Welcome
Units 6E & 7E
Emory University Hospital (EUH)

We’re all in this together.
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Welcome!

Welcome to the Leukemia Service at EUH! We thank you for choosing Emory Healthcare for your healthcare needs. We want to give you the very best patient-centered care. This booklet tells you what it will be like to be a patient on this unit. We hope it will answer some of your questions; please share it with your loved ones. If you have other questions, please ask us. We’ll do our best to answer them. Our team includes Doctors, Physician’s Assistants (PAs), Nurse Practitioners (NPs), Nurses, Nurse Technicians (techs), and Unit Clerks, all here to help you! We hope to make this hard time a little easier for you and your loved ones.
When You Get to our Unit

When you get to our unit, you will meet your nurse, an NP or PA, and your doctor. They will review your medical history, the medicines you take, and will examine you. You may need some blood work or tests. Then your doctor will talk with you about your condition and your treatment options.

If you have a new illness, we will have a meeting with you and your family before treatment is started. Please see section named “Family Meetings” for the details.
Meet our Team

Doctors

Our doctors are experts in the care of patients with blood problems. They each have an area of research that is of special interest to them.

Leonard T. Heffner Jr., MD
Plasma Cell Disorders & Lymphoid Leukemias/Lymphomas

Martha L. Arellano, MD
Acute Leukemias & Myelodysplastic Syndromes

Amelia Langston, MD
Leukemias & Bone Marrow Transplant

Anand Jillella, MD, FACP
Leukemias & Bone Marrow Transplant

H. Jean Khoury, MD, FACP
Leukemias & Bone Marrow Transplant

Jacques Galipeau, MD
Stem Cell Development & Immune Disorders

Manila Gaddh, MD
Myelodysplastic Syndromes

Vamsi Kota, MD
Leukemias & Bone Marrow Transplant
Nurses

Our nurses are a very important part of our team. You might say they are the “backbone” of the unit – always there for you. The nurse tech might check your blood pressure, pulse, and temperature and help you with your morning care; the LPN might give you your medicines and help with some procedures such as changing dressing; and the RN will make sure that you are receiving the care you need and talk with the other team members about your care.
A physician assistant (PA) or nurse practitioner (NP) will direct your medical care and communicate with your doctor daily. The PA or NP might be the person who gives you information about how you are doing, and makes treatment decisions, especially when it comes to managing your symptoms. The RN, NP, and PA are good sources of information about your diagnosis and the care you are receiving.

Chaplains

We also have chaplains to take care of you and your family’s spiritual needs. Chaplains offer:

- help with stress and difficult emotions
- spiritual and religious support, such as prayer
• support with the impact of medical decisions
• support during difficult treatments
• support for family and caregivers
• respectful listening without judgment
• meditation practices
• help with ethical issues

Chaplains can be reached 24 hours a day, seven days a week. If you have your own religious support (for example, a pastor, rabbi or imam), they are always welcome to visit.

At EUH, our chapel is on the second floor. A chaplain can also visit with you and family members on the unit. The best way to reach a chaplain is to ask your nurse to page the chaplain. You may also call the chaplain at 404-712-7200 between 8:30 a.m. and 5 p.m. on weekdays. After 5 p.m. and on weekends, ask the operator to page 1-3002.
Social Workers

A social worker helps you and your family to handle any concerns that come up while in the hospital. The social worker can get you help with hospital and community resources and can help you prepare for the following:

- Support services, such as home visits by a nurse or aide; physical, occupational or speech therapy; medical supplies; Meals on Wheels; a travel escort; or transportation.

- Nursing home care to prepare you for living at home without help.

- Other living arrangements if you need 24-hour nursing care and services that cannot be done in your home.

- Information for you and your doctor about hospital policies, finance issues, insurance coverage, and other issues.

- Referrals to groups in your area that help with finance concerns.

- Checking with you to make sure you are getting the services we have arranged.

- Support to help you cope with changes in your life that result from your illness.

Lysandra Brown, LMSW 7E
Karla Lee, LSW 6E
Courtney Faulkner, MSW 7E
Other Health Professionals

In order to give you the best care, your doctors may need to ask others to help with your care. Your doctor, NP, or PA will tell you if this is needed.

The Palliative and Supportive Care Team

We often ask experts from the Palliative and Supportive Care Team to give advice on how to improve your quality of life and reduce the stress of illness. The Palliative and Supportive Care Team consists of physicians, nurses, chaplains, and social workers. Palliative and Supportive Care is appropriate at any stage of illness and is compatible with curative therapies. Working with your team, the Palliative and Supportive Care Team provides:

- Time for close communication
- Expert management of pain and other symptoms
- Help navigating the healthcare system
- Guidance with difficult and complex treatment choices
- Emotional and spiritual support for you and your family

Palliative and Supportive Care Team
Hospice Care

Palliative Care and Hospice are often confused. Hospice care is the type of palliative care that is provided if all treatments have failed to treat the disease and there are no more chemotherapy options. Hospice care is important to consider at that time because it focuses on managing the symptoms of the disease in a more comfortable environment than the cancer unit. A team of health care professionals and volunteers provides the hospice care. They give medical, psychological, and spiritual support. The goal of the hospice care is to help people who are at the end of life have peace, comfort, and dignity. The caregivers try to control pain and other symptoms so a person can remain as alert and comfortable as possible. Hospice programs also provide services to support a patient's family. Usually, a hospice patient is expected to live 6 months or less. Hospice care can take place at home, at a hospice inpatient unit or center, in a hospital, in a skilled nursing facility.

