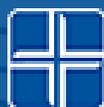


# Stem Cell Transplant Patient Guidelines



UnityPoint Health

## GENERAL INFORMATION

This booklet is designed to help you and your family understand the transplant process. It will take you through the steps of an Autologous Peripheral Stem Cell Transplant and give you an idea of what to expect. Write down any questions that you have while you are reading through the booklet so they can be answered for you at future appointments.

Throughout the course of your treatment, many health care professionals will be involved with you and your family in the various physical, social, and emotional aspects of your Autologous Peripheral Stem Cell Transplant. There will also be many individuals whom you may not see during the transplant process who are involved in your care. These are the professionals performing special procedures, doing lab tests, and coordinating various activities related to your stem cell transplant. All of these individuals comprise the transplant team. They are working with a shared interest in mind, YOUR RECOVERY. The most important person on the team is you, the patient.

We urge you to take an active role in the transplant process. Ask questions and don't be afraid to say that you don't understand an explanation. Feel free to ask questions until you are comfortable with the answer.

### THE TRANSPLANT PROCESS

Bone marrow is the spongy tissue inside the bone that produces many parts of the blood. In diseases involving the bone marrow, such as leukemia and aplastic anemia, normal bone marrow production has been altered. In these instances the bone marrow produces an abnormal number or abnormal kinds of blood cells. In other diseases, such as lymphoma, testicular cancer, and breast cancer, the marrow may not be directly affected, but the cancer does involve other cells in the body.

Bone Marrow Transplantation (BMT) and Peripheral Stem Cell Transplantation (PSCT) are a type of transfusion. In this case, the transfusion is bone marrow or peripheral blood stem cells. Normally in cancer treatment, the effects on the bone marrow limits the amount of cancer therapy, chemotherapy and radiation, which can be given to a patient. It is possible to give higher doses of therapy when we give marrow cells as a rescue transfusion, as is done in bone marrow and stem cell transplant. This, of course, increases the chances of a good response to the therapy.

The bone marrow used for the rescue or transplant is collected from you, the "donor", and then given back to you after the cancer therapy has been administered. This type of bone marrow transplant is an autologous transplant. This is the term used when the patient donates their own marrow for future reinfusion transplant.

The process of obtaining peripheral stem cells for transplant is called a Stem Cell Harvest. The stem cells are first "mobilized" or moved from the bone marrow to the peripheral blood through the use of chemotherapy drugs and/or colony stimulating factors, like Neupogen. These cells are then collected, harvested from the circulating blood, by a machine specifically designed for this purpose. This

collection is coordinated with the Hemodialysis Unit and is usually done on an outpatient basis. These cells are carefully processed, cryopreserved, and stored for use during your transplant.

Since bone marrow/stem cell transplantation involves many aspects of medical advancement, you will be asked to participate in various procedures and tests before and during your transplant process. All of these are aimed at providing you with the best possible care. These include things such as x-rays, lung function tests, EKG's, laboratory studies, and taking medications. You will be given additional information on these as your treatment proceeds.

A special catheter (central line) is inserted early in the transplant process. The special catheter is inserted by a physician into the large veins in your chest that leads to your heart. The catheter will remain in place throughout the collection and transplant period.

The transplant process can be a very stressful for you and your family. Your emotions and how you cope with stress are important to us. Since you will be away from your home, family, and other supportive people, you may experience some loneliness and yet be overwhelmed by the number of people involved in your treatment. Some transplant patients are affected by the loss of privacy and limited activity caused by the isolation. We encourage family members to assist us in supporting you through the transplant experience. Since your family knows you best, we find they are often very helpful in assisting us to meet your needs. There will be Social Worker, Counseling and Chaplain support available to you and your family during this process. We understand that this process can also be physically and emotionally draining for family members. We encourage family members to be attentive to their own needs as well as those of you, the patient.

Concerns such as medical costs and the availability and cost of temporary housing vary with each patient and family. Our Social Work Services and /or Case Management staff will be able to provide you with information regarding possible resources to lessen these concerns.

For some people the most difficult part of the transplant occurs when they are starting to feel a little better, but are struggling with the long wait for blood counts to rise. Although these effects cannot be avoided, diversional activities (i.e., books, movies, and games) can help you to overcome the isolation and boredom.

We want you to be aware of the common stresses and related feelings surrounding transplantation and to know that you are normal. We feel it is important for you and your family to be aware of the risks of the transplant while remaining realistically hopeful regarding your situation. A positive attitude is a very important factor in coping with your transplant. We believe that people cope best when they have information and know what to expect. We encourage you to gather information you need and ask questions.

