Understanding Side Effects of Drug Therapy
A Message From John Walter
President and CEO of The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society (LLS) is committed to bringing you the most up-to-date blood cancer information. We know how important it is for you to have an accurate understanding of your diagnosis, treatment and support options. With this knowledge, you can work with members of your oncology team to move forward with the hope of remission and recovery. Our vision is that one day the great majority of people who have been diagnosed with blood cancers will be cured or will be able to manage their disease with a good quality of life. We hope that the information in this booklet will help you along your journey.

LLS is the world’s largest voluntary health organization dedicated to funding blood cancer research, education and patient services. Since the first funding in 1954, LLS has invested more than $875 million in research specifically targeting blood cancers. We will continue to invest in research for cures and in programs and services that improve the quality of life of people who have blood cancers and their families.

We wish you well.

John Walter
President and CEO
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This booklet provides general information in regard to the subject matter covered. It is distributed as a public service by The Leukemia & Lymphoma Society (LLS), with the understanding that LLS is not engaged in rendering medical or other professional services. Medicine is a constantly changing science. Human error and changes in practice make it impossible to certify the precise accuracy of such complex material. Confirmation of this information from other sources, especially the patient’s doctor, is required. In addition to the patient’s doctor, other sources of information include patient information provided by the drug’s manufacturer and the references listed on page 42.

Always consult with your healthcare provider for information related to drug treatment or side effects. Before having medical or dental exams, tests, treatments or surgery (including dental surgery) or emergency treatment, tell the doctor or dentist in charge about the specific medications and treatment that you are receiving or have received.
Introduction

More than one million people in the United States are living with or are in remission from blood cancer (leukemia, lymphoma, myeloma, myelodysplastic syndromes and myeloproliferative neoplasms). Blood cancers are types of cancer that can affect the bone marrow, the blood cells, the lymph nodes and other parts of the lymphatic system. These diseases are related cancers in the sense that they probably all result from acquired mutations to the DNA of a single lymph- or blood-forming stem cell. The abnormal cells multiply and survive without the usual controls that are in place for healthy cells. The accumulation of these cells in the marrow, blood and/or lymphatic tissue interferes with production and functioning of red blood cells, white blood cells and platelets. The disease process can lead to severe anemia, bleeding, an impaired ability to fight infection and other effects.

The growing number of people who are surviving cancer, and living good quality lives, is largely due to the current drug therapies developed during the last 60 years. Drug therapies can produce long-term remission, or outright cure, for many children and some adults, depending on the type of cancer and other patient-related factors.

Hearing that you or a loved one has cancer is difficult, and you, like many other people, may wonder how you will be able to cope. Ongoing communication between patients, doctors and other members of your healthcare team is a key part of cancer therapy. Getting information about treatment may help during this stressful time.

Understanding Side Effects of Drug Therapy provides questions to ask your healthcare team (see page 13) and lists common side effects and their management (see page 16).

Want more information?

For information about specific FDA approved drugs for blood cancers, visit www.LLS.org/drugs.

Here to Help

This booklet will give you suggestions to help you take care of yourself and help you talk to your doctor. We encourage you to take the lead in asking questions and discussing your fears and concerns. These actions will give members of your healthcare team the opportunity to answer your questions, extend emotional support and provide any needed referrals.
A blood cancer diagnosis is often a shock to the patient, family members and friends. Denial, depression, hopelessness and fear are some of the reactions people may have. Keep in mind that

- Many people are better able to cope once they begin treatment and can look forward to recovery.
- The outlook for people with blood cancers is continuing to improve. New approaches to therapy are being studied in clinical trials for patients of all ages and at every stage of treatment.

**LLS Has Ways to Help.** Your treatment may affect your daily life, at least for a time. You may have questions about your treatment and want to have friends, family members or caregivers help you get information.

Making treatment choices, paying for medical care, communicating with healthcare providers, family members and friends—these are some of the stresses that go along with a cancer diagnosis. LLS offers free information and patient services for individuals and families touched by blood cancers.

**Speak to an Information Specialist.** Information Specialists are master’s level oncology professionals. They provide accurate up-to-date disease and treatment information and are available to speak with callers Monday through Friday, 9 a.m. to 6 p.m. ET at (800) 955-4572. You can email infocenter@LLS.org or chat live at www.LLS.org.

**Clinical Trials.** Our Information Specialists help patients work with their doctors to find out about specific clinical trials. Information Specialists conduct clinical-trial searches for patients, family members and healthcare professionals. You can also use an online clinical-trial search service supported by LLS that offers patients and caregivers immediate access to listings of blood cancer clinical trials. Please visit www.LLS.org/clinicaltrials.

**Advocacy and Public Policy.** The LLS Office of Public Policy (OPP) enlists volunteers to help advocate for policies and laws to speed the development of new treatments and improve access to quality medical care. Visit www.LLS.org/advocacy to find out more or get involved.

**Co-Pay Assistance Program.** This program offers assistance for financially eligible patients with certain blood cancer diagnoses to help pay for private or public health insurance premiums and/or co-pay costs for prescription medications. Check www.LLS.org/copay or call (877) 557-2672 to speak to a Co-Pay Assistance Program specialist for more eligibility information.

**Language Services.** Free language services are available when you speak with an Information Specialist. Let your doctor know if you want a professional healthcare
interpreter who speaks your native language or uses sign language to be present during your visit. Many times, this is a free service.

Información en Español. LLS has a number of resources available in Spanish for patients, caregivers and healthcare professionals. You can read and download these resources online at www.LLS.org/espanol or order printed copies by mail or phone.

Free Materials. LLS publishes many free education and support materials for patients and healthcare professionals. PDF files can be read online or downloaded. Free print versions can be ordered. Visit www.LLS.org/resourcecenter.

Chapter Programs and Services. LLS chapter offices around the United States and Canada offer support and education. Your chapter can arrange for peer-to-peer support through the Patti Robinson Kaufmann First Connection Program. The Patient Financial Aid program offers a limited amount of financial aid for qualified patients. Find your chapter by calling (800) 955-4572 or by visiting www.LLS.org/chapterfind.

Other Helpful Organizations. Our website, www.LLS.org/resourcedirectory, offers an extensive list of resources for patients and families about financial assistance, counseling, transportation, summer camps and other needs.

Telephone/Web Education Programs. LLS provides a number of free, live telephone and web education programs presented by experts for patients, caregivers and healthcare professionals. For more information, visit www.LLS.org/programs.

Suggestions From Other People Living With Cancer

- Get information about choosing a cancer specialist or treatment center.
- Find out about financial matters: What does your insurance cover? What financial assistance is available to you?
- Learn about the most current tests and treatments for your type of blood cancer.
- Keep all appointments with the doctor and talk openly about your fears, concerns and/or any side effects that you experience.
- Talk with family and friends about how you feel and how they can help.
- Contact your doctor if you have fatigue, fever, pain or sleep problems so that any issues can be addressed early on.
- Get medical advice if you have experienced changes in mood, feelings of sadness or depression.
Reach Out. You and your loved ones can reach out for support in several ways.

- LLS offers online blood cancer discussion boards as well as online chats at www.LLS.org/getinfo.
- Local or Internet support groups and blogs can provide forums for support.
- Patients with cancer often become acquainted with one another, and these friendships provide support.

Information for Veterans. Veterans with certain blood cancer diagnoses who were exposed to Agent Orange while serving in Vietnam may be able to get help from the United States Department of Veterans Affairs. For more information call the Department of Veterans Affairs at (800) 749-8387 or visit www.publichealth.va.gov/exposures/agentorange.

Information for World Trade Center Responders and Survivors. Responders, workers, and volunteers who helped with rescue, recovery, and cleanup at the World Trade Center and related sites in New York City; survivors who were in the New York City disaster area, lived, worked, or were in school in the area; and responders to the Pentagon and the Shanksville, PA crash who have been diagnosed with a blood cancer may be eligible for help from the World Trade Center Health Program. For more information, call the World Trade Center Health Program at (888) 982-4748 or visit www.cdc.gov/wtc.