Your Doctor’s Schedule

You may not see the same doctor during your whole hospital stay. This is because doctors are (on call) on the unit for two weeks at a time. You will see one doctor during the first 2 weeks of the month and another doctor during the last 2 weeks of the month. The doctors share all the details of your care with each other when it’s time for the next doctor to be on call, so that your care continues even when the doctor’s schedule is changing. You will usually have the same doctor in the clinic that you had when you first came to our unit. That doctor will guide your care in the clinic and will be your main doctor. Each doctor works with a team that includes a Nurse and an NP or PA. They will also care for you in the clinic.
A doctor’s schedule might look like this:

### Sample Doctors’ Schedule

**May 2013**

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<th>Sunday</th>
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As seen in the table, in May 2013, Dr. A was on call for the first 2 weeks and Dr. B was on call for the second 2 weeks. If you had been admitted during Dr. A’s rotation, you would have seen Dr. A and her team in the clinic after leaving the hospital. On the other hand, if you had been admitted during the second 2 weeks of May, you would have seen Dr. B and his team in clinic after leaving the hospital.
Daily Routine

Bedside Shift Report
The nurses coming on and leaving will briefly discuss with you your current plan of care and goals for the day. Family and friends are welcome to stay in the room during this bedside report. To keep your information private, we will only discuss your care with others in the room if you tell us it is okay to do so.

Your **daily** routine includes:

- ✓ Vital signs will be checked every 4 to 8 hours
- ✓ You will be weighed
- ✓ Your food and fluid intake will be recorded
- ✓ Your linens will be changed
- ✓ You will be assisted with daily hygiene
- ✓ You will be offered fresh ice
- ✓ You will have blood draws to check lab values. These may be taken from a central line or from a vein for special tests
- ✓ **You will be encouraged to keep walking. This will help you stay strong.**
  
  (21 laps around the unit = 1 mile)
  
  YOU CAN DO IT!!!!!
Infection Control

Germs can make us sick. Many of our patients are more likely to have germs grow in their bodies due to having a low white blood cell count or a weak immune system. The immune system is a team of organs, cells, and tissues that work together to protect us from germs which can make us sick. The white blood cells are a very important part of that immune system. When the white blood cell count is too low, the immune system cannot do its part to kill germs. So, we need to be extra careful to try to prevent catching germs that can make us sick.

Here are a few tips to try to prevent germs from making us sick:

- Practice good personal hygiene.
- Wash your hands, especially after using the restroom.
- Do not allow people with cold symptoms or a fever to visit you.
- During the flu season, there may be other limits on who can visit.
- Fresh flowers and plants are not allowed on the unit since they can carry mold/fungus.
- Bottles with foam that kills germs can be found outside or just inside of each patient’s room. It should be used by all people when they enter and leave your hospital or clinic room. Remember to “Foam In and Foam Out”!

Precautions:

During your time in the hospital, we may need to take extra steps to prevent the spread of germs to other patients. This is done for patients who have certain germs. There are 3 types of precautions: contact, enteric, and droplet.

Contact:

There are some germs such as MRSA that are hard to kill with medications. These germs are found in and out of hospitals. People can carry these germs without getting sick from them. All patients must be tested to see if they have these germs.
If they do, then we must take extra steps to prevent these germs from spreading to others. These steps include use of a yellow gown and gloves in the rooms of patients who have these germs. This type of protection is called “contact precaution”. You can have these germs without being sick or even knowing that you have them. Patients on contact precautions are not allowed in the kitchen or bathrooms used by those who visit. Family members are allowed in these areas after taking off their gowns and gloves, and doing good hand washing.

**Enteric:**

Some patients get extra growth of germs that are normal in the colon. This can occur after using medications that kill germs (“antibiotics”) or as a result of a weak immune system. The germ is called “C. diff.” and it can cause your bowel to become inflamed or swollen. This is called, “C. diff colitis”. The symptoms can include: fever, diarrhea, and stomach cramping. C. diff colitis is easy to treat with special antibiotics that are taken by mouth. This germ can spread to other people by touch and is not removed by the foam used to clean our hands. That is why people with C. diff. and any person who comes in contact with the patient or comes into the patient’s room must wash their hands with soap and water when leaving the patient’s room. Yellow gowns and gloves also need to be worn when any person enters the room of a patient with C. diff. Patients with C. diff. are not allowed in the kitchen or bathrooms used by those who visit. Family members are allowed in these places after they take off their gowns, gloves, and wash their hands.

