

1775 Dempster Street
Park Ridge, Illinois 60068
847-723-2210 Main number



Bone Marrow Transplant Center
Advocate Lutheran General Hospital
Patient and Family Handbook

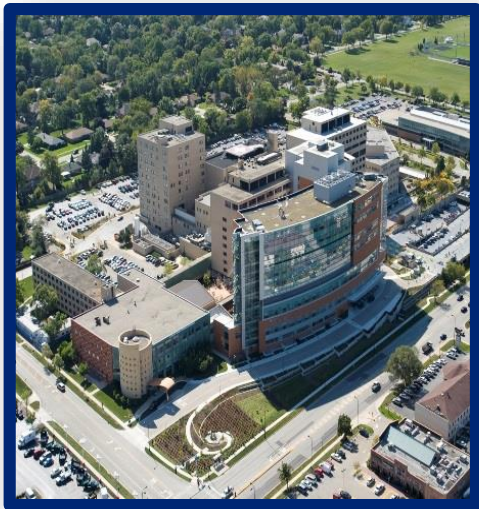


Bone Marrow Transplant Center Advocate Lutheran General Hospital



Top Ten Reasons Why Patients Should be Transplanted at Advocate Lutheran General Hospital

- Collective experience of transplant physicians and Magnet Center of Excellence in Nursing
- Voted Top 100 Hospitals by U.S. News and World Report Thompson Reuters
- Foundation for the Accreditation of Cellular Therapy (FACT) accredited transplant center since 2003



- Accredited with National Marrow Donor Program (NMDP) and a collection center for NMDP since 2000.
- Member of the Center for International Blood and Marrow Transplant Research (CIBMTR).
- The cancer program is approved by the Commission on Cancer of the American College of Surgeons.
- 100% Nursing staff on 8 Tower is certified in oncology, the only in-patient unit in the country to achieve this honor. They will soon be sitting for Transplant certification.
- Advocate Lutheran General Hospital is the only accredited transplant center in the northwest suburbs of Chicago.
- Our program allows us to treat patients who have been unsuccessful with other therapies right here at Lutheran General Hospital. We don't have to refer patients away, we have a

complete program from start to finish for leukemia, multiple myeloma and other cancers. Patients don't have to go downtown for care, we offer the same services closer to home.

- Expanded Survivorship Center programming; Only free-standing hospital-based center in Illinois

[Meet Our Staff/Contact Us for an Appointment](#)

Request an appointment with an Advocate doctor to determine if transplant is right for you.

- Click here -

[Financial and Insurance Questions](#)

Information about costs, insurance options, coverage.

- Click here -

[The Bone Marrow Transplant Process](#)

Our Patient Education Book

- Click here -

[Photo Gallery](#)

- Click here -

[Where Are We Located / Lodging and Transportation Options](#)

- Click here -

[About Our Program – History, Recognitions, Mission Statement](#)

- Click here -

[Patient Stories](#)

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[Patient Resources](#)

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Place copies of your signed consents and legal paperwork here

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Medication handouts and information can be placed here

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-Preparing for the Transplant-

- ❖ Once it is determined a transplant may be right for you there are several steps that must be done in order to prepare for the transplant
- ❖ Most, if not all, of the preparation for the transplant can be done as an outpatient
- ❖ First you must undergo testing to be sure you are healthy enough for a transplant
- ❖ We must verify how much of the transplant will be covered by your insurance.
- ❖ Once you are approved for transplant you will begin preparing your body for collecting your stem cells
- ❖ Next your stem cells will be collected for use during your transplant.

There may be some words in this book that you have not heard before. Please look at the **glossary** at the back of this book for help. If you have questions, please ask your doctor or nurse.



Insurance Coverage

We will call your health insurance company, speak with them about your treatment, and find out how much of the stem cell transplant they will cover. To do this we will need copies of all your current medical insurance cards. We will also:

- ❖ Get coverage information about all the parts of the transplant treatment, including the hospital stay.
- ❖ Give you the coverage information and possible costs.
- ❖ Check the costs of the medicine that you will need.
- ❖ Help you to find financial help if needed.

For further information or clarification of your coverage and benefits, we encourage you to contact your insurance carrier directly. Please know that a stem cell transplant costs a lot of money. In the event there is any amount left unpaid by the insurance carrier(s), the remaining balance becomes the responsibility of you and/or your family.

Pre-Transplant Evaluation & Testing

The pre-transplant evaluation includes several tests to show that you are in good health and can safely have the transplant. These tests will also serve as a “baseline” so they can be compared to the same tests completed after the transplant. You will need the following tests:

Blood & Urine Tests- these are done to see how well your kidneys, liver and bone marrow are working.

Chest X-Ray – An x-ray of your lungs will be taken.

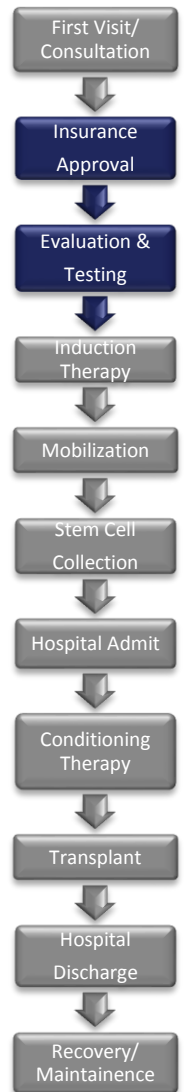
Dental Exam - You will need to see your dentist for a complete exam and cleaning. Any problems, such as cavities or infections will need to be taken care of before starting the transplant process.

MUGA Scan and/or Echocardiogram –measures how well your heart pumps blood through your body. For a MUGA Scan a dye is put into your bloodstream and then pictures are taken.

Pulmonary Function Test (PFT) –You will breathe in and out of a tube and it will measure how much oxygen your lungs can hold and how much oxygen gets to your blood.

Infectious Disease Tests – Your blood will be taken and checked to see if you had contact with certain diseases or viruses in your lifetime and to check for any current infections.

CT scans, MRI, PET scans, and bone scans- these may need to be done to monitor your disease. Your transplant nurse will let you know which tests are needed.



Psycho-social assessment- As part of the pre-transplant testing, it is required you see the transplant social worker or psychologist. The reason for the assessment is to help you and your family with any special needs you may have. Social workers and psychologists can help you cope with social, emotional, family and financial issues you encounter during your transplant. It is recommended that your care partner come with you. Please know that the psychosocial assessment is done to meet *your* and your family needs. Depending on the assessment, more appointments may be needed.

Once all of these tests are done, you will meet with your doctor and care coordinator to go over the results, have your questions answered, and sign consents for the stem cell collection and transplant.

Fertility

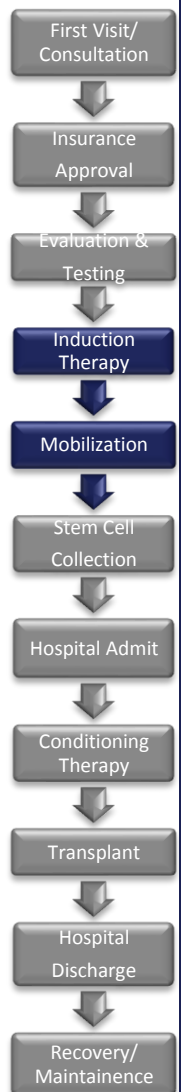
You should know that the high dose chemotherapy given during a stem cell transplant may cause you to become infertile. Depending on where you are in your life you may want to consider egg harvesting or banking your sperm for the future. See the resources section for further fertility treatment information and resources.

Induction Therapy

Induction therapy is the first line of treatment for your cancer. It is used to help put your disease into a remission before your stem cell transplant. During induction, you may get chemotherapy, which is a treatment with drugs that kill cancer cells. Some of the side effects from the chemotherapy can be nausea, vomiting, diarrhea, constipation, low blood counts, which can possibly lead to anemia, infections, bleeding, hair loss and feeling tired. Be sure to let your nurse know when you are having any side effects.

Mobilization

Generally the peripheral blood stem cells are collected for use in an autologous transplant. However, bone marrow collections can be performed if needed. Since stem cells are found in our blood but in low numbers, we need to “mobilize” the stem cells out from the bone marrow into the bloodstream. This is done using a medicine called Filgrastim (Neupogen®). We will then collect the stem cells using a process called **Apheresis**. During apheresis blood is moved from your vein and into the apheresis machine, which filters out the stem cells from the blood. The rest of the blood is then returned your vein. The stem cells that are taken out are saved, frozen, and will be given back to you later during the transplant.



Neupogen® Shots

Filgrastim (Neupogen®) is a medication that will make your body make extra stem cells and move those stem cells into the blood stream so they can be collected.

Filgrastim is given as a shot into the fatty tissue with a small needle. You or a family member will need to learn to give these shots. Your nurse will teach you how and where to do the shots. They will need to be given two times each day, once in the morning and once in the evening, about 12 hours apart until the stem cell collection is done.

There are generally few side effects with Filgrastim but you may experience:

- Redness, burning, bump or bruise where you received the shot
 - Low grade fevers
 - Bone pain in your back, chest, legs or arms
-
- ❖ Call your doctor or nurse if you have a fever of 100.5 degrees or higher
 - ❖ You may take (2) Extra Strength Tylenol® every 4-6 hours if needed.
 - ❖ Call your doctor if your pain is not better after taking Tylenol®.
 - ❖ Your blood counts will be watched closely while taking the Filgrastim.

Steps for Giving Shots

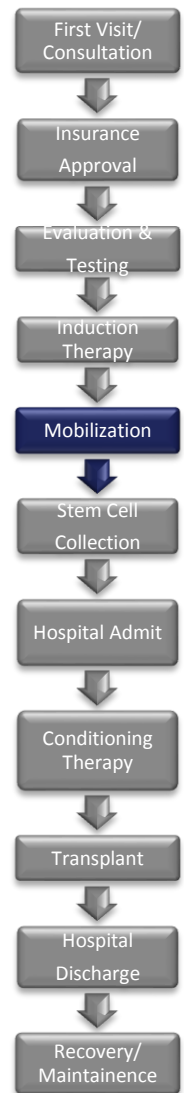
Step 1

1. Take the medicine from the refrigerator about 30 minutes before giving it so that it gets warm.
2. You may put ice on the shot area to numb it for a few minutes before giving the shot
3. Wash your hands with antibacterial soap and water.
4. Gather all of the supplies:
 - a. Medicine-filled syringe
 - b. Alcohol swab

Step 2

5. Find the site for the shot: *
 - a. Back of arms
 - b. Abdomen, except near the belly button and the waist
 - c. Upper thighs
6. Clean the site with an alcohol swab by rubbing in a circle

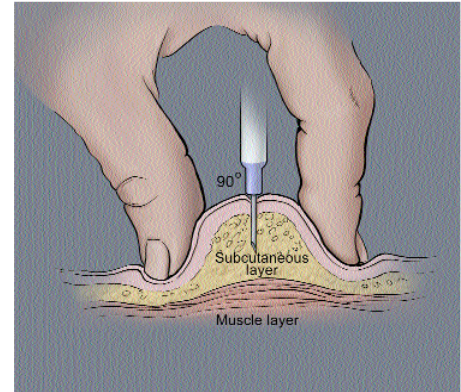
*Change the site each time you get a shot



Step 3

Giving the Injection:

7. Hold the syringe in the hand you will use to give the shot and carefully remove the cap from the needle shot.
8. Use the other hand to pinch the skin that was cleaned.
9. Hold the syringe the way you would hold a pencil, insert the needle either straight up, and down (90-degree angle) or at a slight angle (45-degree angle) to the skin.



10. Gently push needle through the skin.
11. After the needle is in, let go of the skin
12. Slowly push down the plunger all the way, until all of the medicine is gone.
13. Remove the needle from the skin and gently hold an alcohol pad on the injection site
Do not rub
14. If there is bleeding apply a bandage.
15. Place the syringe in a puncture proof container;
Do not replace cover on the needle



How to Give a Subcutaneous Shot



1. Use an alcohol swab to clean the skin where you will give the shot.



2. Gently pinch the skin and insert the needle into the skin at a 45° angle.



3. After you insert the needle completely, release your grasp on the skin.



4. Inject all of the solution by gently and steadily pushing down the plunger.



5. Withdraw the needle and syringe and press an alcohol swab gently on the spot where the shot was given.

The Journey of you Stem Cells



Apheresis Catheter

To collect your stem cells, a Central Venous Catheter will be placed into a large vein that runs under your collarbone. It is a thin plastic tube with three tubes on the end. It will be used to draw blood, to collect the stem cells. It will stay in place and will be used while you are in the hospital to get the transplant.

Your catheter will be put in at Advocate Lutheran General Hospital in the Interventional Radiology Department. This will be scheduled by your nurse. You will be given medicine before to help you relax, and you may only have clear liquids for 4 hours before your appointment. You cannot drive the day of this procedure and you will need someone to bring you home.

