are available. This is called a "boost." Your doctor will discuss various treatment options with you if this occurs.

# Relapse

A risk for many patients is that their disease can come back. This can happen if the treatments you had before the transplant did not kill all your cancer cells. Your risk is higher if you have your transplant when you are in an advanced stage of disease or are already in relapse. Your doctor will follow you closely to watch for any sign of a return of your disease.

### **Infection Precautions**

### Personal Hygiene

Keeping yourself clean is very important. You will follow a shower routine that includes washing your skin daily with Hibiclens® or Dial®. Start at your neck and move down your body. Wash your upper body, middle section, legs, and finally, your feet. Pay extra attention to washing under your arms, groin, and perineum since these areas are moist and harbor germs. The perineum is the area between a woman's vagina and rectum and a man's penis and rectum. Shampoo your scalp with ordinary shampoo or soap once a day. Tell your nurses if you need help.

Germs are often carried on your hands or on objects that you touch. Wash your hands thoroughly with soap after you urinate or move your bowels. Also, wash your hands before eating.

Keep the skin around your central venous IV catheter clean. The dressing that covers and protects it will be changed once a week unless it gets wet or dirty. To reduce the chance of infection, do not let the IV tubing touch the floor.

# Oral Hygiene

Take good care of your mouth throughout your hospitalization. Good mouth care can help prevent infections and other complications in your mouth. The nurse will work with you to plan your mouth care routine. Below are some of the guidelines to follow.

- You will be given a mouthwash to rinse your mouth before and after meals and at bedtime. Use only the mouthwash your nurse gives you. Do not use a commercial mouthwash or toothpaste because these products irritate and dry the mucous membranes of the mouth and throat.
- When your platelet count is low, you may bleed easily. Use extra caution when brushing your teeth, and always use an ultra-soft toothbrush.
- Do not use dental floss.
- Avoid licking your lips. This increases drying and chapping.
- To keep your lips moist, apply a lubricant after mouth care and every two to four hours as needed.
- If your mouth becomes sensitive, avoid hot, spicy, acidic, or coarse foods. You may prefer soft or liquid food served chilled or at room temperature.
- Tell your nurse if you have any tenderness, discomfort, or pain in your mouth. If your mouth becomes painful, your doctor will prescribe medicine to decrease the pain.

#### **Protective Isolation**

You will be on reverse isolation precautions to protect you from outside germs. This was described in more detail on page 9. Once they are started, you will be on them until you are discharged.

# **Bleeding Precautions**

Since platelets work to prevent and control bleeding, you will have a higher chance of bleeding when your platelet count is low. The nurse will check your stool and urine routinely for blood. You should also:

- Use an electric razor when shaving.
- Follow safety measures to prevent falls or accidents. To protect yourself while walking, wear slippers with rubber soles.
- Do not use nail clippers or scissors.
- Tell the healthcare team if you have any signs of bleeding, such as a nosebleed, bleeding from your gums, increased bruising, bright red or black stools, or blood-tinged vomit.

### **Transfusions**

Your blood counts will be checked every day. The counts will be below normal until the stem cells start to grow. You may need red blood cell and platelet transfusions. Red blood cell transfusions are usually given when the hemoglobin falls below 7. You will have platelet transfusions when your platelet count falls below 10,000. Your family members may be asked to donate red blood cells, platelets, or both. However, they should not donate blood products for you until **after** the transplant. The doctors and nurses will tell you more about blood transfusions.

# **Policy For Blood Donations**

We rely strongly on our patients' families and friends to donate blood and blood products. These donations benefit all our patients. We use what we have termed the "buddy system" to recruit blood donors. This simply means that each family is asked to refer as many relatives and friends as possible to donate blood and blood products. It does not matter what blood type the donor happens to be. Donors will go through our normal screening process. This is to make sure it is safe for them to donate and that their blood is likely to be safe to donate. The blood bank staff will then determine which products are the best and most compatible for each patient. In this way, we can maintain an adequate blood supply and provide the best care for all of our patients.

Relatives and friends who have the same blood type as you can "direct" their blood to be given to you. This can only be done if the donors meet our criteria for donating blood.

### **Basic Guidelines For Blood Donors**

Blood products will always be on hand for you. However, we do rely on family and friends to donate. At the start of your treatment, we will ask one member of your family to call the Blood Donor Recruiter. The number is (212) 639-8177. The recruiter will describe the blood and platelet donor program.

Donating red blood cells takes about one hour and involves using one arm. An individual can donate blood again 56 days after his or her donation. Blood can be stored for 30 days.