**Droplet:**

Droplet precautions are started when a patient has a germ that is spread by breathing after someone coughs. Extra steps are taken, such as wearing a mask, to prevent the spread of this germ to others. Gloves may also be worn in some cases. These extra steps may be taken if we suspect that a patient has the flu. During flu season, we may wear a mask in every patient’s room even if the patient does not have the flu or other germ that can be spread by breathing. This is to prevent the spread of these germs to our patients, because a person may have these germs and not know it yet.
Safety

Your health and safety are our main concerns. Falling can cause great harm and can cause you to have to stay in the hospital longer. If you ever feel dizzy or unsteady when getting out of bed, please press the call light, or call your nurse or tech on the cell phone for help. Even though patients walk well by themselves at home, some of the treatments you get in the hospital or clinic may make it unsafe for you to walk by yourself. Remember to "Call, Don’t Fall!"

If you are concerned about your loved one’s safety, please refer to the Code MET sign posted in your room.

Smoking is not allowed in the hospital or anywhere around the hospital. We urge you to stop smoking and can help if you wish to stop.

Please send home any items of value or any medications you brought with you. We are not responsible for lost items. If you wish, our security department will lock up valuables that are not sent home.

All electronics (computers are allowed) must be approved for safety before they can be used.

Notice to care givers: If the patient is confused, please let the care team know right away. In that case, we ask that you stay with the patient or make plans for someone to stay with the patient at all times. We do not have 24-hour sitters.
Visits

EUH visiting policy helps protect the patients on our units from germs and allows time for needed care and rest. Here is a list of our guidelines:

- On our units, visiting hours are left up to the patient.
- One family member may stay with the patient overnight.
- One sleeper chair is allowed in each room.
- Restrooms for those who visit are in front of the nurse’s station.
- Showers for those who visit are on 5BS.
- Sleeping is not allowed in the family waiting room.
- For your safety, children under the age of 6 may not visit you on 6E. If you feel up to it and your doctor says it is okay, you may visit your children under 6 years old in the main lobby on the second floor.
Parking

Parking decks are just off Clifton Road, behind The Emory Clinic Building B. Valet parking is also offered on the south side of the hospital 24 hours a day, seven days a week. Valet charges cover both parking and valet service.

Five-day and long-term parking cards are sold at the Guest Services desk, 404-712-5619, in the hospital's main lobby, seven days a week from 9 a.m. to 5 p.m. These are for self-parking in the visitors’ deck.
Traveling to See Us
There are hotels and motels within five miles of EUH. Many offer special rates for patients’ families. Our Guest Services can help you reserve a room, give you room rates, and provide maps to the hotels. They can be found in the main lobby of the hospital and can be reached by calling 2-5619. If you are calling from outside the hospital, dial 404-712-5619.

Family Meetings
We want your loved ones to know how you are doing. To do this, we hold family meetings for patients with a new illness or for those with a major change in health status. The first meeting takes place within 1 week from when you arrive on our unit for the first time. Future meetings will take place as needed to update your family about major changes in your health status. Meetings will last 30 minutes. To prepare for your family meeting, please think about and complete the tasks listed below. Many people find that writing down their responses helps them to organize their thoughts. Give the nurse a list of health care team members you would like to come to the meeting. Please contact family members you want at the meeting. Health care team members include:

- Doctor in charge
- NP or PA
- Other doctors who are involved in the patient’s care
- Nurses
- Social Worker
- Chaplain

Think about the topics you want to talk about during the meeting. If you have special concerns, worries, fears, or other feelings about your health or your
care, write them down so you can share them at the meeting. During the meeting, you should get the answers to the following questions:

- What is your illness?
- What are your main health problems now?
- What treatments are you getting or planning to get?
- What other treatment choices can you choose from?
- What decisions about your care need to be made?
- What do the doctors expect might happen?

Bring important paperwork with you, such as a health care proxy (the document that says who makes decisions for you if you are unable to make them for yourself), advanced directive or living will, so we have a record of your wishes.

Think about what you want from the meeting and write it down on the next page.
Family Meeting Notes (your nurse can make extra copies of this page)

~Please bring this page to the family meeting~
Learning About the Blood System

Normal blood:

The bone marrow (soft tissue inside of the bones) is the factory for all the blood cells in your body. A blood stem cell in the bone marrow can produce all the different types of blood cells. Blood cells then leave the bone marrow and circulate in your blood vessels (veins, arteries) where they each have a job to do to help you stay healthy. The blood has two parts: a liquid part called plasma, and a cellular part (the blood cells). There are three main types of blood cells: red blood cells (RBCs), white blood cells (WBCs), and platelets.

- **The role of RBCs** is to carry oxygen (O₂) through the body to your tissues. The part of the RBC that carries O₂ is a protein called **hemoglobin**. The **hematocrit** is the word used to describe how much of your blood is made up of red cells. **Anemia** is the word used when the hemoglobin and the hematocrit in
your blood are abnormally low. The normal levels can vary depending on the person and the lab doing the measurements. Normal hemoglobin and hematocrit are not needed to live a normal life. Most people will have some symptoms of anemia when the hemoglobin level is less than 7 or 8 or when the hematocrit is less than 21 to 23. Severe anemia, if not treated, can cause problems due to decreased blood flow to the organs, such as heart and brain. This is why the doctor may give you blood when your hemoglobin level is less than 7 or 8 (hematocrit less than 21-23).