Depression. Treatment for depression has proven benefits for people living with cancer. Depression is an illness that should be treated even when a person is undergoing cancer treatment. Seek medical advice if your mood does not improve over time—for example, if you feel depressed every day for a two-week period. Contact LLS or ask your healthcare team for guidance and referrals to other sources of help, such as counseling services or community programs. For more information you can contact the National Institute of Mental Health (NIMH) at www.nimh.nih.gov and enter “depression” in the search box at the top of the web page, or call the NIMH toll-free at (866) 615-6464.

We’d Like to Hear From You. We hope this booklet helps you. Please tell us what you think at www.LLS.org/publicationfeedback. Click on “LLS Disease & Treatment Publications—Survey for Patients, Family and Friends.”
About Drug Therapies

In the past decade alone, new drugs and new uses for existing drugs have greatly improved cure rates or remission rates for patients of all ages. Newer “targeted therapies” and “risk-adapted therapies” have resulted in higher overall response rates and decreased side effects. More than 50 drugs of different types are now being used singly or in combination to treat blood cancers.

**Blood Cancer Treatment.** Treatment often includes one or a combination of the following:

- **Drug therapy**—patients are usually treated with a type of drug therapy called “chemotherapy” or “anticancer agents” (terms for certain drugs or chemicals used to kill or damage cancer cells in the body).
- **Radiation therapy**—patients are treated with high-energy rays to damage cancer cells (stop them from growing and dividing).
- **Stem cell transplantation**—a treatment used to restore the function of the marrow by using the patient’s own stem cells or the use of donor stem cells.

**Goal of Drug Therapy.** The goal is to eliminate cancer cells so that:

- There is no longer any sign of illness.
- Normal cells are restored (called “remission”).

Cancer cells may grow too fast or fail to undergo cell death at an appropriate rate. Drug therapy can speed up cancer cell death.

**Methods to Administer Drugs.** The most common ways that drugs are given to patients (methods of administration) are:

- Intravenously (IV) (into a vein)
- Orally (by mouth)
- Intramuscular (IM) injection (into a muscle)
- Subcutaneous (SC) injection (under the skin)
- Intrathecal injection (within the spinal canal).

The choice of administration method depends on the drug and the patient’s diagnosis.
Fast Facts About Drug Administration

- Drugs that might damage tissues if given by mouth or by injection under the skin or into a muscle may be infused into a vein (intravenous administration).

- Many patients find that chemotherapy can be given more easily and comfortably through a central line than through a regular IV infusion.

- The central line can also be used to give IV fluids, blood products and other medications, such as antibiotics, and to draw blood for testing.

- Side effects of therapy depend, in part, on how a drug is given.

Intravenous (IV) Medications. These may be given through a vein in the forearm or through a catheter or port to access the vein (for information about catheters and ports, see below). There may be some discomfort during insertion caused by the needlestick. After that, administration of the drug is usually painless. Medication flows from a solution in a plastic bag through tubing into the bloodstream. Any pain or burning during administration should be mentioned to the nurse right away.

Patients who are being treated with intravenous medications may benefit from having one of the following:

IV catheters (central lines). Certain medications irritate the veins and make repeated IV placement difficult. Long-term catheters (referred to as “tunneled catheters,” “central lines,” or “Hickman,” “Broviac” or “Groshong” catheters) can remain in place for extended periods. They are used in the hospital as well as at home. To place the central line, a small incision is made where the catheter enters the vein, and the IV line is passed under the skin to a second small incision at a distance from the first. This distance helps prevent infection. Most catheters are positioned on the chest wall. Placement is usually done under local anesthesia. There may be a few stitches at one or both sites until the areas have healed. Small, clear dressings are changed frequently to prevent infection. Hospital or clinic staff will show patients, family members or other caregivers how to clean and care for the central line.

Ports. A port under the skin allows access to the catheter. The port is surgically inserted under the skin’s surface on the upper chest wall. After the site heals, no dressings are needed and no special home care is required. When medicines are needed, a doctor, physician’s assistant or nurse inserts a needle through the skin to access the port. The patient can choose to have a local numbing cream applied to the injection site before the port is used. Blood can be drawn, and blood products can be received through this device.
PICC or PIC lines (percutaneously inserted central venous catheters). A PICC or PIC line is a long, thin, flexible tube that is used (over an extended period of time) to administer medications, antibiotics, fluids and nutrition; it can also be used to obtain blood samples. Prior to insertion of the PICC, the patient is given a local anesthetic to numb the arm in the area above the elbow and below the shoulder. The PICC is inserted through the skin (percutaneously) into a vein in the arm and advanced until it reaches the superior vena cava just above the heart. The superior vena cava is one of the veins in the central venous system. The PICC can be maintained for several weeks to months, eliminating the need for standard intravenous (IV) administration.

Long-term devices need to be flushed. Your healthcare provider will usually give you a plan that includes instructions to have your device flushed and how often flushing is needed.

**Oral Medications.** Some medications are taken by mouth in the form of a pill, capsule or liquid. Examples of blood cancer drugs that are taken by mouth are thalidomide (Thalomid®), lenalidomide (Revlimid®) and imatinib mesylate (Gleevec®). The side effects of oral chemotherapy are similar to those from IV chemotherapy. For many people, taking medications by mouth is the most convenient method.

Patients must understand

- The dosage of their medication and know how often to take it
- Food-drug interactions
- Drug-drug interactions
- Herbal products and drug interactions
- Over-the-counter drug and prescription drug interactions
- Storage and handling
- Potential side effects

To protect against medication mistakes, patients should double-check with their healthcare providers about these aspects of their medication(s). It is necessary to take these drugs exactly as prescribed. Some patients find that medication calendars and planners are useful. Timers can be set as reminders to take medications.

**Intramuscular (IM) Medications.** These medications are injected into the muscle, usually in the arm, thigh or buttock. There is a slight pinch, lasting a few seconds, as the needle is slipped through the skin and into the muscle.
Subcutaneous (SC) Injections. These are injected into the tissue under the skin, rather than into the muscle. The injection can be given in the arms, legs or abdomen. Your nurse or doctor will select the best site to administer the medication.

Intrathecal Medications. Certain types of leukemia and lymphoma have a tendency to spread to the nervous system. To prevent or treat this, a doctor may perform a lumbar puncture (spinal tap) and inject an anticancer drug into the spinal fluid to destroy cancer cells. This is known as “intrathecal drug delivery.” If many treatments are needed, doctors may place a long-term device, called an “Ommaya reservoir,” under the scalp. Once the device is inserted, drugs can be given through the Ommaya reservoir, and the patient will no longer need spinal taps. The patient can go home with the Ommaya reservoir in place.

Older Adults. About half of all cases of blood cancer develop in people older than 60 years. Keep in mind that chronological age is just one factor that guides treatment options. Many clinical trials are available for older adults (see page 11 for more information about clinical trials).

**Fast Facts for Older Adults**

- The ability to tolerate intensive chemotherapy decreases with age, even in otherwise healthy older persons.
- Doctors are using a series of relatively simple tests to better predict and support tolerance for therapy among older adults. In many cases, older patients can receive full dosages of the appropriate therapy.
- Older people are more likely to have other, unrelated illnesses, such as diabetes mellitus, coronary artery disease, congestive heart failure or impaired kidney function. These conditions may limit the drugs and/or dosages of drugs that can be administered to certain patients, potentially compromising their treatment.
- Newer agents which are targeted to the specific cancer and will spare normal tissue in certain situations (such as imatinib mesylate [Gleevec®], dasatinib [Sprycel®] and nilotinib [Tasigna®] for chronic myeloid leukemia) are well tolerated by older patients.
- Certain complications, such as infection after therapy, are more frequent in older patients.
- Certain blood-cell growth stimulators can be used to increase the tolerance of older patients to chemotherapy, making it possible for more patients to receive appropriate therapy.
Approved Therapies and Cancer Clinical Trials. The US Food and Drug Administration (FDA) approves a treatment if it meets safety requirements and is either more effective than an existing standard treatment or equally effective, but with fewer toxic side effects. Safety and effectiveness are determined through “clinical trials.” Individual drugs, listed at www.LLS.org/drugs, are approved to treat cancer or to provide supportive care. Continued advances in blood cancer treatments depend on clinical trials of potential new therapies.