After your catheter is in place:

- ❖ You will go to the doctor's office 1-2 times per week for line care.
- ❖ The nurses at your doctor's office, collection center, or the nurses on the transplant unit at the hospital may use the catheter.
- ❖ **DO NOT ALLOW ANYONE ELSE TO USE IT.**
- ❖ Do not allow your lines to go under the level of water in a bathtub or swimming pool.
- ❖ Keep the area clean and dry; be sure to cover the site with plastic before taking a shower. Your nurse will show you how to do this.
- ❖ Call your doctor or nurse with any signs of infection:
 - Fever 100.5 degrees or more, chills, swelling, red areas or pain
- ❖ Notify your nurse if any blood is in the tubing – the fluid in the tubes should always be clear.

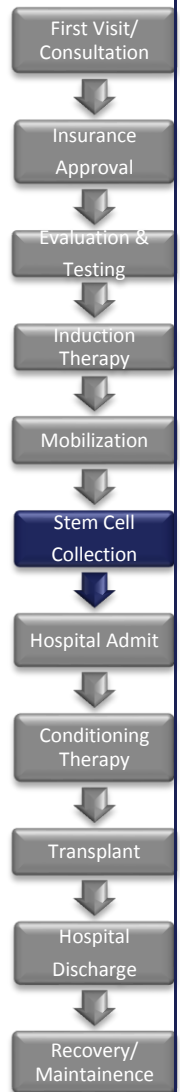


Your catheter may be taken out before going home from the hospital or you may go home with it in place and have it taken out when your platelets reach 50,000 and when the doctor decides you no longer need it.



Neostar Triple Lumen Catheter

Emergency Catheter Care



Cap at end of line missing

Make sure line is clamped. Clean end of line with an alcohol wipe for at least 30 seconds. Place a new cap on tightly or if no cap, wrap with sterile gauze. Call your doctor or nurse.

Swelling of face, neck or chest

Call you doctor or nurse. There may be clot around your line.

Redness, drainage or bleeding

Call your doctor or nurse

Fever above 100.5 degrees and/or chills

Call you doctor or nurse. These are signs of infection.

Damage to the tubes, such as leaks

Clamp the tube between the hole and where the tube exits your chest. Cover the hole with sterile gauze. Call your doctor or nurse as soon as possible.

Line Comes Out of the Chest

Apply pressure with gauze or a clean washcloth to stop the bleeding and tape in place. Call your doctor or nurse.

Sudden chest, neck, shoulder pain or hard time breathing

Make sure the lines are all clamped. If not, pinch it off or fold it over to clamp it. Lie on you left side with your head down, stay like this and have your care partner call your doctor.

Stem Cell Collection

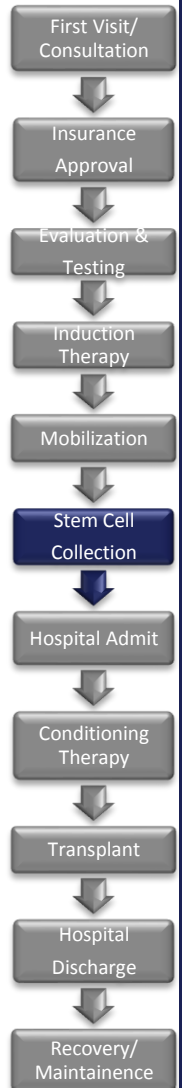
The stem cell collection is done as an outpatient at the Apheresis Center, located on the third floor of the professional building attached to the main hospital, Suite 365. Infusion Center Parkside 1875 Dempster Street, Suite #365, Park Ridge, IL 60068 P: 847-723-5070

When you get there on the first day of collection, a blood test will be done to find out how many stem cells there are in your blood. This test takes about 2 hours to get results from the time it is drawn. You can wait at the center, go out for coffee or breakfast or even go home if you live very close. The nurse will call you with the results.

The collection will be started when your blood counts show that you have enough stem cells in your blood. The cell collection takes about 3-6 hours. All of the stem cells needed may be collected on the first day, or it may take 2-3 days on the collection machine to get the right amount of cells.

The most common side effects of the cell collection are numbness or tingling of the lips, face, and hands. This is caused by too low levels of calcium in your body. Tell your nurse as soon as you are feeling this and they will give you calcium to correct the problem. It is good to eat a diet high in calcium for the few days before the collection. You can do this by eating more dairy foods such as milk, yogurt, and ice cream. You will also need to eat 4-5 Tums® tablets on the morning of collection.

Apheresis Machine



Post Donation Instructions for PBSC Donors

Donor Thank You

On behalf of Lutheran General Hospital's HPCT Program we would like to thank you for your assistance and cooperation in making your stem cell collection as favorable as possible. Your help with your treatment and your continued positive attitude will contribute towards a making the stem cell transplant a success! Now it is time to be good to yourself.

Contact Names & Phone Numbers

Please feel free to call with any questions or concerns. We encourage you to use the medical staff at the transplant physicians as your first point of contact since they are familiar with post-donation recovery and can help coordinate any necessary follow-up care.

Medical Contacts

Weekday	Mary Hurd, MHA, RN, BSN, Program Manager	847-723-8538
	Cathy Majcher, RN, Outpatient Coordinator	847-827-9060
	Josie Rowan, RN, Outpatient Coordinator	847-268-8200
Weekend & Evening:	Leonard Klein, MD, Transplant Physician	847-827-9060
	Jacob Bitran, MD, Transplant Physician	847-268-8200

Review of Possible Symptoms or Complications

It is normal to have a headache and achy bones for a few days. You might feel tired and have mild flu-like symptoms. It is also common to have some pain and bruising at the needle site.

Symptoms that Require Medical Attention

- Temperature of 100.5 degrees Fahrenheit (38 degree Celsius) or higher.
- Increased redness, bleeding, swelling, drainage or pain at the needle site.
- Muscle weakness, swollen lymph glands, or severe headache within two weeks of donation.
- Severe skin rashes or flares in pre-existing skin conditions such as psoriasis or eczema
- Abdominal pain.
- Inflammation in the eyes.

CONTACT YOUR TRANSPLANT PHYSICIAN'S CLINICAL OFFICE IF YOU EXPERIENCE ANY OF THESE SYMPTOMS. ***In the event of life-threatening emergency, call 911 and/or take a copy of these instructions to the Emergency Room.***

Use of Pain Medications

- Use Tylenol or acetaminophen products for minor pain.
- Do not use aspirin during the first week after the donation unless instructed to use aspirin by a physician. Aspirin decreases the blood's ability to clot and increases the risk of bleeding.

Care for Needle Site

- *(If a central line was placed, you will receive a separate set of instructions)*
- Keep the bandage on for at least 4 hours. Rewrap the bandage if too tight.
- If the needle site bleeds, apply firm pressure and raise your arm up straight into the air until bleeding stops (usually 5 to 10 minutes)
- Cold washcloths or ice packs can be used to help reduce swelling, bruising, and bleeding at the needle site during the first 24 hours.
- Note: Do not leave cold pack on longer than 20 minutes at a time and do not reapply for at least 1 hour.
- After the first 24 hours, use warm moist washcloth or a warm pack.

Physical Activity Recommendations and Limitations

General Recommendations

- You may return to light activities within 60 to 90 minutes after donation if you feel well enough.
- If you feel lightheaded or dizzy, lie down immediately. Raise your feet above your head by resting them on a cushion or chair.

Exercise Recommendations

- Avoid strenuous activity for the rest of the day.
- Do not perform any heavy lifting or pulling for 24 hours.

Work & School Recommendations

- Wait 24 hours before operating heavy machinery, climbing ladders, or working from heights.
- Wait 72 hours before piloting a plane or working as flight crew. (It is OK to fly as a passenger).

Dietary and Other Recommendations

- Have a snack before you leave and eat a well-balanced meal this evening.
- Drink plenty of fluids (8-10 glasses of water) for next 24 hours.
- Do not drink alcoholic beverages for the next 24 hours.

Response to Bills Sent

If you receive a bill related to your donation, please do not store it or throw it away. Instead, call the Billing Department at Advocate Lutheran General Hospital (847.723.2399) for assistance.

Follow-Up

A representative from your transplant physician's office will be in contact with you on a regular basis until you report full recovery. Please feel free to contact your transplant physician's office with any questions, concerns, or problems.

Note: It is important that you report all of your symptoms even if you previously reported being fully recovered.

Dear Patients and Families:

We want you to know that you are in good hands and are among a team that is committed to providing you with outstanding health care. As you enter our program, you and your family will be meeting with a team of dedicated professionals. Together, we will work to help you and your family cope with the medical, emotional and financial aspects of your treatment.

The information in this book will help you become more familiar with the roles of your team members and help you learn more about your treatment. We expect that you will have many questions and concerns. We encourage you to contact us as needed. We look forward to caring for you. Having a blood and marrow stem cell transplant can be overwhelming. The decision can be harder for those who just received a recent diagnosis of a life-threatening illness. A transplant offers the possibility of a future, but it does not come with a guarantee. Meeting with the doctors and other members of the transplant team at Advocate Lutheran General Hospital, and reading this handbook, will help you make decisions about your care.

Do not be afraid or embarrassed to ask your doctor, or any team member, to repeat something or explain things in a way that you are better able to understand. We encourage you to use the information given in this book as a guide when you talk to a member of the transplant team. If you and your doctor decide a transplant is the best plan of care for you, remember you are not alone as you go through treatment. The Advocate Lutheran General Hospital Bone Marrow Transplant Program team is here to support you through every part of your journey.

Sincerely,

The Staff of Advocate Lutheran General Hospital Bone Marrow Transplant Program

- Introduction -

Your doctor has recommended a stem cell transplant as part of your treatment. This booklet has information to help guide you during your journey through stem cell transplantation. There is an explanation of the treatment, definitions, important phone numbers, and resources.

You may need to read the information more than once and go back to it during the transplant treatment. You should bring this book with you during your hospital stay.

Please share this information with your family and care partners. Understanding this information will prepare your family and care partners on how best to help you when you do not feel well.

While this packet has important information, it does not have all the answers. Please feel free to ask your doctors and nurses any questions you may have. See the list of important phone numbers in this booklet for your transplant doctor's office number.

Advocate Lutheran General Hospital is committed to exploring new, more effective cancer treatments to promote quality of life and improve health. We are dedicated to bringing innovative, state-of-the-art options to cancer patients in a safe and effective environment. Many of today's best chemotherapy agents were available to Lutheran General patients years earlier because of the hospital's clinical trials.



Inspiring medicine. Changing lives.

Advocate Lutheran General Hospital Main Number: 847-723-2210

Web site: www.advocatehealth.com/lutheran

Advocate Lutheran General Hospital is committed to exploring new, more effective cancer treatments to promote quality of life and improve health. We are dedicated to bringing innovative, state-of-the-art options to cancer patients in a safe and effective environment. Many of today's best chemotherapy agents were available to Lutheran General patients years earlier because of the hospital's clinical trials.

The Hematopoietic Progenitor Cell Transplantation Program (HPCTP) *also known as The Stem Cell or Bone Marrow Transplant Program* was initiated in 1991.

- ❖ Accredited by the Foundation for the Accreditation of Cellular Therapy (FACT) for Adult Autologous stem cell transplants, Bone Marrow Harvest, Peripheral Blood Stem Cell Collection, and Cell Processing. Lutheran General is one of only a few hospitals in the northwest suburbs to have earned this recognition. [NB1]
- ❖ The first oncology facility in the United States to have 100% of the nurses become certified Oncology Nurses (OCN), and 100% of all eligible nurses become certified to work with Bone Marrow Transplantation patients.
- ❖ Member of the International Bone Marrow Transplant Registry (IBMTR)
- ❖ Accredited with the National Marrow Donor Program (NMDP)
- ❖ The cancer program is approved by the Commission on Cancer.
- ❖ The Apheresis Center is the only facility of its kind in the northwest suburbs.

Advocate Lutheran General Hospital's cancer care program and physicians are dedicated to providing comprehensive, *patient-centered*, high quality services to all those in need.

Transplant Team



DOCTORS

Primary Oncologist

Your primary oncologist has been caring for you and has sent you to the transplant doctor. He or she will get updates about how you are doing during the transplant treatment.

Transplant Doctor

Your transplant doctor will take care of you during the transplant and send updates to your primary doctor.

Radiologist

A radiologist studies and reads your x-rays and scans.

Other Specialty Physicians

You may need to see other specialist doctors during the transplant. Your transplant doctor is always the doctor in charge of all your care during the transplant treatment. If you are confused by information given to you by the doctors, always ask your transplant doctor any questions you have.

NURSES

Inpatient Nurse

These are chemotherapy/transplant nurses who will take care of you while you are in the hospital. These nurses have special training in taking care of transplant patients, giving chemotherapy and transplant, and helping you with any side effects you may get. They will stay in close touch with your transplant doctor. Call your transplant nurse at any time if you have questions or problems.

Advanced Practice Nurse This is the nurse with additional training and education in oncology/transplant. She will be in close contact with you, your doctors and other members of your transplant team.

Outpatient Transplant Nurse Coordinator

The outpatient nurse coordinator works with your transplant doctor. This nurse has had special training in stem cell transplant. This nurse will set up any tests you need for the transplant. She or he will teach you about the transplant. This nurse is your contact at the doctor's office. You will call this person with any questions or problems that you have.

Home Care Nurse

This nurse will help you if you ever need to have care at home. Your transplant nurse coordinator will work with the home care agency to set this up if needed.

OTHER STAFF

Apheresis / Infusion / Collection Specialist

The Apheresis Center has nurses with special training using the cell separator machine. They will take care of you while you are getting your cells collected. There is also a transplant doctor at the collection center.