## VISITATION GUIDELINES

Visitors can be an important part of your stay in the hospital. We want you to feel free to have those close to you come to visit. You know who those people are and can help us by identifying them early

during your hospitalization. They are the people we want to work with so they can support you. Family members may visit any time that is convenient for you, but will not be permitted to stay overnight. We ask that other visitors come from 10 A.M. to 8:30 P.M. Those with colds, sore throats, or other signs of illness **MUST NOT** visit until they are feeling well.

Since treatment procedures and care have been planned, it would be helpful if all visitors would check with the nurse before entering your room. **ALL visitors will be required to wash their hands prior to entering your room!** Hand washing has been found to be the most important factor in preventing the spread of germs. We ask that visitors check with the nurse before bringing anything into your room. Visitors will be limited to 2 at a time. Both family and visitors will be asked to leave the room while nursing and housekeeping perform their required duties, procedures and treatments. No visitors will be allowed to use the bathroom or shower in your room. These guidelines have been established to provide the safest and most efficient care possible for you, the patient.

Social support is extremely important during your transplant. Please feel free to give the following address to family and friends so they can send you cards and letters during your transplant:  
Methodist Medical Center of Illinois, 7 Hamilton, (Your Name), 221 N.E. Glen Oak Avenue, Peoria, IL 61636.

# TREATMENT PLANS

## CHEMOTHERAPY

Your treatment will include important anticancer medicine. These medicines, or chemotherapy, are given to you through your Central Line. Your chemotherapy schedule may consist of one or more drugs. These drugs act on rapidly reproducing cells, such as cancer or tumor cells, to stop or slow down cell growth.

The intensive chemotherapy you will receive can affect all cells in your body, both tumor cells and fast-growing normal cells. Areas of fast growing normal cells that are more sensitive to the effects of chemotherapy are the mouth, throat, bowels, bone marrow, skin and hair. The effects of these medicines on your body will cause many different types of side effects.

Your mouth and throat may become tender and develop sores. Good oral hygiene will help to limit these problems. Medications will be given to relieve the mouth discomfort if you need it until your mouth and throat recover. Nurses will work with you to develop a mouth care plan.

Your bowels and stomach are also affected by chemotherapy. Nausea, vomiting or diarrhea, are common effects. Medicines will be given to help if you have these side effects. The nurses will be recording your weight and the fluids you take in and put out to be certain of your fluid balance on a regular basis.

Hair follicles are very rapidly growing cells and thus are also sensitive to the effect of chemotherapy. It is likely that you will lose your hair during your treatment. Physically you will feel cooler at this time, you may want to have a scarf, wig, cap, turban or some type of head covering during your stay.

High dose chemotherapy may also cause infertility. Therefore, if you are of childbearing age you may want to talk to your doctor about the options that are available to you, such as embryo or sperm banking prior to pursuing your transplant.

The ultimate goal of chemotherapy is to destroy all the cancer cells in your body. In so doing, it also suppresses the activity of your bone marrow. The white blood cells, which help your body to fight infections, are produced in your bone marrow. Since they will be suppressed, your body will be less resistant to infection. **This is why the nurses, doctors, hospital staff, and all of your visitors must follow protective measures of washing their hands every time they enter your room.**

Your white blood cell count will be monitored closely. When your white count is down, it is not uncommon to develop infections even with perfect isolation techniques. You will be placed on antibiotics and your care will be tailored to your specific situation.

Different chemotherapy drugs affect different parts of the body. Education will be provided before, during and after your transplant process regarding the chemotherapy drugs and possible side effects. Feel free to ask any questions you may have about your chemotherapy.

### TRANSPLANTATION

A day or two after you have completed chemotherapy you will receive your stem cell transplant (reinfusion of your stem cells). On the day of the transplant your frozen stem cells will be brought up to the transplant unit. Your physician thaws each bag of stem cells individually in a water bath, immediately prior to reinfusion. The procedure is very similar to receiving a blood transfusion. As soon as your stem cells are reinfused they immediately take up residence in your bones and begin producing cells, although the mature cells may take 2-4 weeks before they “go to work.”

During the reinfusion of your stem cells you may experience an odd taste in your mouth and notice the odor of garlic. This is caused by the cryopreservative that is added to your cells to protect them during freezing. The cryopreservative may also cause you to feel nauseated and possibly vomit. These side effects are temporary.

The day after your transplant you will begin to receive a hematopoietic growth factor. The growth factor stimulates your cells and helps them multiply more rapidly; thus helping you recover faster. This begins the waiting period until your cell counts rise high enough for you to be safely discharged from the hospital. During the waiting period you are still susceptible to infection, therefore, you will still be monitored very closely.

## SPECIAL CARE AND CONCERNS

### DECREASING THE RISK OF INFECTION

The treatment you receive will cause your blood cell count to become low; the section on blood counts discusses this in greater detail. When your white blood cell count is low, your resistance to infection is lowered. For this reason, it is important to protect you from infection. We need your help and the cooperation of everyone in contact with you to do this.