- **The role of the WBCs** is to defend the body against germs. **Neutrophils** are the type of WBCs that kill most germs. **Lymphocytes** are another type of WBC and kill viruses. Neutrophils and lymphocytes are a vital part of the immune system. Germs are more likely to grow when the WBC count is low. Normal WBC count is between 3,000 and 9,000 mm\(^3\). The WBC count is told in numbers such as 3 (if its 3,000) or 0.3 (if its 300). The absolute neutrophil count or “ANC” is another number that is used to measure the total number of WBCs you have to fight germs. A patient’s ANC is figured by multiplying the total number of WBCs by the percentage of neutrophils. Severe infections are more likely to happen when your ANC is less than 500. A patient’s WBC count (and their ANC) will most often decrease within 7 to 10 days after starting chemotherapy. Most WBC and neutrophil counts increase between days 21 to 28 after getting chemotherapy.

**This is the formula used to figure out your ANC**

\[
\text{ANC} = (\text{total WBC} \times \% \text{ neutrophils})
\]

Here’s an example: If you have 1,000 white blood cells (WBC) and 50% of those are neutrophils, then:

Your ANC = 1,000 x 0.50 = 500.

That means that, out of your total white blood cell count of 1,000, 500 of those cells are neutrophils. So, you have 500 neutrophils to help fight an infection. This is not many neutrophils. Normally we have thousands of them.
• **The role of platelets** is to help prevent and control bleeding. The normal platelet count is 150,000 – 400,000. The chance of bleeding increases when the platelet count is less than 10,000-20,000. The risk of bleeding also gets higher if you have taken aspirin or ibuprofen-type medications (like Motrin). Tylenol has no effect on platelets. If your platelet count is low (below 10,000-20,000), you may be given platelets in order to prevent bleeding.

**Learning about Blood Cancers**

Blood cancers usually start in the bone marrow. Usually, there is no specific reason why people get blood cancer and blood cancer is not hereditary (does not tend to run in families). In rare cases, a previous exposure to chemicals that can cause damage to the bone marrow stem cells may predispose someone to blood cancer later in life. Those exposures may include having received chemotherapy or radiation therapy (for another cancer) in the past. However, the chance of those exposures causing cancer is very low and most people with blood cancer don’t have a specific reason for it. It is thought that a bone marrow cell that got damaged or mutated was able to survive and turned cancerous. The cancer cells take the place of the normal cells in the marrow and spill out into the blood. This causes symptoms from low blood counts. Some of these symptoms are fever, infection, or bleeding. Blood cancer is called “leukemia”. Leukemia cells are often called “blasts”. They are a cancerous type of white blood cell, but they don’t do the job of a normal white blood cell.

**Types of Leukemia:**

Leukemias are named by the type of cell and by the rate of cell growth. They may be either acute or chronic.

**Acute leukemias** involve rapid growth of very young blood cells (blasts) which can make people sick very quickly. Because of this, treatment is usually needed right away. Acute leukemias are rare in adults, and their treatment is complicated. That
is why most people with acute leukemia go to university cancer centers or centers with doctors who have special training in diagnosing and treating acute leukemia.

Chronic leukemias involve the growth of more mature blood cells. In most cases, patients do not need treatment right away, but some types can progress to a form of acute leukemia.

The most common types of leukemia are:

- Acute lymphoblastic (or acute lymphoid) leukemia (ALL)- This is the most common type of cancer in children, but very rare in adults
- Acute myelogenous (or acute myeloid) leukemia (AML)- This is rare (about 1 in 100,000 people get AML) but is the most common type of acute leukemia in adults.
- Chronic lymphocytic leukemia (CLL)- This is the most common type of chronic leukemia in adults.
- Chronic myelogenous (or chronic myeloid) leukemia (CML)- This is a chronic form of leukemia that is less common than CLL.

Myelodysplastic Syndrome (MDS) is a disease in which the bone marrow does not produce enough normal blood cells, and can sometimes progress into acute leukemia. That’s why MDS is often called, “pre-leukemia”.

Other common blood cancers: Lymphomas are cancers of the lymph nodes and are also considered blood cancers. There are many types of lymphomas and they are grouped based on the type of cell and how quickly they grow. They can be Hodgkin or non-Hodgkin, B-cell or T-cell. The non-Hodgkin lymphomas include:

- low grade lymphomas (ex. follicular lymphoma)- These grow slowly
- high grade lymphomas (ex. burkitt lymphoma)- These grow fast
• intermediate grade lymphomas (ex. diffuse large B-cell lymphoma)-These are in-between.

**Multiple myeloma** is a blood cancer that involves a bone marrow cell called a **plasma cell**. These cells produce an abnormal protein called “paraprotein”. This protein can cause damage to the bones, kidneys, and other organs, and can also cause low blood counts, like anemia.

**What is Chemotherapy & How Does It Work?**

Chemotherapy (chemo) medications are chemicals used mainly for the treatment of cancer. Chemo works by killing cells that are dividing (or growing) quickly. Most normal cells do not divide as quickly as cancer cells. That is why chemo kills cancer cells and not all of the normal cells in the body. However, some of the cells in the body that are still growing normally can be damaged by the chemo.