In-Patient Pharmacist

A transplant pharmacist checks all of your medicines for you while you are in the hospital. This person also checks for drug interactions and allergies. They will also answer any questions about your medicines at home.

Transplant Program Coordinator

The Transplant Program Coordinators work at the hospital and help to ensure things go smoothly between the hospital and the doctors' offices. They schedule stem cell collections and transplant admissions. They work with your insurance to verify what parts of your treatment will be covered. They can help find donors that are not related to the patient if needed. They also make sure that the transplant facility meets all federal, state and local regulations.

Social Worker / Psychologist

A social worker is able to help you and your family to cope with feelings and other concerns you may have. Social workers can also help with issues like transportation and financial help.

It is required as part of your pre-transplant testing that you meet with a social worker. See page 10 of this book.

Dietitian

Your transplant dietitian will help you to make sure that you are eating right. They will help you to choose the right foods to eat for your condition.

Chaplains / Spiritual Care

There are chaplains at the hospital that can see you for religious and spiritual support. You can ask your nurse to call a chaplain if you would like to speak with one.

Financial Coordinator

Physical / Occupational Therapy

Care Management



Your Transplant Team

MEDICAL ONCOLOGISTS

Advocate Medical Group	Illinois Cancer Specialists	Oncology Specialists, S.C.
1875 Dempster Street #640 847-723-4400	8915 W. Golf Rd. Niles, IL 60714 847 827-9060 847-827-9490 After hours	1700 Luther Ln. Park Ridge, IL 60068 847 268-8200
	Leonard Klein, MD David Hakimian, MD John Eklund, MD Robert Galamaga, MD	Jacob Bitran, MD Navkiranjit Gill, MD Pamela Kaiser, MD

Outpatient Transplant Nurse Coordinators

Advocate Medical Group

Katharine Szubski, R.N.
847-723-4400

Illinois Cancer Specialist (ICS)

Catherine Majcher, R.N.
847- 827-9060

Transplant Program Manager

Mary Hurd, R.N., B.S.N., MHA
847-723-8538

Transplant Program Contacts

Nancy Blanchard, B.A.
847-723-8929

Amy Cantore, B.S.H.A.
847-723-8252

Apheresis/Infusion Center

Apheresis
Lynn Myers, R.N.
Agnes Eckley, R.N., OCN

Infusion
Valerie Diaz, R.N.
847-723-5070

847-723-8780

Social Worker

In-Patient- Irene Rooney
847-723-7797

Financial Coordinator - AMG

Shannon Pintz
847-655-8543

Insurance Verifier – Advocate Lutheran General Hospital

Mary Aulesio
847-723-7398

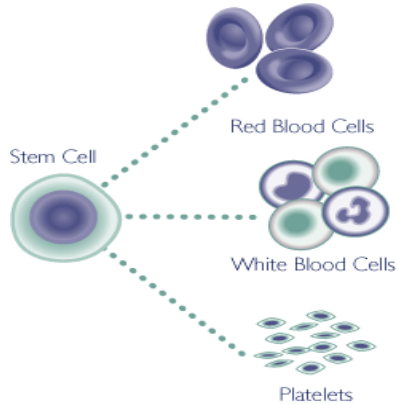
Personal Phone Numbers	
Emergency	911
Home Health Agency	
Care Partner	

Please call the appropriate number and identify yourself as a transplant patient and state the reason for your call --- Emergency or other.

Understanding Stem Cell Transplant Basics

Inside our bones is a soft, sponge-like material called bone marrow. Bone marrow contains stem cells that are capable of producing the different types of blood cells in our body. Stem cells divide to form more stem cells, or mature into white blood cells, red blood cells or platelets.

Red Blood Cells (RBC): RBC's contain hemoglobin (Hgb), a protein that carries oxygen from the lungs to the rest of the cells in the body.



White Blood Cells (WBC): WBC's are the body's defense against infection. There are many different types of WBC's. Each of the different types of white blood cells plays a specific role in destroying foreign organisms to your body.

Platelets (PLT): PLT's are sticky, disc-shaped cells that allow the blood to clot, which prevents excess bleeding.

Blood and marrow stem cell transplants treat many diseases in both children and adults. In a blood and marrow transplant, healthy stem cells are given to replace damaged bone marrow.

Damaged bone marrow can be caused by:

1. Bone Marrow Failure
2. Destruction of marrow by a disease
3. Chemotherapy and radiation

Why Do I Need a Transplant?

- If you have a blood disease or if your bone marrow is failing, a transplant can help you by replacing your damaged stem cells with healthy ones.
- A transplant can also allow the doctor to give you a very high dose of chemotherapy (with or without radiation) to kill your cancer cells. This high dose treatment destroys your bone marrow, so the stem cells are given back as a "rescue".

People with the following problems may need a transplant:

- Aplastic Anemia
- Multiple Myeloma
- Hodgkin's Disease
- Lymphoma
- Leukemia
- Pediatric solid tumors (Neuroblastoma)
- Immune System Diseases
- Myelodysplastic Syndrome

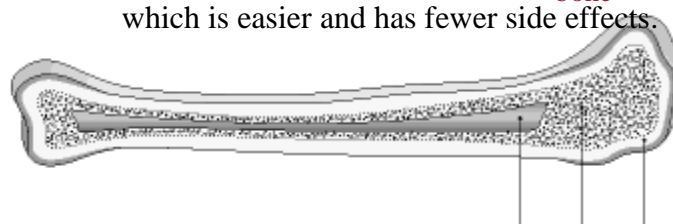
A stem cell transplant is a procedure used to “rescue” the bone marrow that has been destroyed by high doses of chemotherapy and/ or radiation therapy. There are different types of stem cell / bone marrow transplants. The name of each type describes who the cells came from. They may be called by different names, but all of the types of transplant have the same goal, to get rid of bad cancer cells and replace them with good cells.

- **Autologous Transplant**—the stem cells are collected from the patient before the high-dose chemotherapy and returned to the same patient as part of the transplant.
- **Allogeneic Transplant** – the stem cells are collected from someone other than the patient. The donor may be a family member or someone that is found to match the patient from a registry of unrelated donors.
- **Syngeneic Transplant** – the stem cells are collected from the identical twin of the patient and then transplanted to the patient

Further on in this book, different types of transplant will be explained in more detail.

Source of Stem Cells

Before you begin your treatment we will need to collect the stem cells. While stem cells are made in the bone marrow they can also be found in your blood stream. These are called peripheral blood stem cells (PBSC). Stem cells in the marrow are collected through a bone marrow harvest, which is done as surgery with the patient put to sleep. Blood stem cells are collected from the veins by a process called apheresis, which is done as an outpatient. Most stem cells are collected by apheresis which is easier and has fewer side effects.



Care Partner

During the transplant, you will need to have one person who will help you; this person will be your care partner. It can be a family member or a friend. Your care partner will need to come with you when you see the doctor and when you go to the clinic. They can call and talk to your doctor or

nurse for you if needed, and help you deal with stress, your instructions at Discharge, and your post discharge care. You **must** have someone, probably your Care Partner, stay with you for the first 1-2 weeks after your transplant. They will need to help you at home with your medicines, shopping, cooking and anything else you may need. They will also help you with stress, your instructions at discharge, and your post discharge care,

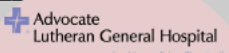
Transplant ID card

You will receive a transplant ID card that contains your name, date of transplant, and your Doctor's phone number. Please keep this in your wallet or on your person at all times. It will serve as a valuable resource should you be admitted to the emergency room or have transplant related issues that would require someone to contact your doctor.

Front

<i>Stem Cell Transplant Patient</i>	
In an Emergency Call 911	
If I am hospitalized please contact my transplant physician	
Dr. Leonard Klein, MD Phone: 847-827-9060 After Hrs: 847-827-9490	Dr. Jacob Bitran, MD Phone: 847-268-8200
<small>Transplant Physician On-call schedule available online: http://ghonline.advocatehealth.com > Departments > Hematopoietic Stem Cell Transplantation > Transplant Weekend On Call Schedule</small>	

Back

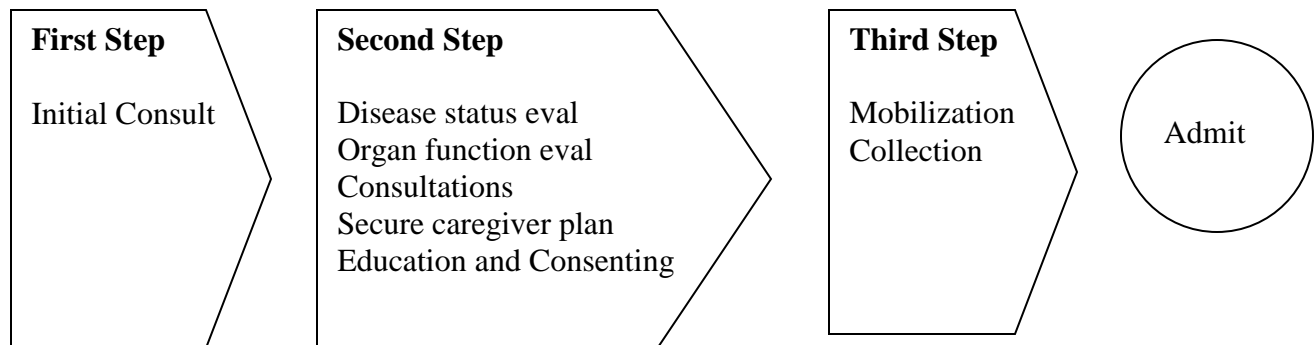
<i>Stem Cell Transplant Patient</i>	
Patient Name: _____	
Transplant Date: _____	
<small>*Patients are at an increased risk for infection within first 100 days of transplant</small>	 <small>Advocate Lutheran General Hospital Making medicine. Changing lives. Hematopoietic Progenitor Stem Cell Transplant Program</small>



Autologous Transplant

This type of transplant allows your doctor to collect your own stem cells, process and freeze them, and then store them. This allows your doctor to give you high doses of chemotherapy (with or without radiation) to kill any remaining cancer cells in your body. Your own cells will then be thawed and infused back to you 24 hours after the chemotherapy and/or radiation finish. It is hoped that your cells will engraft, mature and be healthy once again. It is our goal that this transplant will keep your disease in remission for an extended period of time or even possibly cure your disease depending on your diagnosis.

Getting ready for transplant can be a hard time for patients and their families. How much time it takes between your first visits with the transplant doctor and when you get your stem cells transplanted can be a long time. Some patients may need more chemotherapy or radiation to further shrink their disease before transplant. Tests are needed to find out if you are able to have a transplant. How long it will take depends on your disease status and your general state of health. Every patient does not require every lab test, every organ function test or every consult appointment listed below.



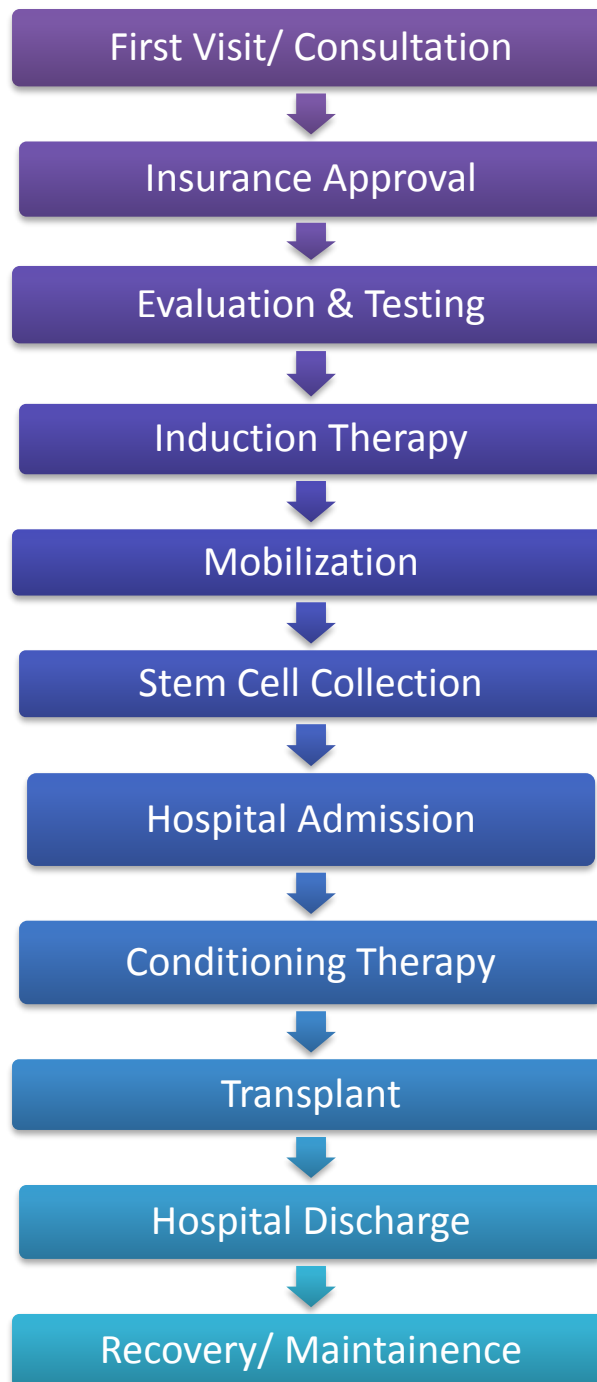
First Step: Meeting with the Transplant Team

- Initial consult:
 - Your medical history is reviewed, and information about stem cell transplants is given.
 - A physical exam is done. This appointment will help you to decide if a transplant is the right treatment for you.
 - The nurse coordinator will conduct an educational overview during this visit.
 - A financial coordinator will contact you with any insurance issues.