It takes about 2 ½ hours to donate platelets. It usually involves only one arm. A donor can give platelets as often as twice a week. It can be done 72 hours before or after a blood donation. Platelets can only be stored for five days.

To schedule an appointment to donate blood or platelets, donors should call the Donor Room Appointment Desk at (212) 639-7643.

Blood product donors must:

- Be 17 75 years of age.
- Weigh over 110 pounds (50 kilograms).
- Not have signs of a cold or active allergy at the time of donation.
- Not have a history of any illness such as hepatitis, jaundice, cancer, etc.
- Call the donor room if they are taking any medication and wish to donate.
- Not take aspirin, or any product that contains aspirin or aspirin-like drugs (ibuprofen, Motrin®, Naprosyn®, Anaprox®, Advil®, Aleve®) within three days before donating. Acetaminophen (Tylenol®, Anacin 3®) is acceptable.
- Not drink alcohol eight hours before donating.
- Have a light meal before donating.
- Avoid fatty foods before donating.

# **Immune Recovery**

It may take up to 18 months for your immune system to recover. With some patients, it takes even longer, while some recover in six months. We will do blood tests to see how your immune recovery is progressing. These begin about two to three months after your transplant. The tests will tell us how many T cells you have and how well they are working. You will take medicine to prevent infection until we know your immune system can fight off infections. When that happens, you will most likely be given vaccinations to re-immunize you against some diseases. These vaccines are similar to some of the vaccines you received as a child.

# **Stress and Anxiety**

We know that it can be frightening to have new treatments or to stay in your room for such a long time. Some transplant patients have told us that they feel bored in the room because "there's nothing to do." Others have said, they are "tired of feeling sick" and "can't wait to go home," or they "are anxious and depressed." It is natural to feel like this, and sometimes it helps just to talk about things. Please talk with your nurse, social worker, or doctor about your feelings. Psychiatrists are also available to talk to you and your family. They can advise the transplant team about medicines for your emotions. It is important that we all work together.

We will try to help you feel as comfortable as possible. Please ask your nurse for other support services you may have from staff at the Integrative Medicine Service, music therapy, and art therapy. Before your discharge, your nurse will give you a copy of "Returning Home after Your Stem Cell Transplant." This booklet will help prepare you for going home. It addresses some of the most common concerns of patients who have had a stem cell transplant. You will have plenty of time to discuss your concerns before you go home. We care about you and your family, and we want to help as much as we can during this time. Please ask us any questions that you have.

# **Commonly Used Medications**

# **Supplements:**

Folic Acid: something the body needs to make normal blood cells

K-Dur/K-Lor: a potassium supplement

Mag Oxide/Slow Magnesium: a magnesium supplement

Magnesium soy protein: a magnesium supplement

Multivitamin: a vitamin supplement that may or may not have iron

TPN (total parenteral nutrition): giving the body the nutrients it needs directly into a large vein

Vitamin K: a vitamin that is needed for blood to form a clot

### **Antivirals:**

Acyclovir: medicine to prevent or treat viral infections (e.g. chickenpox, shingles)

Cidofovir, foscarnet, ganciclovir, and valcyte: medications to prevent or treat viral infections most commonly caused by cytomegalovirus (CMV)

**Antifungals:** Fluconazole, amphotericin (AmBisome®), voriconazole, micafungin, Mycelex®, Mycostatin®, posaconazole: medicines used to prevent or treat fungal infections

**Anti Pneumocystis Carini pneumonia (PCP):** medications used to prevent or treat pneumonia caused by a germ called Pneumocystis carinii

Bactrim®, Pentamidine (inhaled or given intravenously [IV, into a vein]), Mepron® (can also be used to prevent toxoplasmosis)

Antinausea: medications used to prevent or treat nausea and vomiting

Compazine® Reglan® Vistaril® Zofran® Kytril®Ativan® Marinol® Aloxi® Emend®

Anti GVHD: medicines used to prevent or treat graft-versus-host disease.

Mycophenolate Mofetil (CellCept®); Cyclosporin (Neoral®); Tacrolimus (Prograf®), Sirolimus (Rapamune®)

Steroids:Prednisone (Deltasone®, Orasone®), budesonide, dexamethasone (Decadron®), and Solu-Medrol® (methylprednisolone).

Antithymocyte Globulin (ATG): a serum protein preparation made in animals. ATG destroys human T lymphocytes (T cells) and it is used to treat or prevent graft rejections and GVHD. It may also be used in the treatment of aplastic anemia.