Off-Label Use. A drug that has been approved for one use may be prescribed to treat patients with other diseases or conditions. This is sometimes called “off-label usage.” Healthcare plans may not pay for this use, or may require prior approval, so always check with your doctor or healthcare plan.

Off-label use is common and is considered when doctors and researchers have a clear, scientific basis for evaluating and monitoring the drug’s effectiveness for other conditions. It is best for cancer patients who receive therapy off-label to be treated as part of a clinical trial. This enables the medical and scientific community to determine which treatments are effective, based on such factors as disease type or subtype, cytogenetics, disease stage and patient age.

Cancer Clinical Trials. A clinical trial is a carefully controlled research study conducted by doctors to improve the care and treatment of cancer patients. Before a clinical trial begins, a new therapy is often developed and tested in a laboratory. Then it is thoroughly tested in animals. If this early research (called “preclinical trials”) shows the therapy is safe and effective, a carefully planned and monitored clinical trial of the drug or treatment will be conducted in people.

Clinical trials are conducted in four phases.

- Phase 1 is conducted in a small group of patients to determine safety, appropriate dosage and administration of a treatment.
- Phase 2 studies test the treatment in a larger group of patients to determine whether and how well it works. Researchers also continue to monitor safety in phase 2 and throughout the trial. The trial will move into phase 3 if the results of phase 2 studies are positive.
- Phase 3 studies will compare a “study treatment group” to a “control treatment group”; control-group patients will receive the best standard treatment. A treatment that “passes” phase 3 testing may be approved by the FDA if it is found to be both safe and more effective than standard treatment or equally as effective as standard treatment but with fewer toxic side effects.
- Phase 4 studies are often performed on treatments that have already been FDA approved (also referred to as “postmarketing” trials); their purpose is to identify additional uses, gather more information from a larger group of patients regarding safety and effectiveness or establish effectiveness in a patient subgroup, such as patients over the age of 65.
Some patients may consider all treatment opportunities including clinical trials before making a choice about treatment. Others may look for a cancer clinical trial if standard treatment is not working. Patients and their doctors can decide if and when a clinical trial is the right course to take.

Want more information? You can view, print or order the free LLS publications Understanding Clinical Trials for Blood Cancers and Knowing All Your Treatment Options at www.LLS.org/resourcecenter or contact an Information Specialist for copies.

**Getting Information About Treatment and Side Effects.** Patients, especially those who are newly diagnosed, are given a lot of new information. It is important that you understand the information you are given about the treatment you are taking and know about any side effects it may have. Ask questions before you start your treatment. Information is not helpful, and in some cases can be dangerous, if you do not understand it. Some questions you can ask members of the healthcare team are listed on pages 13 and 14. For Healthcare Question Guides about treatment options, side effects, second opinions and other topics that can be printed, visit www.LLS.org/whattoask.

**Keeping Track of Information.** It can be overwhelming to remember everything that is said. Patients, family members or friends should write or record all instructions about the therapy. Some patients bring a tape recorder to the appointment and take notes.

Ask for printed information about the specific diagnosis and its treatment. Information about side effects can be given to you in a paper called a “medication guide.” This will provide detailed information about a drug and its side effects. If anything is unclear, ask the doctor to slow down or go over the information again.

**Side Effects.** Normal body cells may be affected by drugs used to treat blood cancers. Some of these drug side effects may be serious. Other drug side effects, such as hair loss, may not be serious but may cause concern. Patients should ask their healthcare providers about

- Drug dosage
- How the drug is given
- Possible drug side effects
- Which side effects are common and which are considered more urgent
- What side effects, if any, should be reported immediately. When in doubt, call the doctor or oncology nurse right away.
Questions to Ask Your Healthcare Team About Your Treatment

1. Why do I need this treatment?
2. What are the benefits and/or risks associated with this treatment?
3. What are other possible side effects of this treatment? When are they likely to occur?
4. What can I do to relieve the side effects (for example, other medications, complementary or alternative techniques)?
5. Do I need to be concerned about fertility? If I become pregnant? If I am breastfeeding?
6. Will this drug have any effect on the menstrual cycle?
7. Will I have any special diet needs? Are there any known food-drug interactions of my treatment?
8. Do I need to drink extra fluids while taking this medication?
9. Can I drink alcoholic beverages, including beer and wine?
10. Should I be aware of any test results that could be affected by this drug?
11. Will any of the medications I am currently taking interact with this treatment?
12. Are there any other possible treatment methods for my type of cancer?
13. Are there any clinical trials for my type of cancer?
14. How many treatments will I receive? Over what period of time?
15. What is the name of the drug (or drugs) I will be taking? How does it (do they) work?
16. How will the drugs be given and how long will each treatment last?
17. Where will I get my treatment?
18. Do I have a choice about when to begin treatment?
19. Do I have a choice about which days or time of day to schedule my treatment?
20. Will I need assistance on the day of my treatment (for example, should someone drive me to therapy)?
21. Are there signs or symptoms I will need to watch for after I finish treatment with this drug? For what period of time?
22. Will I be able to work or go to school while I’m undergoing treatment?
23. Will this drug cause drowsiness or have any effect on my alertness? Can I drive or do jobs that require me to be alert?
24. Do I need to take any special precautions to avoid sunlight or tanning beds while I am taking this drug?
Taking Medications at Home—Questions to Ask Your Doctor

1. What if I miss a dose?  
2. What if I vomit immediately after taking my medication?  
3. Is it safe to drink alcohol during my use of this drug?  
4. When should I take the medication?  
5. How should I store it?  
6. Do I need to take this medication with food?  
7. Are there any prescription medications, over-the-counter (OTC) products, herbal medicines, or foods that I should avoid while taking this medicine?  
8. When and how should I contact the healthcare team with questions?  
9. How do I contact a healthcare professional after hours?

The following tips for taking medications at home may be helpful to you:

- Set daily routines to take medication. Keep medications where you’ll notice them. It is very important that chemotherapeutic medications be kept out of reach of children and pets.
- Use daily dosing containers.
- Keep a written or computerized schedule. Include the medications you take, how often you take them and any special directions.
- Give a copy of your list to a reliable family member or friend.
- Keep a list of questions you want to ask your doctor at the next visit. Be sure to tell your doctor about any problems you had taking the medicine. Your doctor needs to know if you missed any doses.

Things to Tell Your Doctor Before Treatment. Talk to your doctor about your medical history, ask questions and promptly report any side effects. Whenever a treatment is prescribed, tell the doctor if you

- Have taken this drug before (even if there was no unusual reaction)
- Had an unusual or allergic reaction to this drug
- Have or had any other medical conditions, including diabetes, gout, heart disease (or abnormal heart rhythms or congestive heart failure), head injury, history of alcoholism, infection, immune deficiencies, kidney disease or kidney stones, liver disease, marrow depression, low serum magnesium or potassium levels, or pancreatitis (inflammation of the pancreas)
- Have recently been exposed to varicella (chickenpox) or herpes zoster (shingles)
Have had an unusual or allergic reaction to any foods, such as lactose or egg whites, preservatives, dyes, *E coli*–derived proteins, albumin or retinoid preparations (vitamin A)

Have ever been treated with radiation therapy or other cancer therapies; some drugs used to treat cancers may increase the effects of other medications and/or radiation therapy

Take any other medications, drugs (prescription or over-the-counter)

Use “street drugs,” which may increase the toxicity of certain cancer drugs

Are a smoker

Take any vitamins, minerals, herbs or other supplements

Are taking any other medication

Are planning a family or have any concerns about intimacy, birth control, fertility, pregnancy and/or breastfeeding.

**Survivorship—Life After Cancer.** The risk of long-term effects of anticancer therapy has been recognized for years. In response, treatments continue to evolve. To minimize the risk, the lowest effective doses of drugs and radiation are used. Survivors need to be aware of the kinds of therapy they received and the specific risks resulting from their prior cancer therapy. Regular medical follow-up is encouraged to enable doctors to assess the full effect of therapy, to detect and treat disease recurrence, and to identify and manage long-term or late effects.