Timeline

The transplant process takes about 3-6 months. The time it takes for each step of the transplant may be different for each person. While the dates may change the process will be the same. You can follow this timeline throughout the booklet to see where you are in your transplant journey.

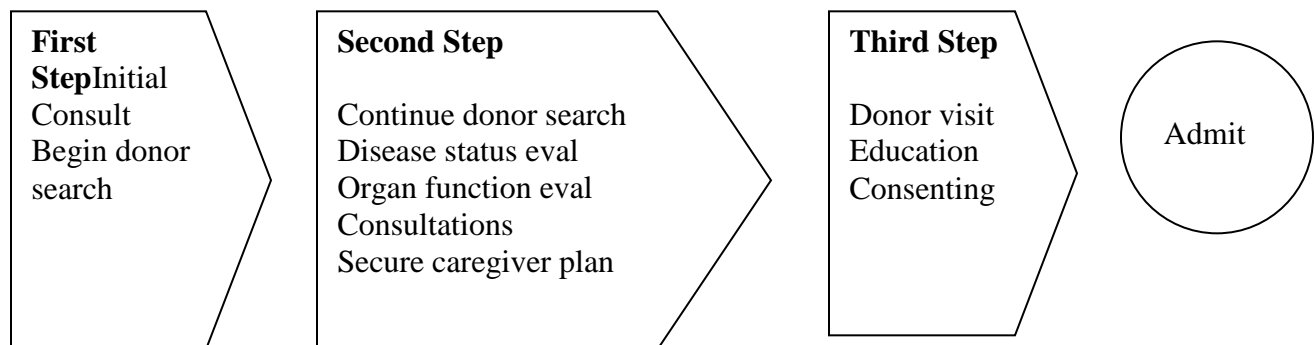
Autologous Transplant Timeline



Allogeneic Transplant

This type of transplant is when another person donates stem cells to you. It might be from a brother or sister (known as “matched sibling”), an identical twin (known as syngeneic), or from a volunteer (known as a “matched unrelated donor”). This type of transplant allows your doctor 2 choices of chemotherapy, with or without radiation, to fight your disease. Depending on your disease and your current health condition, the doctor will tell you which type is best for you. An allogeneic transplant that uses high dose therapy is called “myeloablative” and the goal is to wipe out all your disease bone marrow and replace it with your donor’s. The other allogeneic transplant type uses less toxic doses, is called “mini” or “non-myeloablative” and its goal is to weaken your marrow and mix it together with your donor’s.

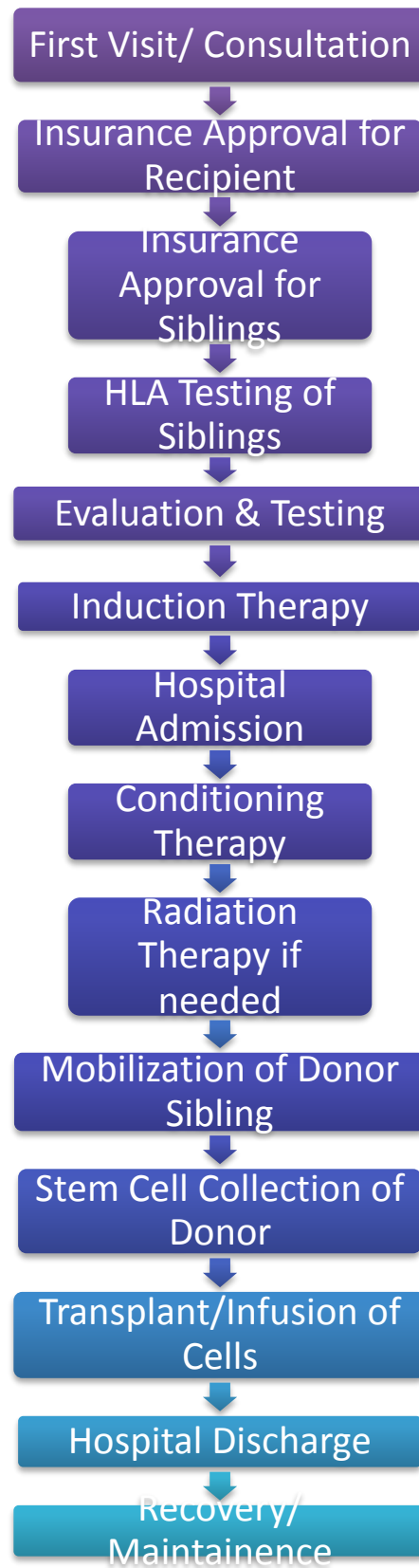
Getting ready for transplant can be a hard time for patients and their families. How much time it takes between your first visit with the transplant doctor and the day you have your transplant can be a long time. The search for a donor can take a lot of time and can be hard on your emotions. Some patients may need more chemotherapy or radiation before transplant to further shrink their disease. Many tests are needed to find out if your body is strong enough for transplant. How long this part takes depends on your disease status and your general state of health. Every patient does not require every organ function test or every consult appointment.



First Step:

- **Initial consult:**
 - Your medical history is reviewed. Information about the transplant process is shared to help you and the doctor know if a bone marrow transplant is the right treatment for you.
 - A physical exam.
 - The nurse search coordinator will conduct a brief educational overview.
 - A financial coordinator will contact you with any insurance issues.
- **Donor Search:**
 - Some blood work from you is drawn to start the search.
 - The nurse coordinator will explain this process and get information about your brothers and sisters.

Allogeneic Transplant Timeline



- Transplant -

- ❖ Once your stem cells are collected, you are ready for transplant.
- ❖ You will have about a week to rest after the cell collection and before you are admitted to the hospital for your transplant.
- ❖ During that week you will see your doctor to review the transplant treatment.
- ❖ You will sign consents for treatment in your physician's office.



 Advocate Lutheran General Hospital

Inspiring medicine. Changing lives.

Admission to the Hospital

You will need to stay at the hospital for the transplant and will be there for about 3-4 weeks. You will have your own private room designed for transplant patients. These rooms have special filters to keep the air clean and extra filters on the faucets and showers. It is important that you do not remove any of these filters as they are there for your protection. Each room has a bed, chair, private bathroom, phone, and television. There is also small kitchen area that has an ice machine, refrigerator, microwave and blender that you can use.

Things you may wish to bring to the hospital:

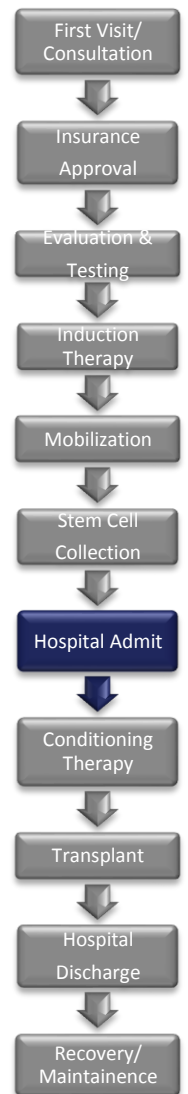
- ❖ Comfortable clothes – *it is a good idea to get dressed every day. Sweatpants and shirts that button or zipper up the front work well. You may bring your own pajamas or use a hospital gown for the night.*
- ❖ Jewelry – *Please do not bring any valuable jewelry. The hospital cannot be responsible if it is lost.*
- ❖ Rubber soled shoes or slippers for daily walks in the halls.
- ❖ Hat, scarf, turban or wig.
- ❖ Soap, toothpaste and shampoo- *you may bring your own or use the ones supplied by the hospital.*
- ❖ Toilet paper and tissue- *the hospital will provide, but you may also wish to bring in your own softer brands*
- ❖ An electric razor (no other razors can be used).
- ❖ Pillow, blanket or comforter.
- ❖ Pictures of family or friends.
- ❖ Snacks in Ziploc bags that you can keep in your room (dry cereals, crackers, and cookies).

Items to help pass the time

- ❖ Laptop
- ❖ Cell Phone
- ❖ Books, magazines, CD / DVD player / Radio
- ❖ Hobbies : knitting, stitching, crossword puzzles

Visitors

Your family and friends are an important part of the support you need during your transplant and recovery and can visit with you while you are in the hospital. There are no set visiting hours, but you will need to rest and not get tired out by visitors. Your care partner can stay with you for as much time as she/he wants. Please limit the number of visitors in your room to help prevent infection and allow you to get enough rest.



Friends and family should not visit if they are sick, think they may be getting sick (sore throat, cough, sniffles), or have the following:

- ❖ Cold, flu, upper respiratory infection, or any known infection
- ❖ Infectious rash, shingles, skin infection, or open sores on their hands
- ❖ Recent exposure to an infectious disease
- ❖ Chicken pox in the last 6 weeks or a rash that looks like chicken pox
- ❖ Flu vaccine in the last 2 weeks
- ❖ Oral polio in the last 6 weeks

All visitors

- ❖ Must wash their hands before going into your room
- ❖ Should not use the bathroom in your room. There are public restrooms available for their use.
- ❖ Are welcome to bring you cards and gifts. However, fresh flowers and plants are not allowed in your room because the dirt and stagnant water can sometimes carry harmful germs. It is a good idea to let your family know about this restriction.

The Hospital Routine

The nurses at Advocate Lutheran General Hospital are specially trained to care for transplant patients. It is these nurses who will be with you every day; therefore, it is important for you to let them know of any concerns you have during your stay. There are many different staff members involved in your care that may be coming and going throughout your time in the hospital.

During your hospital stay we will closely monitor your progress to see how your treatment is going. Some things we will monitor during your stay:

- ❖ **Vital signs-** blood pressure, pulse, and temperature will be taken several times a day
- ❖ **Blood work-** your blood will be drawn from your catheter at least once a day. This is done to monitor your blood counts, kidney function, liver function, and other things such as potassium, sodium, and magnesium. Your transplant physicians may adjust your medications based on these results.
- ❖ **Fluids-** we will monitor how much you eat, drink, and go to the bathroom. It is important to keep track of the fluids you are taking to be sure you are getting enough fluids for good hydration and not retaining too much fluid.
- ❖ **Weight-** the staff will weigh you regularly to monitor your fluid and be sure you are getting enough calories.
- ❖ **Symptoms-** the staff will ask you often if you are having any nausea, pain, or other problems. It is very important to keep all of your transplant team informed of how you are doing. If problems are reported early, actions can be taken quickly to prevent them from getting more serious.

It is important to be as active as you can and even exercise while you are in the hospital. Daily walks with family outside of your room are helpful. There are many germs in the hospital so you will need to wear a mask and gloves when going outside of your room and throw them away when you come back into your room. You should also wash your hands when you come back into your room each time.



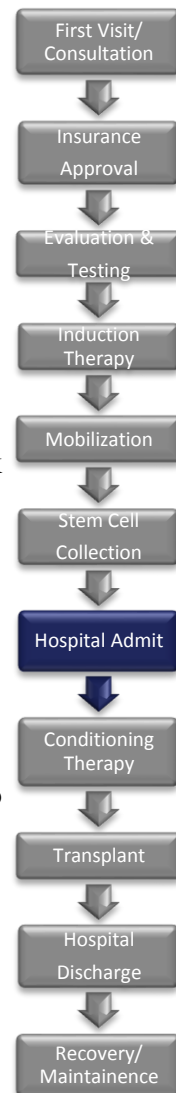
Showering/ Bathing

Because you have a Central Venous Catheter, each day while you are in the hospital, you will need to take a special bath using Chlorhexidine (CHG) wipes. You will receive instructions on how to use these wipes, and your nurse or nursing care technician will be available to help you. These are special moist wipes used to lower the number of germs commonly found on your skin. By decreasing the number of germs, you decrease your risk of developing an infection. After using the CHG wipes your skin will feel sticky until the CHG dries. Allow CHG to air-dry. This helps to lock in the additional layers of germ fighting protection

You may take a shower while you are in the hospital. Make sure your line is covered before you shower and be careful and avoid getting this area wet. After your shower you will still need to use the CHG wipes to help protect your skin from germs. It is important that you wait 1 hour after your shower before you use the CHG wipes. Waiting for one hour will allow your skin pores to return to normal and prevent the CHG from getting into the deeper layers of your skin and causing irritation.