The side effects of chemo happen when the chemo kills or damages the normal cells in the body that are also growing. These include: bone marrow and blood cells, cells lining the mouth and gut (stomach, intestines, rectum etc.), hair follicle cells, and cells of the reproductive system (eggs, sperm). Luckily, as the chemo wears off, the normal cells of the body start to grow again and the side effects wear off. The picture on the next page (pg. 27) shows how cells divide or grow and a list of cells that are still growing. Notice that cancer cells are at the top of the list, because they grow faster than any other cell.
**How Cells Divide**

- Chromosomes inside the cells contain genes

Rapidly dividing cells:

- Cancer cells

- Bone marrow/blood cells

- Cells that line the mouth and intestines

- Hair follicle cells

- Cells of the reproductive tract

- Chromosomes come in pairs

- The cell copies its genes

- The cell divides

- 2 new, identical cells are made!

* Genes carry all the genetic information that determines who we are, like the color of our eyes, our height, whether we are right or left handed, etc.
Symptoms You May Experience and Their Treatments

These are some of the symptoms you may have. They can be caused by your disease or as side effects from the chemotherapy you are getting (or will get). We can help to improve these symptoms.

**Low white blood cell count (“neutropenia”)**

Two things are needed to fight and get rid of germs that can make you sick, the body’s immune system and medications that kill the germs. White blood cells, especially the neutrophils, make up the immune system. People who have certain blood diseases, such as leukemia, aplastic anemia, or pre-leukemia (MDS) have a weak immune system due to having low numbers of neutrophils. Their immune system cannot help kill the germs. Therefore, patients must get medical help quickly at the first sign of a harmful germ. **Infection is a serious problem with certain blood diseases and their treatments.** You may be taking medications by mouth now to prevent germs from making you sick. These germ-fighting medications are called antibiotics. If you are taking antibiotics by mouth and you get a fever, you will most likely need to start taking antibiotics by vein. Getting a fever when you are taking antibiotics by mouth means that the antibiotic can no longer fight the germ you have.

**Please take these steps when your neutrophil count is low (when you are “neutropenic”):**

- If you feel sick or have drenching sweats or chills, check to see if you have a fever.

- Call your doctor or the on-call doctor if your fever is 101 degrees or higher. A fever could be a sign of infection and needs to be looked at right away. Do not use ACETAMINOPHEN (Tylenol®), ASPIRIN, or medications with IBUPROfen (Motrin®, Aleve®, Advil®) to get rid of the fever unless you are told to do so by the doctor. Be ready to tell the doctor your illness (why you see the hematologist), what treatment you are getting, and the date of your last dose of chemotherapy.
• Stay away from large crowds and wear a mask in crowded areas (grocery store, places to eat, clinic or emergency room visits), and outside. Ask a nurse to give you a mask.

• Stay away from people who are ill with a cold or flu, who have been exposed to a disease you can catch, or who were just given a live vaccine (mumps, measles, chicken pox, polio, smallpox, FluMist), because they can make you sick.

• Patients, family members, care givers, and others living in the same house should get the inactivated or killed flu shot each year. They should not get the FluMist vaccine because it is a live vaccine and it can make you sick.

• Wash your hands often.

• Working in the garden may cause you to get a fungus or mold when your neutrophil count is low. Please avoid working in the garden until your neutrophil count is higher. Your doctor, PA or NP will let you know when it is safe to garden or work on the yard.

• Cleaning pet waste (cat litter, fish tanks, etc.) can also cause infection if your neutrophil count is low. Please avoid cleaning pet waste.

• Please DO NOT IGNORE or “tough out” a fever or other signs of infection. Call 1.888.WINSHIP (1.888.946.7447) OR 404.778.1900. The quicker you get help, the better your chances of getting well again.

Nausea/Throwing Up

This symptom is usually a side effect from chemotherapy or due to taking strong pain medications. Here are some tips for treating your nausea:

• Take your nausea medicines. You may need to take them on a regular schedule and not just when you need them. For example, take the
medicine 3 or 4 times per day, instead of waiting until after you get nauseated or throw up to take the medicine.

- Avoid greasy, fatty foods because they can cause more nausea.

- Avoid strong odors because they can also cause nausea.

- If you are not able to keep food or fluids down with medications for more than 24 hours, you could become dehydrated. Please CALL 1.888.WINSHIP for help. We want to avoid dehydration because that can make you sicker.

**Headache**

If you have severe headache and changes in your vision, call your doctor right away (1.888.WINSHIP) because this can be a sign of danger.

**Pain**

Pain can be due to your disease or some of the medications your doctor prescribes. Here’s what you can do to help with your pain:

- Take your pain medications as prescribed.

- Do not take Tylenol, aspirin, or ibuprofen-type medications (Motrin, Advil, Goody’s powders) unless your doctor says it is okay. Ibuprofen-type medications may cause bleeding in people with low platelets. Both ibuprofen and Tylenol can mask a fever which is a sign of infection in people with low neutrophil count.

- Tell your doctor if your medications do not relieve your pain.

- When taking pain medications that can cause constipation, you may need to take a medicine that makes it easier to move your bowels (stool softener) or one that causes you to move your bowels (laxative).

- Please rate your pain on a scale from 0 = no pain to 10 = worst pain ever.
Rash

Some chemotherapy can cause rash or rash can be due to an allergic reaction. Low platelet counts can cause little red dots called “petechiae”. These (petechiae) are not dangerous. Tell your doctor if you have a new rash or any skin changes, and keep your skin dry and clean.