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**Fast Facts About Survivorship**

- Survivors need physical examinations yearly or more often.

- Regular examinations include cancer screening and screening for long-term and late effects of treatment.

- There are survivorship programs, focusing on life after cancer, at several major hospitals around the country.

- Your oncologist should help create a survivorship plan or follow-up plan to monitor for late effects. This can help the primary care doctor who might not be familiar with possible problems. These plans are individualized and long term.

- Survivors do not necessarily need a cancer specialist for routine checkups and screening, but they do need to see doctors who understand their previous treatment and its risks. Specialists and primary care doctors can work as a team to provide the best care.
Part 2

Drug Therapy Side Effects Topics

Certain side effects can be unpleasant, but they must be measured against the benefits of the therapy and the risks of not receiving the treatment.

Fast Facts About Side Effects

- Drugs that damage or destroy cancer cells also affect normal cells and may cause certain side effects.
- Rapidly dividing cells, such as hair follicle cells, cells that line the gastrointestinal (GI) tract and stem cells that produce blood and immune cells are the most affected. This is why hair loss, nausea, diarrhea and low blood cell counts (which can cause easy bruising/bleeding, fatigue, shortness of breath, infections, etc.) are common side effects of cancer treatments.
- Side effects do not always happen and can be different for each patient, depending on the drug(s), amount of drug, length of treatment, how each patient reacts, and the presence of other health problems (such as diabetes or kidney disease).
- Side effects are usually seen during the clinical trials (research studies) that are conducted before a drug is approved by the FDA.
- While unexpected side effects can occur, most side effects can be predicted because certain drugs are more likely than others to affect specific types of body tissues, such as those that make up the nervous system, kidneys, bladder, heart and lungs.
- Most side effects are temporary and go away once the body adjusts to therapy or when therapy is completed.
- Be sure you know the early-warning signs and symptoms of possible side effects so that you can detect them early. You should be able to manage some minor side effects at home. Be sure you know which side effects are serious enough to prompt you to call the doctor or go to the emergency room.
- Keep a list of any minor side effects that you experienced and tell your doctor about them at your next visit.
- During and following the end of therapy, healthy new cells begin to grow and develop each day. Less commonly, a drug or drug combination used to treat blood cancer has side effects that continue for a period of time after treatment ends. These are called “long-term” and “late” effects. Some effects may be permanent.
- Side effects are not always drug-specific and may be related to something other than the medication.
Blood Cells. The degree to which drug therapy affects the blood cells and bone marrow will depend on whether the marrow has already been damaged by the cancer prior to treatment, the type of drug(s) used and duration of therapy along with other factors. Some drugs have little or no damaging effect on the marrow. The effects of others can either be reversed once therapy is stopped or may last for several weeks.

Fast Facts About Blood Cells

- Blood cells begin as stem cells. Stem cells become red blood cells, white blood cells and platelets.
- Marrow is the spongy center inside of bones where blood cells are made.
- Red blood cells carry oxygen around the body. When the number of red blood cells is below normal, the condition is called “anemia.”
- White blood cells fight infection in the body.
- Platelets prevent bleeding by forming plugs that help stop bleeding at the site of an injury.
- Plasma is the liquid part of the blood. It is mostly water. It also has some vitamins, minerals, proteins, hormones and other natural chemicals in it.
- Low blood-cell counts may increase a patient’s risk of problems.
- Certain supportive therapies, such as blood transfusions, may increase a patient’s risk of problems. Talk with your doctor about the potential benefits and risks.
Monitoring Blood Cell Counts. Doctors measure the patient’s blood-cell counts periodically during drug therapy to

- See if red blood-cell, white blood-cell or platelet counts have decreased
- Figure out how well the treatment is working
- Check if the medication amount needs to be adjusted or whether the patient may need a transfusion of new blood cells during the treatment.

Want more information? You can view, print or order the free LLS publication Understanding Lab and Imaging Tests at www.LLS.org/resourcecenter or contact an Information Specialist for a copy.

Anemia. Anticancer drugs may destroy developing cells in the marrow and cause a decrease in red blood cell count. People with a low red blood cell count (anemia) may have side effects, including

- Fatigue or shortness of breath, especially with physical activity
- Pale skin, gums or nails
- Lightheadedness or dizziness
- A tendency to feel cold.

Any of the symptoms described above should be reported to the doctor. Most people with a mild or moderate decrease in red blood cells will not realize that they are anemic; however, if the body continues to not produce enough red blood cells, severe anemia can occur. In these cases, doctors may prescribe a red cell growth factor or, if needed, a blood transfusion to help restore the patient’s red blood cell count.

Erythropoiesis-Stimulating Agents (ESAs). ESAs, such as Epogen®, Procrit® and Aranesp®, are synthetic versions of erythropoietin, a hormone produced in the kidneys that stimulates the body to produce red blood cells. ESAs are given by injection under the skin or by IV. Some studies suggest that correcting anemia too vigorously may increase the risk for blood clots. Also, in some forms of cancer, the use of an ESA may be associated with a worse outcome. Safety concerns about the use of these drugs in certain cancer patients have resulted in revised guidance about their use from the FDA. Patients undergoing chemotherapy who are prescribed an ESA will be given information about the drug and should discuss the risks and benefits of this therapy with their doctors.
**Iron Overload.** Some patients may need red blood cell or platelet transfusions at various times to improve blood cell counts and help lessen symptoms. The decision to give red blood cell transfusions is based on a combination of factors, including the patient’s hemoglobin level, symptoms—for example, feelings of fatigue or shortness of breath—and any other health complications, such as heart disease. Red cells contain iron, and patients who have regular transfusions (ranging from less than 2 units to 4 or more units of blood a month) may be at risk for “iron overload”—a condition that can potentially damage the heart and liver. A blood test called a “serum ferritin level,” which measures the body’s store of iron, is used to monitor the patient.

Certain medications called “iron chelators” (chelation is the use of chemicals to remove certain molecules, such as minerals or metals [like iron] from the body) are FDA approved to remove excess iron in the body that is a result of transfusion-dependent anemia. It is important for patients to talk to their doctor about the potential benefits and risks of using these drugs. Deferasirox (Exjade®) and deferoxamine mesylate (Desferal®) are examples of iron chelators.

**Risk of Infection.** White blood cells help the body fight infection. Anticancer drugs may destroy both the cancer cells and healthy, infection-fighting cells. Moderate decreases in the number of white blood cells do not require special precautions, especially if the cell counts return toward normal levels within a short time. However, a severe or prolonged low white blood cell count, especially after intensive drug therapy, may put a patient at greater risk for infection.
One Dozen Ways to Reduce Infection Risk

1. Medical staff will take steps to avoid exposing patients to bacteria, viruses and other infection-causing agents by practicing frequent and vigorous hand washing or, in some cases, by wearing masks, gowns and gloves.

2. Caregivers for patients with catheters need to be meticulous in cleaning the catheter to reduce the risk of bacteria getting into the body through this device. Patients receiving anticancer therapy on an outpatient basis should discuss with members of their healthcare team how to avoid infection.

3. Wash your hands thoroughly, especially before eating and before and after using the bathroom. This applies to everyone—people in treatment and those around them.

4. Avoid crowds and individuals with contagious diseases such as colds, flu, measles or chickenpox.

5. Check with your doctor about getting any vaccinations. Find out if you should avoid people who have recently received immunizations with live attenuated organisms or viruses (weakened forms of the organism or virus that causes the disease), such as vaccines for measles, and how long you should stay away from them.

6. Clean your rectal area gently but thoroughly after each bowel movement. Ask for medical advice if irritation or hemorrhoids are a problem. Check with the healthcare team before using enemas or suppositories.

7. Take care of your skin by
   - Not cutting or tearing the cuticles of the finger or toenails
   - Avoiding cuts or nicks when using scissors, needles or knives
   - Using an electric shaver instead of a razor to prevent cuts
   - Using an extra-soft toothbrush that will not hurt the gums
   - Not squeezing or scratching pimples.