Important things to remember while you are using CHG wipe

- **DO NOT TOWEL DRY!**
- **DO NOT use other skin supplies from home**
- **Wait 1 HOUR after showering before using the CHG wipes**



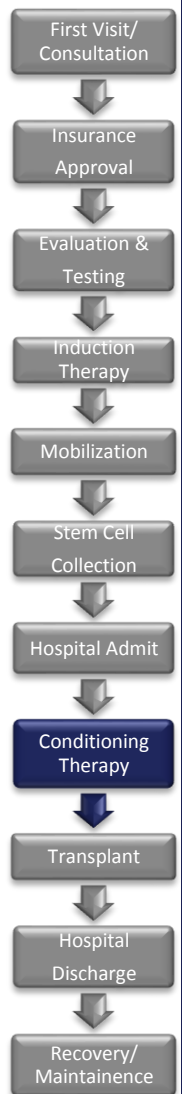
Conditioning Therapy/ Preparative Phase

You will start high dose chemotherapy or radiation on the first day. It may be given over a few days or over a week. The choice of chemotherapy treatment depends on the type of cancer and its stage. Your doctor will decide what medications and doses are best for your disease. You will learn how the drugs work and how you will receive them.

Side Effects of Chemotherapy

The high-dose chemotherapy can cause different side effects as it kills cancer cells and normal cells. Most of these side effects will happen within one to two weeks after the chemotherapy. Other side effects may not occur until weeks or months later. Your body will repair the damage from the chemotherapy, but it will take time. You will be given medications to help prevent some of these side effects and you and your care partner will also be taught ways to reduce and treat these side effects.

- ❖ **Muscle aches and feeling like you have the flu**
- ❖ **Fever**
- ❖ **Nausea & Vomiting-** you will be on anti-nausea medication but it is important to talk to your nurse about how you are feeling so we can prevent nausea from becoming vomiting. Drinking fluids, avoiding strong odors, and eating frequent small meals can help with your nausea.
- ❖ **Loss of appetite/ Loss of taste-** this is a common side effect but nutrition is important to help your body recover. Think of food as the medicine you need to get better. Trying to eat something each meal is important to help re-build your body and recover from transplant.
- ❖ **Diarrhea-** it is common to experience diarrhea because of the effect of chemotherapy on the intestine. However, frequent diarrhea can cause irritation and dehydration. Diarrhea can also be the sign of an infection and samples will be taken to check for bacteria.
- ❖ **Mouth sores-** our mouths naturally carry a lot of bacteria. Therefore it is important you keep your mouth clean so that bacteria do not enter your blood stream when you begin to develop mouth sores. You should use the provided medicated mouth wash and should brush your teeth with a soft toothbrush. Avoid using floss and eating crunchy foods that could scrape your mouth.
- ❖ **Hair loss-** See the resources section for more information.
- ❖ **Fatigue / Feeling very tired-** fatigue can be caused by stress, lack of exercise, poor diet, and low red blood cell counts. You will be given blood transfusions as needed and you will get more energy as your cells begin to engraft. Fatigue may be something you have for several months after transplant and you may need to adjust your routine and save energy for those things you want to do.
- ❖ **Pain-** pain can be controlled with medication and we are committed to pain management. Let your nurse know if you are in pain so we can work to find the right medication and dose for you.



Let your nurse or doctor know as soon as you begin having any side effects or problems.

Low Blood Counts

The chemotherapy you receive during the transplant will lower your red blood cells, white blood cells and platelets.

Hemoglobin-the part of the red blood cells that carry oxygen through your body. When these are low, it is called **anemia**. This may make you feel tired, short of breath and cold all the time.

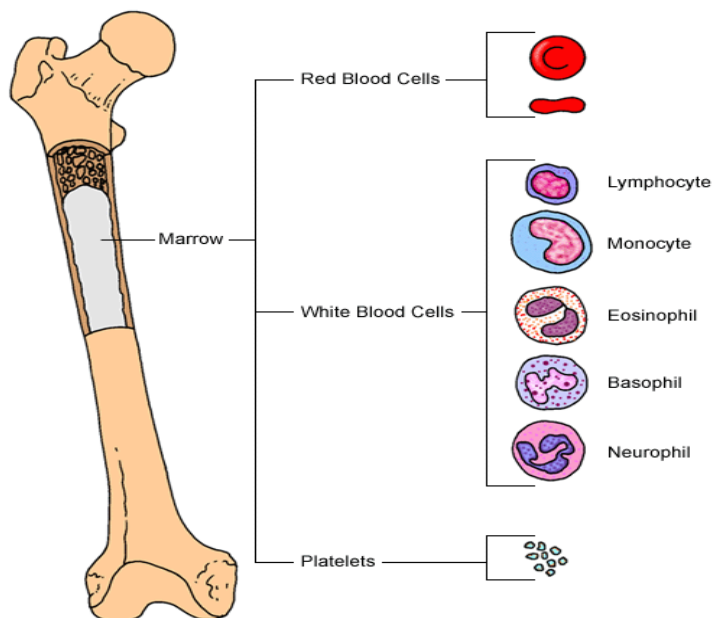
Platelets- part of the blood that clumps together to form a clot. When your platelets are low, you may bruise easily, bleed from your gums when brushing your teeth or have nosebleeds. Any cuts or injuries will bleed more during this time.

White Blood Cells (WBC) - are a part of your immune system that fights infection. The absolute neutrophil count (ANC) is the total number of white blood cells you have to protect you from infections. When your ANC is lower than normal it is called **Neutropenia**. When you are neutropenic, you are at risk for infections. You will need to be careful during this time to avoid getting sick.

Blood Test

Normal Level

White Blood Cells (WBC)	4000 – 10,000
Hemoglobin (HGB)	12 – 16
Platelets	140,000 – 300,000



Neutropenic Precautions

When your white blood cells count is low you are at risk for getting an infection. Some ways to prevent getting an infection include:

- Washing your hands frequently- *This is the best way to prevent infections.*
 - You, your family, and visitors should wash hands with soap and warm water often.
 - It is important to wash before eating and after using the bathroom.
- Do not go into crowded areas without wearing a mask until your doctor tells you it is safe.
- Stay away from people who are ill
- No kissing, hugging and hand shaking
- No contact with anyone who has gotten vaccines recently
- Brush teeth 2-3 times per day with soft toothbrush only
- Use an electric razor so you don't get cuts
- Clean cuts or scrapes and use antibiotic ointment on them
- No gardening or working with plants, no fresh cut flowers
- No cleaning up after your pets

You will need to eat from a special diet, called a **Low Bacteria or Neutropenic Diet**. During this time you are not allowed to eat fresh, uncooked vegetables such as lettuce and tomatoes. All vegetables must be cooked. Only thick skinned fruit that can be scrubbed prior to opening may be eaten, such as bananas, oranges and melons. Thin-skinned fruit, such as apples, pears, and grapes must be cooked prior to eating, canned fruit is okay. Deli meats and cheeses are also not allowed during this time.

See the **Low Bacteria Diet, Guidelines for Eating Fresh Fruits and Vegetables**, and **Transplant Patient Food Safety Guidelines** in the resources section of this handbook for more detailed diet information.

Signs of an Infection:

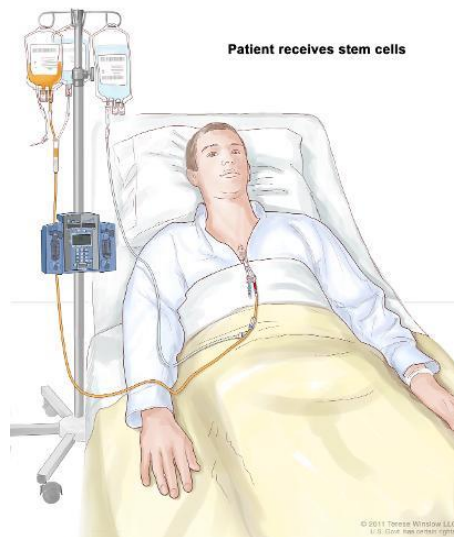
- Fever 100.5 degrees or higher
- Chills
- Cough with colored phlegm
- Pain or burning when you urinate
- Any areas of redness or swelling
- Mouth sores, white patches in your mouth or a sore throat

Call your doctor or nurse right away if you notice any of the above

Stem Cell Transplant/ Infusion

A few days after the high-dose therapy is complete, you will receive your stem cells. The day you get your stem cells is called Day 0. If the stem cells were frozen they will be thawed and given to you in your hospital room. The infusion can take about 20 minutes and is similar to a normal blood transfusion.

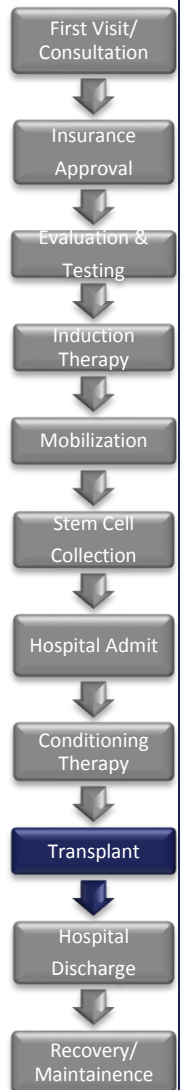
There are few side effects of the infusion of stem cells. Your nurse and or doctor will discuss some of the possible side effects with you before your infusion. There is a preservative in with the cells that will cause a funny taste in your mouth. This preservative has a smell like garlic and for about 24 hours after getting the cells others will smell this when they enter your room, but you will not smell it. Also, your urine may be pink colored for about 24 hours after getting the cells.



Engraftment

After your infusion the cells will travel into your bone marrow and go to work making new blood cells. This may take anywhere from ten days to three weeks after your transplant. During this time, you may need to get bags of blood and platelets. There will be signs that your stem cells are growing (engrafting) and beginning to produce new blood cells. As this starts, you may notice pain in your bones, especially your pelvis, lower back, and thighs. As your blood counts begin to rise, your white blood cells will start to fight and help stop infections. If you had fevers while your white blood count was low, they may get better now. Your doctor or nurse will let you know when you may stop taking antibiotics and when you can begin your normal activities again.

You will no longer need platelet transfusions and will notice that you do not bruise or bleed as easily. You will not feel as tired and will soon no longer need red blood cell transfusions. You also will notice that other side effects you have been feeling will begin to get better.



Discharge / Going Home

You will be discharged from the hospital only when:

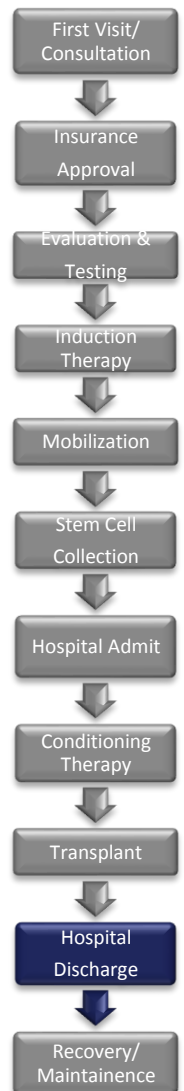
- ❖ Your white blood counts have returned to normal
- ❖ You are able to eat enough calories each day
- ❖ You are drinking enough fluid
- ❖ You have someone to help you care for yourself at home
- ❖ You can take all of your medicines by mouth

Your nurse will give you special written instructions (discharge instructions) to follow at home. Your nurse will go over the discharge instructions with you and your care partner and answer all of your questions. You will also be given information on what prescription medications you should take at home. Some of your symptoms may be treated using over-the-counter medications. You should check with your doctor before taking any new over-the-counter or prescription medication. The central line in your chest may be removed before you go home, or you may go home with it until your platelets are high enough to have it safely taken out. Please do not hesitate to call us with any questions or concerns. We are here to help.

While at home

- ❖ Follow your discharge instructions
- ❖ Follow the low bacteria diet. Your doctor will let you know when you can stop
- ❖ Take your prescribed medications
- ❖ Check with your transplant doctor before taking over-the-counter medications
- ❖ Tell your transplant doctor about any new medications being prescribed by other doctors
- ❖ Call your transplant physician if you have any symptoms, questions, or concerns

When in doubt check it out!



- Recovery-

- ❖ After your discharge from the hospital you will need to rest and recover at home
- ❖ You will have regular appointments with your transplant physician to see how you are recovering.
- ❖ Know that you can contact your transplant doctor or nurses if you have any questions or concerns during your recovery.
- ❖ Your doctor may start you on maintenance therapy to help maintain your cancer remission
- ❖ You and your doctor together will decide when it is a good time to go back to work. You may need to return part time at first, working fewer hours per day or fewer days per week.



Once you get home, you may find that you may not feel as well as in the hospital. This is because you will need to do more to take care of yourself at home. It is important to eat well, drink fluids, get enough sleep, and be as active as you can when you get home.

Follow-up Care

It is important for the transplant team to see you often to be sure you are making good progress and not having any new problems. An appointment will be set up for you to see your doctor shortly after you have been released from the hospital. At first you will visit the doctor 1-2 times per week.

Around 3 months after the transplant, your doctor will run tests to check on your cancer. He will then meet with you to go over the tests and the results of the transplant. At this time, you will talk about what happens next. Some patients may not need any more treatment. Some patients may go on **maintenance therapy**, which is chemotherapy given at small doses for up to a year or more.

You will have regular visits for many months to check your disease and for any long-term side effects. Even after you have returned to seeing your oncologist, the transplant team will receive updates about you and follow you.