You will be on “Modified Protective Isolation” in a private room. This means special precautions are taken to protect you from infection. The door to your room must be kept closed at all times. **Everyone entering your room must wash their hands carefully prior to entering.** Although these precautions are necessary, this does not mean you have to avoid physical contact such as hugs and touching.

Fresh flowers will NOT be allowed in your room because of the likely presence of bacteria on them. All through your hospitalization and after dismissal, it will be important for you to continue with daily hygiene measures (i.e. – daily showers, hand washing, and oral care).

Please feel free to ask your nurse any questions you may have about the above information. The Transplant Team asks for cooperation from you and your family members with these protective measures. If you notice anyone not observing these protective measures, please notify the staff.

### ACTIVITY

Physical Activity is very important during your treatment. Although there may be exceptions, we want you to be as active as possible every day, within the limits of your condition. Our goal is to maintain your current activity level and exercise program as able. Activity assists in preventing secondary complications.

Inactivity and bedrest can decrease physical strength up to 3% a day. Establishing a daily exercise routine will enhance your skin, muscles, heart, and lungs. Your room is provided with an exercise bicycle, which we hope will become a part of your exercise program. Other activities for strengthening and flexibility may also be identified based on your individual needs.

### NUTRITION

Nutrition is an important part of helping your body tolerate the treatment and assisting you in your recovery. The clinical dietitian will assess and plan for your nutritional needs with the physician and nursing staff. Since the cancer treatments affect the cells and tissues of the mouth, stomach, and bowel, adjustments in your diet will be made. Your treatment may cause nausea and vomiting which will also interfere with nutrition. We will monitor and treat any of these common side effects aggressively. You may also notice taste changes, we will work with you to identify foods that are appealing to you. With these common side effects often eating smaller, more frequent meals is

beneficial in maintaining your nutrition. The clinical dietitian as well as your healthcare team will monitor closely and assist in obtaining the foods or supplements you may need to maintain your nutrition.

### **DENTAL/ORAL CARE**

Dental and oral hygiene are a very important part of your care. Infections in your mouth can be severe and potentially life threatening. You will play an active role in helping to prevent problems of this kind. After chemotherapy and the transplant you will very likely develop sores in your mouth. It is important to start good oral hygiene early and continue it throughout your hospitalization. Your nurse will work with you to identify a special plan for you to follow. Regular assessments of your mouth will be part of the care you receive. Always remember to report any changes you might notice, especially pain and difficulty in swallowing.

### **BLOOD COUNTS, LABS**

Blood is made up of cells and fluid. The three major kinds of cells are 1) red blood cells or RBCs, 2) white blood cells or WBCs, and 3) platelets. These cells are made in the bone marrow, the soft material that fills the cavities of bones. After the cells mature or “grow up” in the bone marrow, the RBCs, WBCs, and platelets, are slowly released into the blood stream / circulation.

Chemotherapy and the transplant process will affect these cells by decreasing them, we call this a low blood count. It is an expected side effect of your cancer treatment. Transfusions, to replace the red cells and platelets, in addition to special medications to fight infections, will be given to you to prevent problems from low blood counts as needed. This is temporary; as your bone marrow gradually recovers, your counts will rise again in the days to weeks after your transplant.

Blood specimens must be collected frequently to monitor your blood count during the transplant process. (The majority of these will be drawn from your central line.) These counts will be reviewed by the team daily and help determine your need for transfusions, progress of treatment, and stage of recovery. An adequate number of RBCs, WBCs, and platelets are necessary for the body to function properly and fight infection.

### **CENTRAL LINE CATHETER**

The Central Line Catheter (Right Atrial Catheter/Triple Lumen Subclavian Catheter, et al.) is a specially designed hollow silicone tube. This catheter will be used for drawing blood, infusing your chemotherapy, and other I.V. therapy. You will likely have this catheter placed as an outpatient prior to your stem cell harvest. The procedure is completed under “twilight” anesthesia by the Interventional Radiology team, you will be monitored for a brief time and then discharged to home that same day. Catheter management (cleaning, flushing, etc) at home until your admission to the hospital may be completed by home health team or at an outpatient infusion center daily. This is determined and scheduled on the last day of harvest and will be provided to you.

## DISMISSAL GUIDELINES AND INFORMATION

As you prepare to return home, it is important you know how to care for yourself. The treatment(s) you have received are very extensive and will continue to have some effect on you. Although we want you to resume YOUR normal activities as soon as possible, it is important that you pace yourself and understand that recovery time varies for each individual patient. The transplant team will help you to understand YOUR plan.