8. Clean cuts and scrapes right away with warm water, soap and an antiseptic, such as hydrogen peroxide, rubbing alcohol and others.

9. Take a warm (not hot) bath, shower or sponge bath every day. Pat skin dry using a light touch. Do not rub. Use lotion or oil to soften and heal skin if it becomes dry and cracked.

10. Wear protective gloves when gardening or cleaning up after animals, young children or others.
11. Check with members of the healthcare team for diet and nutrition advice.

12. Report any signs or symptoms of infection to your doctor immediately. These include

- Fever of 100.5°F or greater; do not use aspirin, acetaminophen (such as Tylenol®) or any other medicine to reduce a fever without checking with the doctor
- Chills
- Sweating
- Loose bowel movements
- A burning feeling when you urinate
- A severe cough or sore throat
- Unusual vaginal discharge or itching
- Redness, swelling or tenderness, especially around a wound, sore, pimple, IV catheter site or vascular access device
- Abdominal pain.

**White Blood Cell Growth Factors.** Growth factors are drugs used to prevent or reduce the risk of infection while patients are being treated with certain therapies that affect the white cells that fight infection. They can be administered and may stimulate the marrow to make new white blood cells. They may also be used to help the marrow recover after marrow transplantation and stem cell transplantation. Colony-stimulating growth factors may cause mild bone pain, usually in the lower back or pelvis, about the time the white blood cells start to come back in the marrow. This mild pain lasts only a few days. The doctor can prescribe a painkiller for the patient to take during that time. Doctors exercise caution when prescribing these medications for people with cancer that involves the bone marrow, because growth factors might stimulate cancer cell growth. To see specific side effects information about Granulocyte Colony-Stimulating Growth Factors (G-CSF) and Granulocyte-Macrophage Colony-Stimulating Growth Factors (GM-CSF), please visit www.LLS.org/drugs.
**Bleeding.** Anticancer drugs may cause a decrease in platelets. A mild or moderate decrease usually does not cause bleeding. However, people with a severely low platelet count can experience the following side effects:

- Excessive bleeding from cuts or bruises
- Pinhead-sized bleeding points in the skin, called “petechiae,” especially on the lower legs and ankles
- Black-and-blue spots on the skin from minor bumps or in the absence of any injury
- Reddish or pinkish urine
- Black or bloody bowel movements
- Bleeding from the gums (such as after brushing your teeth) or nose
- Headaches
- Dizziness
- Weakness
- Pain in joints and muscles.

Once therapy is stopped and the platelet count is brought back to a safe level, these side effects rapidly fade. However, if a patient needs to receive additional drug therapy and the platelet count remains very low, transfusions of platelets may be required. Certain medications can weaken the platelets and worsen bleeding problems, so check with your doctor.
Low Platelet Counts—7 Ways to Avoid Problems

1. Ask your healthcare provider if it is safe to take NSAIDs (nonsteroidal anti-inflammatory drugs) such as aspirin, ibuprofen (Advil®/Motrin®) and naproksen (Aleve®); acetaminophen (Tylenol®/Excedrin PM); or other over-the-counter or prescribed medicines.

2. Do not drink alcoholic beverages without medical advice.

3. Use an extra-soft toothbrush; follow medical and dental advice for caring for teeth and gums or for having dental work while in treatment and after treatment ends.

4. Blow gently into a soft tissue to clean the nose.

5. Take care to avoid cuts or nicks from scissors, needles, knives or tools; use an electric shaver instead of a razor.

6. Be careful not to burn yourself when ironing, cooking or baking.

7. Avoid contact sports and other activities that might result in injury.

Cognitive Issues (“Chemo Brain”). Cancer treatments such as chemotherapy and radiation therapy can cause problems with mental functions, such as concentration, memory and the ability to multitask (to keep track of and do different tasks at the same time). Most chemotherapy patients experience these effects to some degree. The effects are sometimes referred to as “chemo brain” or “brain fog.”

The cognitive effects of chemotherapy are real and, for some, long-lasting. A small percentage of patients have prolonged effects that are known medically as “chemotherapy-induced cognitive impairment.” The symptoms include a mental fogginess and effects on memory, word retrieval, concentration, processing numbers, following instructions, multitasking and setting priorities. Doctors do not have any way of predicting who might be affected.

Patients who have trouble focusing or trusting their memory do well to write things down as a reminder; place items such as car keys, cell phones and planners in the same place; and allow extra time needed to accomplish personal and professional activities.

Deep Vein Thrombosis. Some patients may be predisposed to a condition called “deep vein thrombosis,” “deep venous thrombosis” or “DVT.” Certain drugs, relative immobility, the systemic effects of cancer or tumors that compress veins can increase the risk of DVT. DVT is a life-threatening condition in which a blood clot forms in a vein deep inside the body, usually in the legs. Some symptoms
include swelling, usually in one leg, leg pain or tenderness, reddish or bluish skin discoloration or a leg that is warm to the touch. The clot can block blood flow and, if left untreated, can break away and travel through the bloodstream to the heart, lungs or brain, causing severe damage and possibly even death. Early diagnosis is important so that anticoagulants or other therapies to help thin the blood can be used. Leg exercises and supportive hose may be used to help prevent DVT.

Additional Ways to Prevent DVT

- Lose weight, if you are overweight
- Stay active
- Exercise regularly; walking is fine
- Avoid long periods of staying still
- Get up and move around at least every hour whenever you travel on a plane, train, or bus, particularly if the trip is longer than four hours
- Point and flex your toes and make circles with your feet if you cannot move around while sitting for prolonged periods to get your blood circulating
- Stop at least every two hours when you drive, and get out and move around
- Drink a lot of water and wear loose-fitting clothing when you travel
- Talk to your doctor about your risk of developing blood clots whenever you take hormones, whether for birth control or replacement therapy, or during and right after any pregnancy
- Follow any self-care measures to keep heart failure, diabetes, or any other health issues as stable as possible.

Dental Issues. Dental care is an important part of overall cancer care. Patients should contact their dentist to update their medical history to include cancer diagnosis and treatments, and provide the name and contact information of their oncologist. Patients may be advised to have any necessary major dental procedures completed prior to beginning therapy. Patients with mouth, teeth or jaw pain—or any other symptom that might suggest dental problems—should speak with their oncologist and dentist as soon as possible.

Osteonecrosis of the Jaw (ONJ). This is an uncommon but serious condition that has occurred in some cancer patients receiving bisphosphonates (a class of drugs that prevent the loss of bone mass and may be used for myeloma patients)
such as pamidronate (Aredia®) or zoledronic acid (Zometa®). Although no cause-and-effect relationship between bisphosphonate therapy and osteonecrosis has been established, it is suspected.

ONJ may develop when the jaw fails to heal after minor trauma such as a tooth extraction, which may result in the bone being exposed. Symptoms include pain, swelling, poor healing or infection of the gums, loosening of teeth, or numbness or a feeling of heaviness in the jaw. Some factors that may increase the risk of ONJ are radiation therapy to the head or neck, chemotherapy, corticosteroid therapy, anemia (low red blood cell count), infection, poor dental health, alcohol abuse or cigarette smoking, poor nutrition, poor blood circulation or clotting problems.

Treatment with bisphosphonates should be managed by an experienced oncologist in close coordination with an oral surgeon and/or a dentist. A dental examination before patients begin therapy with intravenous bisphosphonates is advisable. Dental treatments and procedures that require bone healing should be completed before initiating intravenous bisphosphonate therapy. Patients should receive and follow instructions on maintaining good oral hygiene and having regular dental assessments. At this time, there is no evidence to suggest that interrupting bisphosphonate therapy will prevent or lower the risk of ONJ for patients who are currently receiving bisphosphonates and require dental procedures.

Treatment of patients who develop ONJ may include frequent clinical assessments, antibiotics, oral rinses and removable mouth appliances. Minor dental work may be necessary to remove injured tissue and reduce sharp edges of the bone. Typically, surgery is avoided because it may make the condition worse.