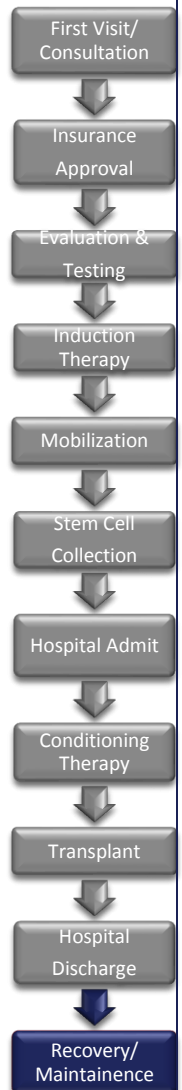
Eating & Drinking

You will need to follow the **Low Bacteria Diet** found in the resources section of this handbook while you are at home. Your doctor will let you know when you may return to your normal diet. Eating a well-balanced, high calorie, high protein diet is important in helping you recover from the transplant. If you are having difficulty eating 3 meals a day because of nausea, or if you get full easily, try eating 5-6 small meals a day. Drinking fluids is also very important to your recovery. You should drink plenty of water and juices but you can also get fluids through soups, Jello®, and ice cream. Gatorade and other similar drinks are excellent in helping to replace salts and minerals if you are having problems with diarrhea or vomiting.

Infections

While your risk of infection has decreased after your stem cells have engrafted, your immune system will take much longer to completely recover. During this time you will be more prone to infections or viruses. There are many things you can do to help prevent infection:

- ❖ Wash your hands frequently with soap and water
- ❖ Follow a Low Bacteria Diet
- ❖ Avoid those who are sick, even those with colds
- ❖ Avoid home construction projects as molds and fungus are released into the air
- ❖ Avoid soil, lawn waste, or compost
- ❖ Avoid cleaning up pet waste



Vaccinations

You will need vaccinations after your transplant to help your immune system recover. It is important for you to listen to your transplant doctor's recommendations as to what vaccinations you should receive and when you should receive them. Getting a vaccination too early, before your immune system has recovered, could make you very sick. Do NOT get any vaccinations without first consulting with your transplant doctor. For general vaccination guidelines after transplant see the Immunization schedule in the resources section of this handbook.

Shingles

Shingles is caused from the same virus that causes chicken pox. Chicken pox usually occurs during childhood and is then dormant in the body for many years. Patients whose immune system is suppressed after a bone marrow transplant are at risk of the virus becoming active again. Once the virus is active, shingles will appear as pain or burning. Then raised, red, fluid filled blisters will emerge on the skin. While shingles can appear anywhere on the body it generally follows a nerve and occurs as a strip of rash or pain from the back to around the front of the chest or stomach on one side. Tell your doctor immediately if you notice any of these signs of shingles.

Sun Exposure

The chemotherapy and/or radiation and other drugs given during the transplant can increase the sensitivity of your skin to sunlight. Protect your skin with sun protection factor (SPF) of 15 or higher when outdoors even on overcast days. Wear protective clothing such as hats, sunglasses and long-sleeved shirts and pants.



Smoking and Alcohol

The chemotherapy and/ or radiation can cause lung damage; therefore, it is important to avoid smoking and secondhand smoke. Alcohol can also be damaging to organs such as the liver. Ask your transplant doctor when you can resume drinking alcoholic beverages.

Anxiety and Depression

Many patients feel depressed at some point during their recovery. Fears of disease recurrence, changes in your family and work roles, and loss of energy are some issues you may experience during your recovery that could lead to anxiety and depression. Community support groups such as the American Cancer Society may help. Other patients of stem cell transplants are also a good support. Ask your nurse or doctor for names of patients who are willing to talk to you.

Sex and Fertility

Your sex activity and fertility is something you should consider both before and after your treatment. During your transplant you will receive high doses of chemotherapy and other treatment medications. An unplanned pregnancy could not only affect your health, but also the medicines you will be taking might be harmful to a developing baby. Therefore it is recommended that both men and women who are sexually active; should use some form of birth control while you are recovering from transplant.

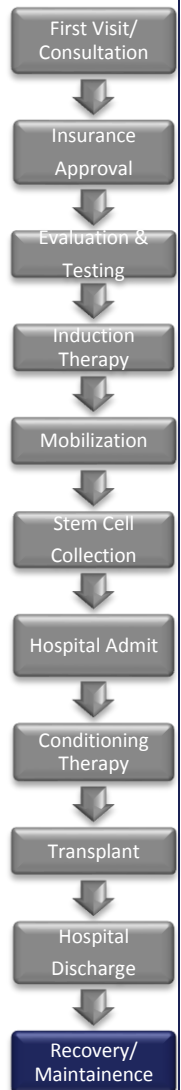
Unfortunately, the high doses of chemotherapy used during transplant put both men and women at high risk of infertility after their treatment. It is common for women to go into early menopause. Some signs of this are not having your period, hot flashes and mood swings. Talk to your doctor if you have any of these signs. For patients who want to have children, talk to your doctor before any treatment to discuss the possibility of infertility and help plan for the future. Additional information on fertility treatment can be found in the resources section in this handbook.

You might notice a decrease in your sexual desire after your bone marrow transplant. As your hormone levels return to normal and as you regain your strength and endurance, your sexual desire should return to normal. The following are some general guidelines regarding sexual activity:

- ❖ You may begin having sexual relations with your partner when you feel well enough and your platelet count is 20,000 or more.
- ❖ Women may have vaginal dryness after chemotherapy and may need to use a water soluble lubricant such as K-Y® jelly.
- ❖ You should NOT perform oral sex on your partner for at least 6 weeks post transplant. Oral sex is safe if you are the recipient.
- ❖ Wash your genital area carefully before and after sex to decrease your chance for infection
- ❖ Because of the risk of infection, you should NOT have anal sex.
- ❖ Women should not douche.

Long Term Recovery

It may seem to take a long time before you start to feel better. It may take up to a year to feel like you again. Some patients describe adjusting to a “new normal”. It is important for you and your family to know that recovery takes time and not to try to rush it. Try to keep positive during this time and listen to your body. It is also important to stay active. Exercise such as walking may help you get your energy level back faster. If you have any concerns while you get better, talk with your doctor or nurse about them.



There are some problems that may result from the stem cell transplant. These problems may happen or continue even after you seem to be getting better. These may include:

- ❖ Feeling numb or tingling in your hands or feet
- ❖ Loss of nails
- ❖ Body aches
- ❖ Fatigue
- ❖ Dry mouth, skin, or eyes
- ❖ Hearing loss or ringing in the ears
- ❖ Poor vision
- ❖ Upset stomach
- ❖ Taste changes

You may not have any of these long term side effects, but should tell your doctor or nurse about any problems that you have. Rarely, patients may develop a different cancer because of high-dose chemotherapy.

Recovery after transplant can sometimes be a bumpy road. Most times there are small problems or infections that may require you to return to the hospital because they cannot be managed as an outpatient. Don't become too discouraged because this is very common and it is part of your recovery.

Do not hesitate to call us with any questions or concerns and from all of us on your transplant team, we wish you well during your recovery.



MEDICAL TERMS GLOSSARY

Absolute Neutrophil Count (“ANC”) — Neutrophils are a type of white blood cell that helps keep the body from getting an infection. We look at how many neutrophils are in your blood to see when the transplant is beginning to work, or to see when your body heals from chemotherapy treatment. (See Engraftment, Neutrophil)

Allogeneic Transplant (*al-o-je-n'ay-ik*) — Also known as an Allo transplant. Stem cells are taken from someone other than you. The other person (“donor”) may be a family member or someone else who is found to be similar to you.

Anemia — The red blood cells carry oxygen through the body. When red blood cell numbers are too low, it is called anemia. This can make you feel tired, short of breath and cold all the time.

Apheresis (*af'ě-re'sis*) — The procedure used to remove stem cells from the peripheral blood. Blood is moved from a vein, through a tube, and into an apheresis machine. This machine filters out the stem cells and returns the rest of the blood to the body through another vein. The stem cells that were removed are saved for use later in the transplant.

Autologous Transplant (*aw-to'l-o-gus*) — Also known as an Auto Transplant. In an autologous transplant, the patient's own stem cells are collected before chemotherapy and are later given back during transplant. The patient is both the donor and recipient of the stem cells.

Benign — Not cancerous

Bone Marrow — The soft tissue inside of large bones where stem cells and blood cells are created. Stem cells in the bone marrow create white blood cells, red blood cells and platelets.

Bone Marrow Harvest- A surgical procedure used to collect bone marrow.

Bone Marrow Transplant (“BMT”) — A BMT is done to replace damaged cells from cancer with new healthy stem cells. A bone marrow transplant may be autologous or allogeneic (Also see Peripheral Blood Stem Cell Transplant. It can also be referred to as a Hematopoietic Progenitor Cell Transplantation (HPCT).

Chemotherapy — A drug that destroys cancer cells. Chemotherapy is used before a stem cell transplant. The kind of drugs used in chemotherapy depends on your disease, your age, and your health.

Central Line Catheter — The Central Line is a catheter, or thin plastic tube that is put into a large vein that runs near your neck. Your stem cells can be collected (Apheresis) through this tube. The catheter will stay in place through your transplant and will be taken out when your doctor decides you no longer need it.

Collection — See Apheresis

Colony Stimulating Factors (CSFs) — Proteins that are made by the body to speed up the growth of blood cells. CSF's can be given by a shot to help the body make more blood cells in preparation for collection by Apheresis.

Conditioning — The process of getting a patient ready to have a marrow or blood cell transplant is called conditioning. Chemotherapy with or without radiation therapy is often used. It is also known as a preparative regimen.

Discharge Planning — Preparing to leave the hospital. Staff will look at what you will need at home and give you instructions for getting better while at home. This plan will also tell you when you should see your doctor.

Donor — A donor is a person who can give stem cells from their blood to be used for your transplant. This donor can be a family member, like a brother or sister, in an allogeneic transplant. You can also be your own donor, in an autologous transplant.

Engraftment — The point when the stem cells given to you during your transplant start to grow and make new blood cells

Fatigue — The feeling of being tired and having little energy

Filgrastim (G-CSF) — The man-made version of a normal human protein that increases the number of blood cells in the body. (See Colony Stimulating Factors (CSFs))

Graft-Versus-Host-Disease (GVHD) — This can develop after an allogeneic transplant if the immune cells from the donor see the recipient's tissues as foreign. GvHD can arise even when the transplant comes from a matched related donor. This does not happen when you get your own cells in an autologous transplant.

Harvesting (See Apheresis or Bone Marrow Harvest) – Collecting/ removing stem cells from the body

Hematopoietic Cells – Blood stem cells found in the bone marrow and blood. These cells can grow into red blood cells, white blood cells or platelets. Also called blood-forming cells or progenitor cells

Hemoglobin (Hgb) – The part of a red blood cell that carries oxygen

HLA Typing – HLA stands for Human Leukocyte Antigens. These proteins are present on each individual's cell and allow the immune system to recognize 'self' from 'foreign'. HLA typing is used to match patients and donors for stem cell and organ transplants. It is also called HLA testing.

Immune System – The body's system to fight against disease.

Induction Phase – This part of the transplant is the regular chemotherapy you get before your transplant. Induction is done first in order to shrink the cancer or disease as much as possible before transplant.

Infusion – An infusion is when fluid is introduced into your blood through a vein. Red blood cell, platelets, and stem cells are all given through infusion.

Low Bacteria Diet (see Neutropenic Diet)

Lymphocyte — A type of white blood cell. It is an important part of the body's immune system.

Maintenance Treatment – Your doctor may talk to you about continuing treatment after your transplant. Usually this is treatment in a smaller dose given for up to a year or more to help keep your transplant successful.

Malignant – Cancerous

Marrow (See Bone Marrow)

Mobilization – Is the treatment given to prepare you for your transplant. This is done to get the stem cells to move from the bone marrow into the blood stream where the cells can be collected.

Myeloablative Transplant – A stem cell transplant which uses very high doses of chemotherapy and/ or radiation prior to transplantation with autologous or allogeneic hematopoietic stem cells.

Neupogen® – The brand name for Filgrastim. **See Filgrastim (G-CSF)**

Neutropenia – A condition that occurs when your white blood cell count is very low. White blood cells work to fight off infections in your body. When you are neutropenic, you are at risk for getting very sick with infection.

Neutropenic Diet – A special diet for patients who have a low number of white blood cells. Following a neutropenic diet can help protect you from bacteria and other harmful organisms found in some food and drinks. You cannot eat fresh, uncooked vegetables on this diet. You can eat fresh fruit, but only if it has thick skin, like bananas, and only if the fruit has been washed on the outside. Fruit with thin skin, like apples or grapes, must be cooked before you can eat it. You cannot eat deli meats and cheeses on this diet. See the resources section for more detailed diet information.

Neutrophil – Neutrophils are a type of white blood cell that help protect the body from infection. We look to see how many neutrophils are in your blood to tell us if you are engrafting after transplant, or healing after chemotherapy.

Non-Myeloablative Transplant – Also known as a “mini-transplant” or “low intensity” or “reduced intensity” transplant. This type of transplant uses smaller doses of chemotherapy and/or radiation therapy.

Peripheral Blood Stem Cells (PBSC) - While most stem cells are found in your bone marrow, peripheral blood stem cells are those found circulating in your blood stream throughout your body. PBSC are easier to collect than those found in the bone marrow.