Even after you leave the hospital, we remain available to answer your questions. Any time you have a concern, do not hesitate to call the UPM Transplant Unit 7Hamilton, at (309) 672-4842 or Illinois Cancer Care, LLC (309) 243-3000.

### EMOTIONS

Transplantation can be one of the most stressful experiences, emotionally as well as physically, that you and your family may ever face. You and your family have been a part of this experience and are still adjusting. Certainly, going home is something everyone wants. You may experience many emotions upon returning home. Do not be frustrated if your lifestyle does not return to normal immediately.

**Now is the time to turn the energies you used to get through the transplant into energies for LIVING!** Remember to be patient, pace yourself, and set reasonable goals.

### CARING FOR YOURSELF

When you are home, you will be responsible for caring for yourself. It will be important to watch things closely. Your body has not totally recovered from the treatment, and you may require additional care.

#### **NOTIFY YOUR DOCTOR IMMEDIATELY FOR ANY OF THE FOLLOWING:**

- 1. Anything that changes or worries you**
- 2. Fever of 38.5°C/101°F or greater**
- 3. New or persistent cough**
- 4. Shortness of breath at rest or with exercise**
- 5. Any type of bleeding**
- 6. New or persistent diarrhea or constipation**
- 7. Mouth lesions, sore throat, or trouble swallowing**
- 8. Pain with urination or bowel movements**
- 9. Before making plans to travel in the near future**

## HOME ENVIRONMENT

As you return home, a few precautions need to be taken to protect you from infections. Generally, pets that have been in the home can remain. Although flowers and plants may remain in your house, you should avoid close contact with them. Do not work directly with the plants or soil. Keep your furnace filter changed regularly as well.

## ACTIVITY

Physical activity remains an important part of your recovery. Initially, you may notice that you are weak and tire easily. Once again, remember, it takes time to recover fully from your treatment. You may need to build your strength and endurance slowly. Start by doing the exercises you have been doing in the hospital and gradually increase back to your normal workout routine.

You may be out in public without a mask (unless instructed otherwise), remember to continue utilizing good handwashing and avoid contact with people who are ill. Although it is a good idea to avoid contact with anyone who may be ill, do not totally isolate yourself. Close contact by those you love is a very important aspect of life.

## FOOD AND DRINK

Food preparation at home should continue as usual with the following considerations:

1. Be sure to cook food thoroughly and according to package directions.
2. Leftovers should be used within two days.
3. Store foods as instructed on the package (ie milk in refrigerator, etc)

You may continue to experience some taste changes and food dislikes. Hopefully, most of the nausea and vomiting, which occurred with the transplant procedure, has resolved. If you continue to experience some difficulty, utilize your anti-nausea medicine as needed. It may be weeks to months before your appetite completely returns to normal. In order to eat a well-balanced diet with enough calories to maintain your weight, it may be helpful to eat small meals with snacks in between. Also, try to drink 6-8 glasses of water or other fluids daily. Eating at a restaurant on occasion is acceptable. Always be certain that any food you eat is adequately cooked.

## SUPPORTIVE CARE

Once home you may use over the counter medications for diarrhea, constipation, gastric reflux, stomach distress, etc. Follow instructions on the packaging or contact your physician's office for questions.

Continue with good oral hygiene including daily brushing, flossing, mouth rinses Notify your Physician of any persistent or new sores, or other concerns. Dry mouth and taste changes may take time to

resolve. You can utilize hard candies, mouth rinse and pushing fluids to help. You may use saline eye drops or nasal sprays for moisture if needed.

Continue good personal hygiene, wash your hands frequently and bathe or shower every day using a mild soap. You may notice that your skin is more dry and flaky than usual. You may use over the counter moisturizing creams with do not contain alcohol or perfumes (ie: Udder cream, Eucerin, Aveeno, Aquaphor, Lubriderm). If you have questions please contact your physician's office.

Tylenol products or prescription pain medications may be used if needed. If treating a **FEVER** or any **INFECTIOUS** symptom you should contact your physician s office first. **Avoid all ASPIRIN products**, unless instructed by your physician to take.

Please refrain from Smoking or being around people or places that contain smoke.

## SUMMARY

Remember, everyone is different. You may or may not experience many of the things discussed in this booklet or you may experience other effects. Most important is that we answer any questions YOU have now or at any time in the future. Your return appointment will be scheduled when you are discharged from the hospital. You need to be very certain not to miss this appointment. Remember to take your dismissal medicines as directed. Do not take any old medications you may have left from earlier illnesses.

Feel free to contact us regarding any questions or concerns you or your family has after your dismissal. You or your family may call the Transplant Unit (309) 672-4842, or Illinois Cancer Care (309)243-3000 at any time.