Fatigue. More than half of the people diagnosed with cancer experience cancer-related fatigue (CRF). Many patients find CRF to be more distressing and disabling than other cancer-related symptoms such as pain, depression and nausea. The fatigue often begins before cancer is diagnosed, worsens during the course of treatment, and may persist for months—even years—after treatment ends. It is an important issue that can have a major impact on quality of life, with physical, emotional and economic consequences. The reasons so many people with cancer feel fatigue are under study. However, there are steps that people can take to feel better. Medical treatment, regular exercise, good nutrition, psychological support, stress management and other lifestyle changes can help a person feel more energized and better able to cope with fatigue.

Want more information? You can view, print or order the free LLS publication Cancer-Related Fatigue Facts at www.LLS.org/resourcecenter or contact an Information Specialist for a copy.
**Fertility.** Patients may be less fertile after undergoing certain cancer treatments. The risk of infertility varies according to the nature of the treatment—the type and amount of chemotherapy, the location of radiation therapy and the patient’s age. Men who are at risk of infertility can consider banking sperm before treatment. Freezing testicular tissue is the only option currently available to patients before puberty, however it is still being studied. Women who have ovarian failure after treatment will experience premature menopause and require hormone replacement therapy. There are studies currently investigating ovarian suppression medication including several drugs, like leuprorelin and triptorelin, that may prevent infertility in women by inducing menopause so that the ovaries are not damaged. In couples of childbearing age where one partner has received treatment, the incidence of fetal loss and the health of the newborn are very similar to those among healthy couples.

**Want more information?** You can view, print or order the free LLS publication *Fertility* at www.LLS.org/resourcecenter or contact an Information Specialist for a copy.

**Food and Nutrition.** Eating well, both during and after cancer therapy, helps people cope with side effects, fight infection, rebuild healthy tissues and maintain their weight and energy. Whenever possible and in accordance with medical advice, eat a variety of foods including fruits, vegetables and whole grains on a daily basis. Protein foods (chicken, fish, meat, soy products and eggs) help the body rebuild tissues that may be harmed by drug therapy. Low-fat dairy products like milk, cottage cheese and yogurt also supply a good amount of protein and calcium, along with other important vitamins and minerals.

People living with cancer have different nutrition goals and challenges depending on their age, type of disease, therapies used and stage of treatment. Patients who cannot eat well for extended periods of time may be prescribed supplements that are high in calories and protein or be given IV nutrition until they can resume normal eating. Others may experience an increase in appetite or fluid retention because of certain drug therapies. Weight-loss diets are not recommended without medical advice. Patients may be advised to switch to a diet lower in fat (less butter, margarine, oil; lean meats only) or sodium (salt).

Side effects that interfere with good nutrition should be managed so that patients can get the nutrients they need to tolerate and recover from treatment, prevent weight loss and maintain general health. People undergoing cancer therapy may not feel like eating because of the side effects of cancer or cancer treatment, including changes in the taste and smell of food; mouth, throat or GI effects (dry mouth, nausea, diarrhea, constipation); infections; fatigue; or depression.
To avoid infection or other food-borne illnesses, it is important for patients and caregivers to handle foods safely by

- Keeping hands and food-preparation surfaces clean
- Cooking food at proper temperatures
- Refrigerating food promptly
- Keeping raw meat, poultry, seafood and eggs and their juices away from ready-to-eat foods.

Patients with blood cancers should ask to be referred to a registered dietitian or nutritionist to discuss specific nutrition needs and any restrictions.

**10 Ways to Boost Your Nutrition**

1. Eat frequent, small meals or snacks, perhaps four to six times a day.
2. Keep prepared snacks or small meals on hand.
3. Have liquids such as juices, soups or shakes available if eating solid foods is a problem; fluids can provide calories and nutrients.
4. Choose soft foods or foods that can be cooked until tender.
5. Cut foods into bite-sized pieces or grind or blend them so that less chewing is needed.
6. For extra calories, blend cooked foods or soups with high-calorie liquids such as gravy, milk, cream or broth instead of water.
7. Try new foods and recipes to accommodate changes in taste or smell.
8. When possible, take a walk before meals to improve appetite.
9. Eat with friends or family members when possible. When eating alone, listen to the radio or watch TV.
10. Accept help with food shopping and meal preparation.

**Want more information?** You can view, print or order the free LLS publication *Food and Nutrition Facts* at www.LLS.org/resourcecenter or contact an Information Specialist for a copy.
**Gastrointestinal (GI) Tract.** The cells lining the mouth, esophagus, stomach and intestines undergo rapid growth and renewal, making them particularly vulnerable to damage from drug therapy that targets rapidly dividing cells. If this occurs, sores (called “ulcers”), vomiting or diarrhea can develop.

**Mouth and Throat Symptoms.** If sores develop from chemotherapy, you may experience a burning sensation or pain in the mouth or throat, and ulcers may appear. This is a condition called “stomatitis.” With some anticancer drugs, the amount of saliva in the mouth may decrease early on and increase later. The tongue may also be red and swollen. A stinging sensation in the throat or difficulty swallowing, called “dysphagia,” may develop. Some people may develop a white, shiny coating or white patches on their tongue, inside of the cheeks or on the floor of the mouth. This symptom may indicate a yeast infection, also called “thrush” or “oral candidiasis.”

These symptoms, or other changes in the mouth or throat, can be managed by prescription medications and other remedies.

Chemotherapy can also damage the rapidly dividing cells in the border of the lips, causing dryness, cracking, soreness, bleeding, fungal infections and cold sores from herpes simplex. Seek advice from your doctor about what types of lip products to use to moisturize your lips. Petroleum-based lip products may not be recommended.

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**5 Ways to Manage Mouth and Throat Side Effects**

1. Visit the dentist before treatment begins, if possible.
2. Maintain good dental and oral hygiene to help prevent gum disease and infection, including the use of prescribed mouthwash. If you wear dental braces, check with your doctor about the possible need to have them removed before starting treatment.
3. Inspect your mouth daily to detect problems such as
   - Mouth sores
   - Swollen tongue
   - White, shiny coating or white patches on tongue, inside of cheeks or on the floor of the mouth.
4. Tell members of your healthcare team about any pain or discomfort.
5. Seek medical advice on oral hygiene tips and dietary suggestions to reduce or relieve discomfort.
**Diarrhea.** This is a side effect of some anticancer drugs, caused by the drug’s effect on normal cells in the GI tract. If it occurs, it should be treated as soon as possible.

**Constipation.** Certain drugs may intensify this problem in people who were prone to constipation before treatment. Older people and those with low-fiber diets may be at greater risk. There are many causes of cancer-related constipation which can include a lower fluid intake, low-fiber intake, another disease such as diabetes or it can be medication related. Many cancer patients may be taking opioids for pain. Opioids can cause constipation.

Constipation and diarrhea can be managed. Patients should keep track of daily bowel movements and notify their healthcare providers right away if cramping, gas, loose stools, diarrhea or constipation occurs. For diarrhea, doctors may prescribe antidiarrheal medication, antibiotics, intravenous fluids or changes in diet. It may also help to drink water. Liquids to avoid may include caffeinated beverages (coffee, tea and certain soft drinks), alcohol and milk. For constipation, doctors may recommend a stool softener and a stimulant laxative; the choice of laxative should be individualized to the patient. Other options include intravenous fluids or changes in diet. Drinking warm or hot fluids, especially in the morning, may be helpful. Talk to your doctor about the best way for you to treat constipation.

**Nausea and Vomiting.** These are side effects resulting from direct irritation to the GI tract and from stimulation to an area of the brain that affects the GI tract. People often associate nausea and vomiting with chemotherapy. Yet there are many anticancer drugs that do not always cause these side effects. The occurrence and severity of nausea and vomiting vary among patients. Sometimes, nausea and vomiting go away as a person adjusts to the treatment. When needed, there are antinausea drugs (called “antiemetics”) that healthcare providers can prescribe to prevent or minimize this side effect. Acupuncture has been evaluated in a number of studies and is now recognized as a safe method for managing chemotherapy-associated nausea and vomiting that may be effective for some patients. Therapeutic massage may be effective in reducing cancer treatment-related nausea for some patients.