Constipation

Less frequent or hard to pass bowel movements (constipation) can be caused by strong pain medications or certain chemotherapy drugs, like vincristine or thalidomide. It is normal to have 1-2 bowel movements per day, even if you are not eating much. Constipation can be a big problem if it is not picked up and treated. It can result in blockage of the bowels and other serious life-threatening problems. Please tell your team if you are not having normal bowel movements each day. These are some things you can do to try to prevent constipation and some precautions to keep in mind:

- Drink plenty of fluids every day.
- Exercise regularly. Remember to walk your 21 laps every day.
- Do not eat foods that cause gas because they can cause your stomach to hurt.
- Suppositories and enemas can cause infection or bleeding if the neutrophils or the platelets are very low. They may be used only if the hematology doctor says it is okay.
- Take stool softeners to prevent constipation and laxatives to treat constipation.
Diarrhea

Diarrhea is commonly due to irritation of the bowels caused by chemotherapy. It can also be a side effect of other medications, c. diff colitis, or another infection. If you develop watery stools:

- Stop taking stool softeners and laxatives (if you were taking them).
- Drink 8-10 glasses of fluids each day, (water is best), to prevent dehydration.
- Do not eat high fiber foods because they can make the problem worse.
- Keep a record of the amount and number of bowel movements you have.
- Call your doctor if you have large amounts of watery stool, pain in your stomach, or blood in the stool (1.888.WINSHIP).
- Keep your skin clean and protected (A&D Ointment).

Bruising and Bleeding

Bruising and bleeding can be caused by having a low platelet count or as a side effect of taking blood thinners or anti-platelet medications, like aspirin.

- Having a low platelet count can make it more likely that you will bleed if you fall down or get hurt. Please notify your doctor RIGHT AWAY (at 1.888.WINSHIP) if you hurt your head and you have a low platelet count. You may need to be checked for bleeding inside your head.

- Use soft tooth brushes to prevent your gums from bleeding when you brush your teeth.

- Do not blow your nose when the platelets are less than 10,000 because this may cause your nose to start bleeding.
• Use pads (rather than tampons) if you have your period. There is a risk of increased bleeding when using tampons if your platelet count is too low. There is also risk of getting germs from the tampon if your neutrophil count is very low. Tampons are okay for use when the blood counts are normal.

• Please do not use dental floss or straight edge razors when your platelet count is very low because they can cause you to bleed.

• If your platelet count is very low, we ask that you not use aspirin and ibuprofen-type medications. They can cause you to bleed because they prevent the platelets from working properly.

Sore Mouth

Certain chemotherapy drugs can cause mouth irritation and mouth sores. These can hurt and can make it easier to catch an infection. When there is broken skin (in your mouth), bacteria that live in your mouth can get inside your body and can make you sick. These are steps that you can take to protect yourself:

• Keep your mouth nice and clean. This can prevent germs from growing in your mouth.

• Use mouthwash that is not alcohol-based because alcohol can cause burning or pain if your mouth is already irritated or sore.

• Drink plenty of fluids to prevent dehydration.

• You may want to avoid very hot or cold food or fluid because your mouth may be more sensitive to those.

• Keep moist lips to prevent them from cracking.
Other Side Effects that can occur from chemotherapy:

- Decreased proteins that help clot the blood. This can cause bleeding. This can be due to the disease itself, like in acute leukemia, or can be a side effect of drugs like asparaginase. These proteins can be replaced by transfusion if needed to prevent or stop bleeding.

- Bad taste in the mouth

- Nerve damage. This can cause imbalance, feeling confused, numbness and tingling in the fingers or the toes.

- Changes in electrolytes in the blood, such as sodium, potassium, or magnesium. This can cause abnormal heart beats if the problem is not corrected.

- Blood clots: mainly at IV line (or catheter) sites.

- Damage to the liver

- Damage to the kidneys

- Damage to the lungs

- Bladder irritation

- Increased blood sugar levels, mainly as a result of steroid use

- Memory and concentration problems (sometimes called “chemo-brain”)

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Fatigue

Fatigue (mental and body) is one of the most common side effects of chemo. Reasons for fatigue may include:

- Poor fluid balance, nausea, throwing up, poor hormone balance, anemia, infections, poor thyroid hormone balance, lack of proper diet
- Feeling depressed, anxious, or fearful
- Pain, problems with sleep
- Tumor cytokines (“the bad humors”)

Daily exercise can decrease the amount of fatigue you feel during the day and can help you sleep better at night. Exercise also helps to prevent blood clots in the legs or lungs and pneumonia by keeping the blood flowing and keeping your lungs moving air well.

We suggest you walk about 21 laps around our unit each day (1 mile each day). Your nurse can help you move the IV pole and get you moving. A physical therapist or occupational therapist can help you with your strength.
Feeling Depressed

Feeling depressed is not just a way to adjust to an illness. It is normal to react with sadness, feeling nervous, or angry. But, depression can happen from a lack of balance of chemicals in the brain. Specific medications can help to bring back the balance.

- Feeling depressed can keep you from doing what is most important to you. It can also cause you to have aches, pains, problems sleeping, or feeling anxious.