Peripheral Blood Stem Cell (PBSC) Transplant – Stem cells found in the blood are collected through a procedure called apheresis. The stem cells are then frozen and stored. Next, the patient will receive treatment such as chemotherapy or radiation therapy. After treatment, the collected peripheral blood stem cells are given back by to the patient infusion. (Also see Bone Marrow Transplant)

Plasma – the liquid part of blood.

Platelet – a type of blood cell that helps stop bleeding by forming clots.

Prophylaxis- a measure taken to maintain health and prevent disease. You will be given prophylactic treatment as part of the transplant procedure. Medications, such as anti-viral and anti-bacterial, will be given to you in order to help stop an infection before one occurs.

Radiation Therapy –Treatment with high-energy rays to destroy or shrink cancer cells.

Recipient – The person receiving the infusion of stem cells is known as the recipient.

Red Blood Cell – A type of blood cell that carries oxygen to all parts of the body.

Re-Infusion –The process of putting stem cells back into your blood after treatment for your disease or cancer.

Recovery -The process of healing after your stem cell transplant. It will take time to get back your strength, energy and appetite.

Relapse – When signs and symptoms of disease return.

Remission – When signs and symptoms of disease are not present.

Stem Cells - Unspecialized cells that are able to produce many different types of cells. These master cells are able to divide throughout their life and create new cells. These new cells can become highly specialized and will take the place of old cells that die or are lost. Stem cells contribute to the body's ability to renew and repair its tissues. There are many different types of stem cells including; embryonic, ocular, and hematopoietic. For your transplant, we are concerned with the adult hematopoietic (blood) stem cells.

Stem Cell Transplant – In your case, stem cell transplant refers to the use of blood or bone marrow stem cells as a treatment for cancer or other diseases.

T Cell – A type of white blood cell that plays an important part in the immune system.

Tissue –Materials from your body, including skin, hair, nails, blood and urine.

Total Body Irradiation (TBI) –Radiation treatment that is given to the entire body with high-energy rays to destroy or shrink cancer cells.

Tumor – Any strange growth of cells. Tumors can be caused by cancer cells (malignant) or non-cancer cells (benign).

White Blood Cell – A blood cell that helps fight infection and is part of the immune system.

INSURANCE TERMS GLOSSARY

Appeal –To ask the insurance company to go back over a decision to not pay for a treatment or service

Approval- An insurance company agreeing to pay for a treatment or service

Co-Insurance – The part or percentage of the cost of a medical service or procedure that the insured person will need to pay. For example, if the co-insurance in 70/30 the health plan pays 70% and the insured person pays 30% of a medical bill.

Co-Payment/Co-Pay – A set amount that is owed by the insured person for each medical visit, procedure or prescription. This could be a set dollar amount or a percent. For example, an insured person may have a \$20 co-payment for an office visit. This means they will have to pay \$20 for a basic doctor office visit. The health plan would pay the rest. Every health plan is different. It is important that you review your health plan and coverage.

Deductible – The amount the insured person must pay for a treatment or service before the health plan coverage begins. Not all treatment or services may require a deductible.

Denial –The insurance company refusal to pay for a medical service or procedure. The opposite of approval.

Drug Formulary – A list of drugs that are paid by a health plan.

Exclusion –Treatments or services that are not paid for by a health plan. For example: elective cosmetic surgery.

Explanation of Benefits – A written statement showing what the health plan will pay, what the insured person needs to pay, and/or any action that still needs to be taken.

Out-of-Pocket Costs – Health care costs that the insured person must pay on their own because they are not paid by the insurance plan. Examples: co-payments, deductibles and co-insurance.

Network Provider/Participating Provider –A doctor, hospital or other health care provider who has an agreement with a health insurance plan to provide services to its members for specific rates. These rates are usually lower than those of providers outside of the network. Out-of-Network providers may be available at a higher out-of-pocket cost to the insured, or none of their charges may be paid by the health insurance plan.

Pre-Certification/Prior Authorization- Approval given by the health plan before the insured person starts treatment. The patient must notify the health plan before admission to the hospital, to give the health plan time to decide if the treatment or procedure is necessary.

Low Bacteria Diet

FOOD GROUPS	ALLOWED	NOT ALLOWED
Dairy	<ul style="list-style-type: none"> • All pasteurized, grade A milk and milk products. • Commercially packaged cheese and cheese products made with pasteurized milk (i.e. mild and medium cheddar, mozzarella, parmesan, Swiss, etc.) • Pasteurized yogurt • Dry, refrigerated, and frozen pasteurized whipped topping • Ice cream, frozen yogurt, sherbet, ice cream bars, homemade milkshakes • Commercial nutritional supplements and baby formulas, liquid and powdered 	<ul style="list-style-type: none"> • Unpasteurized or raw milk, cheese, yogurt, and other milk products • Cheeses from delicatessens • Cheeses containing chili peppers or other uncooked vegetables • Cheese with molds (i.e. blue, Stilton, Roquefort, gorgonzola) • Sharp cheddar, brie, camembert, feta cheese, farmer's cheese
Vegetables	<ul style="list-style-type: none"> • All well washed and thoroughly cooked vegetables. • All frozen or canned vegetables • All cooked herbs and spices (add at least 5 minutes before end of cooking) 	<ul style="list-style-type: none"> • Raw vegetables, salads • Dehydrated vegetables • Caesar Salads with Caesar dressing • Pepper • Garnishes • Uncooked herbs and spices
Fruits and Nuts	<ul style="list-style-type: none"> • Canned and frozen fruit and fruit juices • Raw thick-skinned, well washed fruits (un-bruised bananas, oranges, tangerines and melons) • Canned or bottled roasted nuts • Nuts in baked products • Commercially packaged peanut butter 	<ul style="list-style-type: none"> • Dried fruits • Raw fruit; foods containing raw fruits • Unpasteurized fruit and vegetable juices • Raw nuts • Roasted nuts in the shell • Precut fresh fruits
Bread, Grain, and Cereal Products	<ul style="list-style-type: none"> • All breads, bagels, rolls, pancakes, sweet rolls, waffles, French toast • Potato chips, corn chips, tortilla chips, pretzels, popcorn • Cooked pasta, rice, and other grain • All cereals (cooked and ready-to-eat types) 	<ul style="list-style-type: none"> • Raw grain products • Bakery breads, cakes, donuts, muffins • Potato/macaroni salad • Cereal with dried fruit

Low Bacteria Diet

FOOD GROUPS	ALLOWED	NOT ALLOWED
Entrees, Soups	<ul style="list-style-type: none"> • All cooked entrees and soups 	<ul style="list-style-type: none"> • All miso products (i.e. miso soup)
Meat and Meat Substitutes	<ul style="list-style-type: none"> • All well-cooked or canned meats (beef, pork, lamb, poultry, fish, shellfish, game, ham, bacon, sausage, hot dogs) • Well-cooked eggs (white cooked firm with thickened yolk acceptable, i.e. hard boiled, over hard) • Pasteurized egg substitutes (i.e. Egg Beaters) • Canned and commercially-packaged hard smoked fish, refrigerated after opening • Cooked tofu (which must be cut into 1" cubes or smaller and boiled a minimum of five minutes in water or broth before eating or using in recipes) 	<ul style="list-style-type: none"> • Raw or undercooked meat,, poultry, fish, game, tofu • Meats and cold cuts from delicatessen • Hard cured salami in natural wrap • Cold smoked salmon, lox • Pickled fish • Tempeh products • Sushi • Raw oysters/clams
Beverages	<ul style="list-style-type: none"> • Tap water • Commercial bottled distilled and natural waters • All canned, bottled, powdered beverages • Instant and brewed coffee, tea; cold brewed tea made with boiling water • Brewed herbal teas using commercially-packaged tea bags • Commercial nutritional supplements, liquid and powdered 	<ul style="list-style-type: none"> • Well water (unless tested yearly and found safe) • Cold-brewed tea made with warm or cold water sun tea • Eggnog • Fresh apple cider • Homemade lemonade • Spring water
Fats	<ul style="list-style-type: none"> • Oil, shortening • Refrigerated lard, margarine, butter • Commercial shelf-stable mayonnaise and salad dressings (including cheese-based salad dressings, refrigerated after opening) 	<ul style="list-style-type: none"> • Fresh salad dressings containing aged cheese (i.e. blue, Roquefort) or raw eggs, stored in refrigerated case

Low Bacteria Diet

FOOD GROUPS	ALLOWED	NOT ALLOWED
Desserts	<ul style="list-style-type: none">• Refrigerated commercial and homemade cakes, pies, pastries, and pudding• Refrigerated cream-filled pastries• Homemade and commercial cookies• Shelf-stable cream-filled cupcakes (i.e. Twinkies, Ding Dong), fruit pies (i.e. Poptarts, Hostess fruit pies), and canned pudding	<ul style="list-style-type: none">• Un-refrigerated cream-filled pastry products (not shelf-stable)• Cream or custard filled donuts• Pastries with fresh fruit
Other	<ul style="list-style-type: none">• Salt, granulated sugar, brown sugar• Jam, jelly, syrups (refrigerated after opening)• Commercially-packaged (pasteurized) honey• Catsup, mustard, BBQ sauce, soy sauce, other condiments (refrigerated after opening)• Pickles, pickle relish, olives (refrigerated after opening)	<ul style="list-style-type: none">• Raw or un-pasteurized honey• Herbal and non-traditional (health food store) nutritional supplements, Chinese herbs• Brewers yeast, if eaten uncooked



Transplant Patients' Guidelines for Eating Fresh Fruits and Vegetables

Eating thick skinned fruit only (oranges, tangerines, melons, bananas) is allowed during periods of neutropenia. Please check with your transplant physician before eating other fruit and vegetables.

1. Select fruits and vegetables without spots, bruises or damage. Fresh fruits and vegetables should look and smell fresh.
2. A caregiver, not a patient, should do all preparation and washing of produce.
3. Wash hands thoroughly before handling fresh produce. Use plenty of hot water and soap and wash for at least 20 seconds. Always use clean cutting surfaces. Use a clean knife.
4. Wash all fruits and vegetables (including bagged pre-washed salad greens) thoroughly under running cold water before using.
5. Using a clean vegetable scrubber, scrub produce that has thick skins or rinds (such as melons, potatoes) to remove excess soil.
6. Wash the outside of all fruits and vegetables even if the produce is to be skinned or peeled. Bacteria on the outer skin can be transferred to the inside of fruit and vegetables when cutting with a knife.
7. Do not wash fruit and vegetables with produce rinses, soaps, detergents, or chlorine bleach solutions. Produce can absorb these cleaning agents.
8. Refrigerate produce promptly. The refrigerator must be clean and cold (40°F or colder).
9. Throw out fruits and vegetables that have been stored too long. Throw out fruits and vegetables that are slimy or show mold.

Food Safety Guidelines for Transplant Patients

These food guidelines are intended to supplement immune-suppressed patient diet guidelines, which identify higher risk foods. By following safe food practices, patients and caregivers can reduce the risk of food-borne illness.

All handling, cleaning, and preparing of meats and produce should be performed by someone other than the immune-suppressed patient.

Safe Food Handling

1. Purchase a food thermometer. They are available at most kitchen stores and have either a dial read or a digital read.
2. Caregivers preparing food should always wash hands frequently- before, during, and after food preparation. Use plenty of hot water and soap and wash for at least 20 seconds.
3. Hold food at safe temperatures: hot food above 140°F and cold food below 40°F.
4. Cook meat until well done and measure the final temperature with a thermometer. Red meat should reach an internal temperature of 165°F and poultry to 180°F.
5. Thaw meat, fish, or poultry in the refrigerator away from fruits and vegetables. Place on a dish to catch drips. Cook defrosted meat right away; do not refreeze. If you are in a hurry, you can thaw in the microwave- but you must cook the meat immediately and thoroughly clean the microwave to stop the spread of bacteria.
6. Never leave food that can spoil out of the refrigerator for over two hours.
7. Wash the tops of canned foods before opening. Clean the can opener before and after use.
8. During food preparation, do not taste the food with the same utensil used for stirring.
9. Cook eggs until the whites and yolks are completely hard cooked.
10. Never taste food that looks or smells strange.

Grocery Shopping

1. Check “sell by” and “use by” dates. Select only the freshest food product.
2. Do not buy/avoid damaged, swollen, rusted, or deeply dented cans. Check that packaged and boxed foods are properly sealed.
3. Do not buy/avoid foods with any mold present.
4. Avoid foods from delicatessens, including prepared salads and sliced meats and cheeses. In the bakery, avoid unrefrigerated cream and custard containing desserts and pastries.
5. Avoid foods from self-serve bulk containers or bins.
6. Avoid yogurt and ice cream products from soft serve machines.
7. Avoid tasting free food samples.
8. Avoid cracked and unrefrigerated eggs. Liquid pasteurized egg product may be used instead of eggs in the shell.
9. Purchase frozen and refrigerated foods last, especially during the summer months.
10. Store groceries promptly after purchase. Never leave perishable food in the car.



Dining Out...Is It Safe?

(Please check with your transplant physician to see when it is appropriate to start)

1. Eat early to avoid crowds.
2. Since it is hard to know the cleanliness of the handler and produce preparation, do not eat raw fruits and vegetables when dining out.
3. Avoid high-risk food sources: salad bars, delicatessens, buffets, smorgasbords, potlucks, bake sales, fast food restaurants, and sidewalk vendors.
4. Check the general conditions of the restaurant environment. Are the plates, glasses, and utensils clean? Are the restrooms clean and stocked with soap and paper towels? How the manager and employees take care of the restaurant may tell you how clean they are when preparing the food.