**Heart.** Some chemotherapy or other drugs can affect your heart. The effect may be temporary but can sometimes be permanent. If cancer treatments are combined, such as chemotherapy with biological therapies, they may be more likely to affect your heart. Some possible symptoms include puffiness or swelling in the hand(s) or feet (fluid retention), shortness of breath that gets worse with exercise or lying flat, dizziness, erratic heartbeat and/or dry cough. Tell your healthcare team right away if you notice these symptoms. Before each treatment session you may have tests such as an electrocardiogram (ECG) to see how well your heart is working.

**Kidneys.** Many drugs are excreted through the kidneys. Patients with preexisting kidney damage or impaired kidney function may need modified dosages of drugs. The patient’s doctor will order blood tests to assess kidney function before starting therapy to determine if a lower dosage is needed. Signs of possible kidney problems include headache, pain in the lower back, fatigue, weakness, nausea, vomiting, high
blood pressure, faster breathing rate, change in how often you urinate, change in color of urine and/or swelling or puffiness of the body.

**Liver.** Patients with preexisting liver disease may require dosage reductions for drugs that are metabolized in the liver or excreted into the bile. Some agents may be toxic to the liver; a patient’s doctor may order periodic blood samples to assess liver function and check for possible damage. Signs of liver damage include yellowing of the skin and whites of eyes (jaundice), fatigue, pain under the lower part of the ribs on the right side and/or swelling of the abdomen or feet.

**Lungs.** Some chemotherapy or other cancer drugs may affect your lungs and breathing. This may happen gradually over months or years. If you are taking drugs that are likely to cause lung problems, your doctor will check how well your lungs are working during your treatment and again afterwards. Symptoms may include shortness of breath, dry cough and/or possible fever. Let your doctor or nurse know if you experience any of these symptoms.

Possible treatment options to alleviate shortness of breath include

- A fan blowing across the face/an increase of air circulation
- An increase of oxygen in certain situations
- Anxiety medications and relaxation techniques
- Morphine
- Treating the cause, such as taking antibiotics for pneumonia, diuretics (sometimes called “water pills,” which help rid your body of salt [sodium] and water) for congestive heart failure (CHF), or nebulizer treatments.

Your doctor can give you information about these options and coping with shortness of breath.

**Peripheral Neuropathy.** “Peripheral neuropathy” (PN) is the term for damage to nerves of the peripheral nervous system, which consists of all parts of the nervous system except the brain and spinal cord (these are referred to as the “central nervous system” or CNS). The peripheral nervous system connects the CNS to the remainder of the body. PN is estimated to affect 10 to 20 percent of people with cancer and can be caused by certain chemotherapeutic agents, such as vincristine (Oncovin®), bortezomib (Velcade®), thalidomide (Thalomid®), lenalidomide (Revlimid®), cytarabine (Cytosar-U®), interferon (multiple brand names) or methotrexate (multiple brand names). Radiation therapy may cause nerve injury, although it may take several years for symptoms to appear. Shingles, a rash that may develop in people with weakened immune systems, may also result in neuropathy. PN may also be a symptom of certain diseases, such as myeloma.

Patients should seek medical advice as soon as possible if they experience numbness, tingling, burning, coldness or weakness in the arms or legs. These may be symptoms of PN. It is also important to let your doctor know if you already
have symptoms of neuropathy before starting treatment, or if you have any of the conditions that are associated with PN, including diabetes; nerve compression caused by vertebral fractures or vitamin deficiencies, particularly folate or vitamin B₁₂; autoimmune diseases, such as lupus and rheumatoid arthritis; hypothyroidism; or kidney disease.

While a person is undergoing cancer treatment, his or her doctor may prescribe certain medications and/or vitamins to help prevent neuropathy. Be sure to talk with your doctor before starting any over-the-counter medications, vitamins, or supplements on your own. With medical advice, patients who develop PN as a result of chemotherapy may be helped by taking a reduced dosage of the prescribed drugs or stopping the drugs completely. Treatment-caused PN may gradually decrease after treatment is completed. Many people recover fully from the disorder over time, whether it is in a few months or a few years. In some cases, the symptoms may persist.

10 Safety Measures to Help People With PN Avoid Injury at Home

1. Keep all rooms, hallways, and stairways well lit.

2. Install handrails on both sides of stairways.

3. Remove small area rugs and any other clutter that you could trip over or slip on.

4. Install grab bars in the shower or hand grips in the tub, and lay down skid-free mats.

5. Use a thermometer to check that any water you bathe in or use is below 110°F, or set your water heater temperature accordingly.

6. Clean up any spilled water or liquids immediately.

7. Use nonbreakable dishes.

8. Use pot holders while cooking and rubber gloves when washing dishes.

9. If you drive, make sure you can fully feel the steering wheel and gas and brake pedals. Also, make sure that you can quickly move your foot from the gas to the brake.

10. If prescribed, use a cane or walker when moving from one room to the other.
**Skin, Hair and Nails.** Skin-related side effects include dry skin, redness, itchiness or skin lesions that can occur with some drugs during or after treatment. Treatment for these side effects can make patients more comfortable and may prevent serious problems from developing. Skin changes should be evaluated as soon as possible as they are sometimes related to primary disease or infection. A visit to the doctor can determine appropriate treatment including topical solutions (creams, lotions or gels) to soothe, soften or moisturize the skin or to relieve itching.

**Hair Loss.** Some anticancer drugs can cause hair loss by interfering with the normal growth of hair follicle cells. However, this is temporary, and hair growth resumes when the drugs are stopped or the dose is reduced.

**6 Ways to Cope With Hair Loss**

1. Wash the hair and scalp every few days, using a mild, moisturizing shampoo.

2. Drugs that affect the hair shaft will cause hair to fall out whether or not it is combed. However, combing hair during periods of hair loss will prevent tangles.

3. Some people with long hair decide to get a short haircut or shave their heads before hair loss begins.

4. Patients who plan to buy a wig can cut a portion of their hair prior to hair loss so that their natural color and texture can be matched more easily.

5. Some people who have hair loss choose not to wear wigs. Bandannas, hats or scarves may be worn to keep the head warm.

6. Mineral oil can be applied to the scalp to ease dryness.

**Fingernails and Toenails.** Chemotherapy can affect the color and texture of fingernails and toenails. Nails may darken, crack or become brittle. Some patients develop white ridges or bands of discoloration along the nails or develop a darkening of the nail bed. A small number of patients receiving chemotherapy will lose all or part of their fingernails and toenails. Any changes to the nails should be discussed with members of the patient’s healthcare team.

In all cases, it is important to keep fingernails and toenails clean, dry and relatively short. Except in extremely rare cases, a patient’s nails will grow back or return to normal after chemotherapy ends.
### 8 Ways to Take Care of Your Nails During Treatment

1. Keep your fingernails and toenails trimmed.

2. Wear gloves when working. Cotton gloves can protect your hands during gardening. Consider rubber gloves when cleaning or washing dishes to keep your hands from drying out further.

3. Avoid manicures, pedicures, or cutting your cuticles, which could increase the risk of infection. Avoid using artificial nails.

4. In general, it is best to avoid nail polish, although some women find that using clear polish helps strengthen, and may protect their nails.

5. Some people find that soaking their hands in natural oils, such as olive oil, is helpful.

6. Increase iron in your diet.

7. Cut back on or avoid caffeine.

8. Wear comfortable, loose-fitting shoes.
Complications Requiring Emergency Attention

Complications that result from the cancer itself, the consequence of the presence of cancer or from treatment of the cancer are called “oncologic emergencies.” These complications require immediate attention. Listed below are some examples of oncologic emergencies.

**Febrile Neutropenia (Neutropenic Fever).** This is a condition when a patient has a fever and when neutrophils in the blood are too low. A neutrophil is a type of white blood cell that helps fight infection. Having too few neutrophils increases the risk of infection. You should monitor your body temperature and other symptoms of infection. If you have a fever of 100.4°F or higher, you should go to the emergency room immediately.