- Feeling depressed can best be treated by using a counselor or therapist and sometimes, by adding medications. Tell your team if you feel depressed, so that we can get you the help you need.
Taking Care of Your Central Line (catheter)

Your nurse will teach you and your care-taker how to care for your central line after you leave the hospital. You will also be given a DVD and something in writing that explains the steps.

Being Active

Being active can help you to stay strong and can help you breath better. These are things that you can do to help:

• Be active.

• Do as much of your self-care as you can.

• Take daily walks. Remember to walk your 21 laps per day!

• Balance activity with rest.

• Wear your mask in crowded areas (stores, shopping malls, airports, places to eat, clinic and emergency room visits) and outside.
Your Diet

Eat a normal, healthy diet. Fresh fruits and vegetables should be washed fully. You do not need to avoid any foods unless you are already on a special diet for other reasons.

Your Sex Life

Sex and intimacy are a normal part of life. There are no special limits. Use caution if your platelet count is low.

Use a method of birth control during treatment. Getting pregnant while you or your partner is getting chemotherapy is not safe because the medications may harm the unborn fetus.

Even if you are taking the pill, you (or your partner) should use a condom to make sure your partner is safe. We do not think any of the medications would get into your body fluids, but there is a small chance that they could. Tell your doctor or health care team if you are having problems with low sex drive or erectile dysfunction. There may be medications that can help.

Fertility

Some chemotherapy medications can cause you to not be able to have children due to damage to sperm and eggs. This may be short-lived or long-lasting depending on the medications, your age, and other factors. There are methods to preserve sperm ("sperm banking"), which should be done before starting chemotherapy. Preserving eggs is more difficult and is not widely available. Ask your health care team about sperm banking or egg preservation, if you wish.
The Goals of Chemotherapy

**Induction**
- Induction chemotherapy is given to cause a remission, meaning, no cancer cells can be found by the tests we have. The invisible seeds of leukemia/cancer may remain. That is why consolidation is needed.

**Consolidation**
- Consolidation chemotherapy is given after induction to kill any remaining cancer cells. It also helps keep a remission. This process may also be called "intensification".

**Maintenance**
- Maintenance chemotherapy is given in lower doses to try to prolong a remission. Not all diseases require maintenance. Some of the ones that do are ALL and acute promyelocytic leukemia (APL, a type of AML).
Types of Chemotherapy

Chemotherapy can be given in different forms. This depends on your illness and health status. Four types of medications and their side effects are listed below:

- **Cytotoxic Therapy**
  - These chemotherapy medications cause the usual expected side effects, meaning: low blood counts, nausea, hair loss, mouth sores, diarrhea, etc.
  - Examples of medications used here include cytarabine, doxorubicin, daunorubicin, & cyclophosphamide.

- **Targeted Therapy**
  - These medications may cause unusual side effects (allergic reactions)
  - Examples include antibodies, such as rituximab.

- **Hypomethylating Agents**
  - These medications cause few side effects. However, they can cause blood counts to decline, mild nausea, and fatigue.
  - Examples include decitabine and azacitidine.

- **Tyrosine Kinase Inhibitors**
  - Some side effects of this treatment include fluid build-up, swelling, and abnormal heart beats.
  - Examples include imatinib mesylate, dasatinib, nilotinib, and ponatinib.
Classes of Chemotherapy

First Line
- First line of chemotherapy presents the best chance of treating a cancer.
- Treatments that are first line have been proven through clinical trials and research.
- First line treatments may also be known as "standard therapy".

Second Line
- Second line chemotherapy treatments are used when a disease has not responded to or has come back after first-line therapy.
- These treatments have also been proven through research studies and clinical trials.

Palliative
- Palliative treatments focus on managing the symptoms and not treating the disease. Palliative treatments are a very important part of cancer care.
Research Studies

Winship Cancer Institute of EUH is committed to teaching cancer patients and their families about standard cancer treatments and new treatments that are offered. Research studies and clinical trials are needed in order to improve the outcomes of our patients and to find a cure for cancer. A cancer clinical trial is an option to think about when you decide on a course of action. The research team consists of those who do research, nurses, doctors, and other health care staff, as seen below.
Cancer **clinical trials** are research studies that test new treatments or new groupings of standard treatments to find better ways to treat cancer. All medications that are approved by the Food and Drug Administration (FDA) had to be tested in humans in order to prove that they are safe and that they work. There are 3 phases that new medications must go through before they become standard treatment.

**Phases of clinical trials:**

We take part in Phase I, Phase II, and Phase III clinical trials.

**Phase I:**

- These are studies testing a new drug for the first time in humans. These new medications have been tested on cells in test tubes and in animals. The goal of Phase I clinical trials is to find the right dose of the drug by trying to figure out what it does to the body and checking for side effects. Whether the drug works for a specific disease is not the main goal of Phase I clinical trials, but that information is also collected. Phase I clinical trials usually test new medications. Phase I clinical trials often include patients with several types of cancer or other illness.

**Phase II:**

- After the correct dose of a new medication is known based on the phase I clinical trial results, the drug or group of medications are tested in Phase II clinical trials. The goal of Phase II clinical trials is to find out if the drug works against a certain disease. Phase II clinical trials are designed to answer the question, “does this drug work against this disease?”