Cancer Survivorship Center

The Advocate Lutheran General Hospital Cancer Survivorship Center is the first stand alone hospital affiliated survivorship center in Illinois. The Center provides comprehensive, holistic support for patients as well as their family members and caregivers by providing support and resources. These include:

- Offering evidence-based patient centered care
- Providing assistance in achieving a healthier lifestyle
- Empowering patients and aiding them in navigating the healthcare system
- Supporting the patient and healthcare provider relationship

The programs and classes offered are designed to focus on the physical, social, psychological and spiritual needs of patients, family members and caregivers. The Center offers classes and support groups helping our patients to live life beyond cancer.

Exercise classes

Gentle and Restorative Yoga for Cancer Patients/Survivors

A yoga classes which helps individuals open the body with gentle breathing and some restorative yoga postures. The class is appropriate for all levels of fitness. Postures can be modified for those to take the class from a chair. This class is for cancer patients and survivors.

Exercise for Cancer

An exercise class to improve strength, stamina and flexibility. All levels of fitness welcome. This class is for cancer patients and survivors.

Gentle Yoga for Cancer Patients/Survivors

A yoga class focusing on balance, flexibility and strengthening through gentle yoga postures. Practice is appropriate for all levels of fitness and can be done in a chair if needed. This class is for cancer patients and survivors.

Classes and programs

Stress Reduction for Cancer Patients/Survivors

This class will teach practical stress reduction techniques which can be used in daily life. Healthy lifestyle and healthy thinking approaches will be incorporated. This class is for cancer patients and survivors.

Nutrition for Optimal Cancer Wellness

This class is designed to educate individuals about foods and nutrients that help cancer patients and survivors make healthy food choices. The goal of this class is provide energy, strength and an overall improved quality of life to those with cancer through optimal nutrition. This class will involve some lecture, class discussion, and activities in a fun, friendly environment. This class is for cancer patients and survivors.

Look Good, Feel Better Program

"Look Good, Feel Better" is a free program that offers beauty techniques to female cancer patients to help them combat the appearance-related side effects of cancer treatment. This

program is sponsored by Advocate Lutheran General Hospital and the American Cancer Society.

Wig Boutique

Sponsored by the American Cancer Society, free wigs to women in need, who are experiencing hair loss due to cancer treatment.

Patient Assistance Program

Education program to give cancer patients an overview of their health insurance and provide information about financial assistance programs.

Focus on Wellness

6-week program for cancer survivors. Group will focus on relaxation, self-care and help to reduce stress. Groups forming now. Please call Louise DiMiceli-Mitran, Mt-BC, LCPC, 847-723-7265

Spiritual Enrichment

Monday-Thursday 9:30am-4:00pm, Chaplain Stanley Buglione will be available for a session of spiritual enrichment for those seeking such an encounter. This enrichment will be based on the person's own centers of meaning, religious or otherwise. Stan will meet persons seeking spiritual enrichment outside the Lutheran General Chapel. If you wish to meet with Stan, a staff member of the Cancer Survivorship will arrange the day/time with Stan.

For more information, to view the calendar of classes and support groups, or to register for a class go to: <http://www.advocatehealth.com/luth/cancer-survivorship-center>

The Cancer Survivorship Center
1999 Dempster St. Park Ridge, IL 60068
1-847-723-5690



Hair Loss

Hair loss is a common side effect of chemotherapy and occurs about two weeks after you begin chemotherapy treatment. Hair usually thins and falls out over a short period of time. This can be stressful unless you are ready for it. Your hair will fall out but it will begin to grow back in the weeks and months after the transplant. The new growth may not be the same color or texture as your original hair. As your new hair grows back, use a mild shampoo such as baby shampoo. Stay away from harsh products such as hairspray, dyes, curling irons and hot rollers.

There are various options available for hair loss. Some people will feel most comfortable choosing a wig, others may choose head coverings like a scarf or head wrap. The goal is to choose what will make you the most comfortable and create a natural look. You may want to get a wig before treatment or hair loss begins, so it can more easily be matched to your own hair color and style. It is a good idea to bring a friend or family member with you for support and help with the decision.

Most insurance companies will cover wigs. Ask your doctor to write a prescription and/or letter for a hair or cranial prosthesis, not a wig. This will let your insurance know that this is for a medical condition, not a cosmetic one. Also, be sure the receipts say prosthesis and not wig.

Resources

Studio 1999 Wig Boutique

Offers **FREE** wigs, wig fittings, and head wear sponsored by The American Cancer Society and Advocate Lutheran General Hospital's Cancer Survivorship Center. For more information or to schedule an appointment visit: <http://www.advocatehealth.com/luth/cancer-survivorship-center> or call 847-723-5690



WIG RESOURCES

The following list has been compiled by your American Cancer Society as a public service. Our goal is to provide a comprehensive list. However, inclusion should not be viewed as an endorsement of these organizations by the American Cancer Society. Should you experience difficulties with any of these local resources, please notify your local American Cancer Society.

American Cancer Society (FREE wigs)
1114 N. Arlington Heights Road
Arlington Heights, IL 60004
Phone: 1-800-782-7716 (call for appointment)

Amazing Wig World (wigs, hats, scarves)
457 N. Lake St. Rt. 45
Mundelein, IL 60060
Phone: 847-566-0686

A Total Look Hair Design, Inc. (wigs, scarves, hats)
1214 W. Park Ave.
Libertyville, IL 60048
Phone: 847-362-3411

Beauty Image Center (wigs, hats, turbans, scarves)
1280 Bambers Ct.
Hanover Park, IL 60133
Phone: 630-483-9225
www.lavese.com

Carol's House of Hair (wigs, hats, scarves, turbans)
1828 South Arlington Heights Road
Arlington Heights, IL 60005
Phone: 847-858-9844

City Lights Hair Center (wigs, hats, scarves, sleep caps)
120 West Eastman, Suite 100
Arlington Heights, IL 60004
Phone: 847-222-8065

Hair For You Salon, Inc. (wigs, scarves, hats, sleep caps)
737 E. Dundee Rd.
Arlington Heights, IL 60004
Phone: 847-259-4968

Hair Response, Inc. (wigs, hats, wraps, scarves)
701 W. Deerfield Pkwy #10
Buffalo Grove, IL 60089
Phone: 847-541-9799

Jerome Krause (wigs, hats, scarves, turbans)
9150 Crawford Ave.
Skokie, IL 60076
Phone: 847-673-2442 (by appointment)

JuliAnne's Total Image Salon and Day Spa (turbans)
1439 W. Schaumburg Rd.
Schaumburg, IL 60194
Phone: 847-895-4591 (contact Juli Scully)

Kathleen's Creative Expressions (wigs, turbans, sleep caps, hats)
Kathy Devyak
665 Ridgeview Drive
McHenry, IL 60050
Phone: 815-759-0329

Linda's Head Quarters (wigs, hats, scarves, turbans)
3339 W. Dempster
Skokie, IL 60076
Phone: 847-679-0669

LuLu's Wiggin Out (wigs, scarves, hats, sleep caps)
128 S. Main St. (Rt 31)
Algonquin, IL 60102
Phone: 847-854-9611

Options (wigs, hats, scarves, turbans)
Roberta Williams Salon – Diana Smith
2146 S. Plum Grove Rd.
Rolling Meadows, IL 60008
Phone: 847-991-1186 (for appointment, 847-358-0335)

Shear Pleasure (wigs, scarves)
237 W. Dundee Rd.
Palatine, IL 60074
Phone: 847-991-6877

Transformations (wigs, hats, scarves, turbans)
110 S. Arlington Heights Rd.
Arlington Heights, IL 60005
Phone: 847-454-0600 (by appointment)

Inclusion on this list does not imply endorsement by Advocate Lutheran General Hospital.



Fertility Treatment

Patients' fertility can be affected from a stem cell transplant. Recovery after BMT can take months to years; so many patients are not physically or psychologically ready to consider parenthood for several years after transplant. However, a pre-transplant discussion of options to preserve fertility might help you plan for your family's future.

Preserving Fertility in Women

There are several ways to try to preserve fertility in women, but most remain experimental, with unknown success rates. Some options are not appropriate for certain patients, depending on the type of cancer.

Embryo Freezing: Eggs are removed from the patient and fertilized in a test tube with the sperm of a partner or donor. The resulting embryos are then frozen and stored.

Egg Freezing: Some women opt to have the eggs frozen unfertilized, particularly if they are not in a committed relationship. Later, the eggs can be thawed and in vitro fertilization attempted.

Other options for becoming a mother after cancer treatment include using donor embryos or eggs, having a surrogate (where another woman carries the child), or adoption.

Preserving Fertility in Men

Fertility preservation is much easier, cheaper and more effective for most men. It simply involves collecting a sample of semen and freezing it. Sperm must be banked before any chemotherapy or pelvic radiation therapy begins in order to avoid storing damaged sperm. The sperm can be thawed later and used for intrauterine insemination or in vitro fertilization.

Resources

Fertility Centers of Illinois

866-364-1418

www.fcionline.com

Multiple locations in Illinois. Make an appointment to speak with a fertility specialist.

Fertile Hope

Toll-free number: 1-866-965-7205

www.fertilehope.org

A non-profit organization that offers fertility resources for cancer patients. Along with information about treatment options, this organization provides excellent suggestions to help overcome some of the financial barriers you might meet.

Oncofertility

myoncofertility.org

Has a timeline for patients with information about fertility at all cancer stages, from diagnosis to after treatment; also offers fertility information for parents of children with cancer.

International Council on Infertility Information Dissemination (INCIID)

703-379-9178

www.inciid.org

Offers information on getting early care with qualified specialists and how to find them; fertility fact sheets; online support forums and weekly chat sessions; and “From INCIID the Heart,” help for in vitro fertilization for those with financial and medical need, but without health insurance to cover it (Click “Programs and Initiatives” on the INCIID home page.)

RESOLVE: The National Infertility Association

703-556-7172

www.resolve.org

Provides information on the infertility journey, including treatment, coping, third party reproduction, adoption, child-free living, advocacy, and more. Also has fact sheets and personal stories. Local chapters/affiliates can be found on the Web site. Offers education and support groups; online community also available.

American Society for Reproductive Medicine (ASRM)

205-978-5000

www.asrm.org

Offers infertility information, fact sheets, and booklets on adoption, genetic screening for birth defects, in vitro fertilization, sexual problems, reproduction information for cancer patients, and more; choose “Resources” tab on the home page. Some info available in Spanish. Has a directory of ASRM member doctors.

American Academy of Adoption Attorneys

202-832-2222

www.adoptionattorneys.org

Offers list of experienced adoption attorneys.

American Association of Tissue Banking (AATB)

703-827-9582

www.aatb.org

Lists those sperm banks that have received accreditation by the AATB.

Directory of Sperm Banks

Web site: www.spermbankdirectory.com

Maintains basic sperm banking information along with lists of sperm banks in the United States.

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Immunization Schedule for HPC Transplant Patients

This schedule is meant to serve as a general guideline and is not specific for any one patient. Do NOT get any vaccinations without first consulting with your transplant physician.

Disease	Vaccine	Assessment	Time Post HCT					
			3 months	6 months	8 months	12 months	18 months	24 months
Diphtheria, Tetanus, Acellular Pertussis	diphtheria tetanus pertussis vaccine (DTaP) is preferred, over (tetanus toxoid diphtheria-toxoid reduced acellular pertussis vaccine (Tdap))	Titer		DTaP	DTaP		DTaP	
Haemophilus Influenzae Type b	Haemophilus influenzae b conjugate (Hib)	None		Hib	Hib	Hib		
Hepatitis A*	Polyclonal immune globulin for intramuscular administration (IGIM) is preferred	Assess risk factors		IGIM		IGIM		
Hepatitis B	Hepatitis B Recombinant	Titer		Hep-B	Hep-B		Hep-B	
Influenza	Trivalent inactivated influenza vaccine (TIV)- Do NOT use the live intra-nasal vaccine	None		TIV ≥6 months post HCT		TIV- annually at flu season ≥ 6 months post last injection		
Measles, Mumps, Rubella	Measles, Mumps, Rubella Vaccine (MMR)	Titer and Contraindications						MMR
Pneumococcus	13-valent pneumococcal conjugate vaccine (PCV-13) & 23-valent polysaccharide pneumococcal vaccine (PPSV-23)	Draw titer at 14 months post HCT	PCV-13	PCV-13		PCV-13	PPSV-23	Chronic GVHD Pts: draw add'l titer for PPSV [^]
Poliomyelitis	Inactivated Polio vaccine (IPV)	None		IPV	IPV	IPV		
Varicella Zoster	Varicella zoster immune globulin (VZIG)- Do NOT give the live Herpes Zoster/ shingles vaccine (Zostavax [®])	Titer						VZIG

*Immune globulin should be administered to hepatitis A-susceptible HCT recipients who anticipate hepatitis A exposure (e.g. during travel to endemic areas) and for post- exposure prophylaxis.

[^] If PPSV titer naïve administer PCV-13 at 30 months post HCT