Methotrexate: a chemotherapy drug given in very small doses to prevent GVHD.

Campath®: a monoclonal antibody used to treat certain types of leukemia and lymphomas. It is also used to prevent or treat GVHD.

Rituximab – a monoclonal antibody used to fight foreign invaders such as lymphoma cells.

Chemotherapy: high doses of chemotherapy are used to destroy cancer cells. You may receive several different drugs for your transplant. Your doctor will discuss with you the specific drugs that you are going to receive. Your nurse will review chemotherapy fact cards with you. They describe the drugs and their possible side effects. Below are chemotherapy drugs you may receive.

Busulfan Cytoxan® Thiotepa Fludarabine Melphalan

# Other drugs you may receive:

Benadryl®: a medication that may be given before you receive blood products. It is an antihistamine, which helps to prevent allergic reactions. It also may be used as a sleeping medication.

Tylenol<sup>®</sup>: a medication, which may be given before blood products. It may be used to control fever and minor aches and pains.

Hormones: given to women to prevent vaginal bleeding when their platelet count is very low. Ovral®, Lo-Ovral®, and Provera® are some examples.

Heparin: a medication that helps keep blood from clotting. It is also used to flush a long term IV catheter to stop it from clotting when it is not in use. You may also receive a very low dose IV solution of heparin during your transplant to prevent veno-occlusive disease.

Prevacid®, Protonix®, Zantac®, Prolisec®, Nexium®: medications used to decrease stomach acid secretions.

# **Glossary**

This glossary contains commonly used terms that you may hear during your hospital stay.

**Allogeneic Stem Cell Transplant** – stem cells are taken from someone other than the patient and then given to that patient.

**Antibiotic** – a drug that destroys bacteria and is used to treat or prevent infections.

**Antiemetic** – a drug that prevents or lessens vomiting.

**Aplastic Anemia** – a disease in which the bone marrow is not able to make the blood cells the body needs.

**Autologous Stem Cell Transplant** – the patient's own stem cells are harvested, preserved, and later returned to the patient.

**Bacteria** – small germs that can cause infection.

**Betasept**® – a liquid anti-infective soap used to cleanse the skin.

**Blasts** – the youngest white blood cells. Normal blasts are the forefathers of all our blood cells. In acute leukemia, the growth of these cells is abnormal or malignant; they may grow quickly and crowd the other cells in the bone marrow.

**Blood Culture** – a blood sample drawn to determine the presence of a specific infection in the blood.

**BMT Team** – the group of professionals caring for you during your transplant. This includes an attending physician, a fellow, (an intern, resident on certain floors), a nurse practitioner, a clinical nurse specialist, a staff nurse, nursing assistants, a social worker, a psychiatrist, a dietitian, a pharmacist, a physical or occupational therapist, and consultant physicians.

**Bone Marrow** – the spongy material in the center of bones where blood cells are made.

**Bone Marrow Aspiration or biopsy** – the taking of a small sample of bone marrow from the center of the hip or breast bone.

**Cardiomyopathy** – damage to the heart muscle affecting the way the heart pumps blood through the body.

**Cataracts** – a clouding of the lens of the eye that can result from radiation therapy.

**Chemotherapy** – drugs used alone or in combination to treat cancer.

Chimerism Studies – tell the doctor how much of the blood is the patient's and how much is the donor's

**Complete Blood Count (CBC)** – a blood test to measure the type and number of blood cells.

Cytomegalovirus (CMV) – a virus that can cause serious illness in immunosuppressed patients.

**Donor Leukocyte Infusion** – a transfusion of whole blood or isolated lymphocytes containing a calculated dose of T lymphocytes sometimes given to treat a recurrence of a patient's original disease or for the treatment of certain viral infections.

**Engraftment** – the growth of transplanted stem cells.

**Epstein-Barr Virus (EBV)** – a virus that can cause infection and, rarely, lymphoma. Symptoms include fever and enlarged lymph nodes.

**Esophagus** – the part of the digestive tract that connects the throat to the stomach; the food tube.

**Esophagitis** – an inflammation of the esophagus.

**Fractionated Radiation** – the total dose of radiation treatment divided over several days.

Fungus (Candida, Thrush) – germs, different from bacteria, that may cause infection.

**Gamma Globulin** – a blood protein that contains antibodies that help protect the body from infection.

**Graft** – new stem cells, which are growing.

**Graft vs. Host Disease (GVHD)** – an immunologic reaction of allogeneic donor cells (graft) against the patient's (host's) body. This can be short-term (acute) or long-term (chronic).