**Phase III:**

- Once a medication or group of medications shows that it works against a specific disease, it can be tested in Phase III clinical trials. Phase III clinical trials are designed to show that the new medication or group of medications is better than the current standard treatment. Medications that meet the goals
of a Phase III clinical trial are then sent to the FDA to be approved. If there is a standard treatment option that can be used on the given disease, most Phase III clinical trials will compare the new drug to the standard option.

**Getting Blood and Blood Products (Transfusions)**

Because blood diseases and chemotherapy can affect your bone marrow and blood counts, you may need to receive blood and platelets some time during your treatment.

There are some side effects that can happen when getting blood and blood products. They include:

- An allergic type of response. This can include fever, changes in blood pressure, or rash

- Certain infections can be passed on with the blood, but this is rare since the blood products are highly screened to exclude infected blood.

Over time, proteins called antibodies may form. These antibodies can destroy the transfused blood cells. This blood cell destruction is most common with platelets and less of a problem with red blood transfusions. When this happens, getting the platelet transfusion may not increase your platelet count as well as expected (because the antibodies destroy the transfused cells right away). If this happens, your doctor may give you a drug called Amicar to prevent bleeding. Amicar does not increase the platelet count but it can prevent bleeding by making the blood thicker.
Before Going Home from the Hospital

What to Expect?

When you are ready to leave the hospital, you must know how to take care of yourself once you are home. The nurse who is getting you ready to go home will go through a list of symptoms that may happen while at home. These symptoms are also described in this packet. Listen to your body. Let us know right away if you have symptoms such as fever or bleeding. Treating your symptoms early can prevent problems from getting worse.

The health care team who plans your discharge from the hospital will discuss the following:
- what you need to know about your medications
- your next clinic visit
- how to care for your line
- phone numbers you should have
- when to call your doctor

Please take this information with you to your first clinic visit along with all of your medications so we can give you the best possible care.
If you have any questions after leaving the hospital, please call us at: 1.888.WINSHIP (1.888.946.7447) or 404.778.1900. When you call, tell the call center what service is taking care of you (Hematology or Bone Marrow Transplant), your full name, date of birth, and your clinic doctor. Please be ready to tell the on-call doctor your diagnosis, the type of chemotherapy you are getting, and the last time you got chemotherapy.

Non-emergency questions can be answered with your care team during clinic hours (8am - 5pm) by calling 404.778.1900.

Here are some ways that you can help make your time with us productive and get you out on time:
• Follow the plan of care advised by your doctor or NP/PA.
• Ask questions if you don’t know something.
• Ask a family member or loved one to take part in your care so you will have some help at home.
  • Have your loved one visit you two or more times during your hospital stay so they can be taught how to care for you at home.
  • Try to avoid getting those “last-minute instructions” as you are leaving the hospital.
• On the day you are going home, have your ride come to pick you up before 8 AM. The nurse will be prepared to discharge you so you don’t have to wait. This will help with the following:
  • Help you avoid traffic
  • Allow plenty of time for you to pick up your medications and other needs.
  • Keep you from feeling anxious and stressed with change-of-shift report.

If calling after hours (5:00 PM) Monday – Friday, weekends, or holidays, please tell the operator that you are a hem/leuk (or bone marrow transplant) patient. They will connect you with the doctor on call.

Phone: 1.888.WINSHIP or if in the Metro Atlanta area 404.778.1900.
To Prepare for Clinic Visits

Checklist to Prepare for Clinic:

- Bring all your medications to every clinic visit.
- Call ahead of time if you need to cancel or change your appointment.
- Not feeling well is no reason to miss your appointment. Your symptoms may need to be checked by your doctor.

Being Prepared for a Crisis

In the event of a crisis, call 404.778.1900. If the crisis occurs during weekends, holidays, or weekdays (before 8am and after 5pm), call 404.778.1900 or 404.686.1000.

Please provide the following information to the operator and your doctor:

Your name
Your date of birth
Your illness (what disease the doctor is treating you for)
Your doctor’s name
Last time you had chemo
Type of chemo you are getting

Please be as precise as you can about your symptoms or your reason for calling, since the on-call doctor may not know your case.
Thank you

We welcome you to our family of caretakers. We value our patients, their families, and the quality of care they receive each day. This welcome packet gives you a detailed idea of what to expect while at Emory. Please let us know how we can better help you and don’t forget to ask questions!
…And another thing,

What:

Come run, walk, or cheer with us!

When:
Every year in October (Winship 5K is an annual event). Check the Winship website or ask any one on your care team.

Why:
Every year in October since 2011, the Emory community, including patients, their families and friends, physicians, nurses, staff, friends of Emory, and people who like to run and have fun, meet and participate in the Winship 5K “Win the Fight” run/walk. We do this to raise awareness and funds for cancer research. It’s a fun activity and a chance to see all of your care takers in their running clothes! Some of them even run in tutus! You can join the Leukemia/BMT team or form your own team. There is even a training program that you can join if you need some practice. The link is posted below for you to learn more about the event including how to sign-up. It is never too late to start a healthy, fun habit. We hope to see you there!!!

https://winshipcancer.emory.edu/support-winship/WinshipContentPage.aspx?nd=887