**Harvesting** – collecting the stem cells needed for a transplant.

**Hemoglobin** – the part of the red blood cell that carries oxygen.

Herpes Simplex – a virus that usually produces fluid-filled blisters on the skin and mucous membranes.

**Herpes Zoster** – a virus that causes shingles, painful skin eruptions that follow the underlying route of nerves inflamed by the virus.

**Host** – the person into whom the stem cells have been infused.

**Immunosuppression** – a decreased ability of the immune system to fight infection, induced by drugs, radiation, or infection.

**Interstitial Pneumonia** – inflammation of the lung caused by a virus or due to damage from chemotherapy and radiation.

**Irradiated Blood Products** – blood products that have been exposed to a radiation source to inactivate the lymphocytes that could otherwise cause GVHD. The blood is not damaged, and it is not made radioactive by this treatment.

**Jaundice** – a "yellowish" skin color usually reflecting damage to the liver.

**Leukemia** – a disease in which the bone marrow makes abnormal white blood cells.

**Leukocytes** – white blood cells. They play a major role in the body's defense. These cells are divided into three main subgroups: granulocytes, lymphocytes, and monocytes.

Low Microbial diet – a diet designed to minimze bacteria, viruses, yeast, and molds in your food and beverages

**Lumbar Puncture (LP or Spinal Tap)** – a procedure in which a thin needle is passed between the vertebrae in the lower back and into the sack that surrounds the spinal cord. It is performed to obtain a small amount of spinal fluid, which is checked for infection or growth of leukemia cells.

**Lymphatic System** – that part of the circulatory system consisting of lymph nodes and vessels that filter out germs and diseased cells.

**Lymphoma** – a cancer of the immune system involving lymphatic tissue.

**mL** (**milliliter**) – a unit of measurement. There are 30 mL in one ounce, 15 mL in one tablespoon, and 5 mL in one teaspoon.

**Mucositis** – inflammation of the mucous membranes of the throat (esophagitis) and the mouth (stomatitis).

**Neutropenia** – a condition characterized by a low neutrophil count (white blood cells that fight infection), making the patient prone to infection.

**Neutrophils** – a type of white blood cell that plays a major role in the body's defense against bacterial and fungal infections.

**NPO** – abbreviation for "nothing by mouth".

**Platelet** – the blood cell that helps clot the blood and stops bleeding.

**Radiation Therapy** – the use of high-energy x-rays to treat diseases.

**Red Blood Cell** – the blood cell that carries oxygen in the body.

**Rejection** – the body's inability to accept transplanted stem cells.

**Relapse** – the recurrence of a cancer during or after treatment.

**Severe Combined Immuno-Deficiency (SCID)** – a genetic disease characterized by the absence of the body's natural ability to fight infection.

**Solid Tumor** – abnormal growth of cells that form a solid mass in an area of the body.

**TBI** (**Total Body Irradiation**) – high-dose radiation treatments given to the whole body.

**T Cell** – a subset of white blood cells that can cause graft rejection or Graft vs. Host Disease. Normal T cells play a major role in the body's defense against viral and fungal infections.

**T Cell depleted stem cell transplant** – a special transplant in which the T cells are removed from the donor's marrow before it is given to the patient; this reduces the likelihood of Graft vs. Host Disease.

**Tissue Typing (HLA, Human Leukocyte Antigen)** – a special test of white blood cells to check the genetic match between a donor and the patient.

**TLI** (**Total Lymphoid Irradiation**) – radiation treatments given to the parts of the body where most of the lymphatic system is located.

**Veno-Occlusive Disease (VOD)** – a disease caused by a block in the flow of blood through the small blood vessels in the liver. It results in mild, moderate, or severe liver damage.

**Virus** – a small germ that may cause infection; examples are adenovirus, cytomegalovirus (CMV), or herpes virus.

White Blood Cell – the blood cell that helps fight infection.

# The Metric System

In the hospital, temperatures are recorded according to the Centigrade scale. The following is an approximate conversion table from degrees Centigrade (°C) to degrees Fahrenheit (°F):

°C		°F
36.0	_	96.0
36.5	_	97.7
37.0	_	98.6
37.5	_	99.5
38.0	_	100.4
38.5	_	101.3
39.0	_	102.2
39.5	_	103.1
40.0	_	104.0
40.5	_	104.9
41.0	_	105.8

Weights are measured in kilograms. To find your weight in pounds, multiply your weight in kilograms (KG) by 2.2.