Your diagnosis, stage, treatment, treatment response and certain patient characteristics are considered by your doctor when assessing risk of febrile neutropenia. A neutropenic fever is most often seen as a complication of chemotherapy, when the treatment suppresses the bone marrow (does not allow the bone marrow to make enough cells). Antibiotics are used to treat this, however, as more chemotherapy combinations are developed, new antibiotics are used and new infection risks are found. Treatment with an antifungal prophylactic may also be used. You may be treated in a hospital or as an outpatient in a doctor’s office.

According to the current American Society of Clinical Oncology (ASCO) guidelines, interventions such as footwear exchange, protected environments, respiratory or surgical masks, nutritional supplements and a “neutropenic” diet are not recommended to be followed since research has shown that there is lack of benefit to patients.

It is important to have a written/electronic febrile neutropenia management plan available if you are at risk and to make it easier to advocate for care in emergency situations. Talk to your doctor and find out if you are at risk and if having a management plan is important for you.

**Hypercalcemia.** This is a condition when a patient’s calcium level is above normal. A patient could have mild hypercalcemia (few or no signs and symptoms) or severe hypercalcemia with signs and symptoms that may include nausea and vomiting, loss of appetite, excessive thirst, frequent urination, constipation, abdominal pain, muscle weakness, muscle and joint aches and fatigue.

A patient with hypercalcemia could develop complications that include osteoporosis, kidney stones, kidney failure, nervous system problems and abnormal heart rhythms. Treatment options for hypercalcemia include
intravenous (IV) administration of fluids and administration of medications, such as bisphosphonates or other drugs to stop the break down of bones.

To prevent bone and kidney damage if you do develop hypercalcemia, it is important to drink plenty of fluids, exercise and not to smoke.

**Tumor Lysis Syndrome (TLS).** This condition occurs when a large number of cells are killed rapidly, particularly in patients with leukemia or lymphoma when they are being treated with cancer therapies. TLS may occur spontaneously, but is rare. TLS is a preventable and treatable condition, particularly in its early stages. Early recognition of signs and symptoms of patients at risk for TLS can lead to successful prevention of the otherwise life-threatening complications of the condition.

Signs and symptoms include

- Tiredness or fatigue
- Excess fluid
- Abnormal blood work results
- Nausea and/or vomiting
- Shortness of breath
- Clouding of urine
- Loss of muscle control
- Congestive heart failure (CHF)
- Irregular heartbeat
- Fainting.

Patients with acute leukemia or lymphoma may still be considered at high risk of developing TLS even when their disease is very responsive to chemotherapy. Patients with preexisting kidney dysfunction are also at an increased risk of developing TLS. Patients who are considered to be at risk of developing TLS are typically treated with preventive measures before and during their treatment for cancer. Intravenous fluids to keep the patient hydrated and medications including allopurinol or rasburicase (Elitek®) are some of the treatments used. Once TLS has developed, a patient is also treated for the specific medical abnormality that is present, which typically includes one of the following:

**Hyperuricemia.** This occurs when there is an excess of uric acid in the blood. Uric acid is a waste product remaining after the body’s normal chemical processes. Any abnormal buildup of uric acid can lead to various health conditions.
Treatment for hyperuricemia may include intravenous (IV) administration of fluids, diuretics (sometimes called “water pills,” which help rid your body of salt [sodium] and water) to help uric acid pass in the urine and medication such as rasburicase or allopurinol to reduce the formation of uric acid.

**Hyperkalemia.** This refers to excess potassium in the blood which can cause irregular heart rhythms and neuromuscular dysfunction.

Treatment for hyperkalemia may include IV administration of calcium, dextrose (sugar) and insulin and other medications.

**Hyperphosphatemia.** This refers to the presence of excess phosphates in the blood which can cause low levels of calcium in the blood, or hypocalcemia.

Treatment for hyperphosphatemia may include medications that bind to phosphates and promote elimination through the bowel. Eating foods or drinking liquids with phosphates should be restricted or eliminated.

**Hypocalcemia.** This is when there are low levels of calcium in the blood that may result in severe cardiovascular effects and neurologic dysfunction (i.e., seizures, hallucinations and numbness).

Treatment for hypocalcemia may include IV administration of calcium and a diuretic to promote excretion of phosphates in urine.

Before starting treatment for cancer, patients should discuss their risk of developing TLS with their doctor, as well as early-warning signs that may indicate the onset of TLS.
Medical Terms

**Absolute Neutrophil Count (ANC).** The number of neutrophils (a type of white blood cell) that a person has to fight infection. It is calculated by multiplying the total number of white blood cells by the percentage of neutrophils.

**Anemia.** A decrease in the number of red blood cells and, therefore, the hemoglobin concentration of the blood. The blood is less able to carry oxygen as a result. If severe, anemia can cause a pale complexion, weakness, fatigue and shortness of breath on exertion.

**Anticoagulant Therapy.** Drugs used to block blood clotting when abnormal blood clotting is occurring or is at risk of occurring. The drug heparin may be used because it acts right away. It must be injected, and if long-term treatment is required, heparin is often replaced later by another anticoagulant, warfarin, which can be taken by mouth in pill form.

**Blood Count.** A laboratory test requiring a small blood sample, which is used to measure the number and types of cells circulating in the blood. The term “complete blood cell count” or “CBC” is often used to refer to this test.

**Bone Marrow.** See Marrow.

**Central Nervous System (CNS).** The brain and the spinal cord. This term distinguishes these portions of the nervous system from the vast network of peripheral nerves that emerge from the brain and spinal cord.

**Chemotherapy.** Treatment with chemical drugs to treat cancer. Because the cells of the marrow, the gastrointestinal tract, the skin and the hair follicles are most sensitive to these chemicals, injury to these organs causes the common side effects of chemotherapy, such as nausea, mouth sores and hair loss.

**Clinical Trials.** Careful studies done by doctors to test new drugs or treatments, or new uses for approved drugs or treatments. The goal of clinical trials for blood cancers is to improve treatment and quality of life and to find cures.

**DNA.** The genetic material in the cell. DNA stands for deoxyribonucleic acid. DNA is responsible for passing genetic information to new cells during the process of cell division; for passing genetic information from one generation to the next during reproduction; and for providing the instructions for building proteins, which in turn carry out the major functions of a cell. Mutations in DNA can lead to cell death, to changes in the way a cell functions or, in some cases, to cancer.

**Dysphagia.** Difficulty in swallowing. It is often accompanied by a feeling of discomfort as food passes from the esophagus to the stomach.
Emesis. The medical term for vomiting.

Esophagus. Part of the body’s digestive system, it is the tube that food travels down from the mouth to the stomach.

FDA. The short name for the United States Food and Drug Administration. Part of the FDA’s job is to assure the safety and security of drugs, medical devices and the US food supply.

Hematocrit. The amount of the blood that has red cells.

Hemoglobin. The part of the red blood cell that carries oxygen.

Hemorrhage. Excessive or unchecked bleeding either inside or to the outside of the body.

Immune System. Cells and proteins that defend the body against infection. White blood cells, lymph nodes and the spleen are parts of the body’s immune system.

Intramuscular (IM) Injection. Administering drugs into a muscle.

Intrathecal. Designation for the space between the covering or lining of the central nervous system (CNS) and the brain or spinal cord. That lining is called the “meninges.” In some situations drugs have to be administered directly into the spinal canal when cancer cells are in the meninges. This procedure is called “intrathecal therapy.”

Intravenous (IV) Infusion. The administration of antibiotics, blood products, anticancer drugs or nutrient fluids into a patient’s vein over a period of time.

Leukemia. A cancer of the marrow and blood. The disease appears in four major forms. Each major form has several subtypes. Acute lymphoblastic leukemia (ALL) and acute myeloid leukemia (AML) are characterized by the uncontrolled accumulation of abnormal cells, referred to as “leukemic blasts.” These cells fill the marrow and enter the blood. Chronic myeloid leukemia (CML) and chronic lymphocytic leukemia (CLL) progress less rapidly than the acute leukemias. However, CML requires treatment at the time of diagnosis; certain subtypes of CLL may not progress for long periods.

Lumbar Puncture. A procedure to remove spinal fluid from the space surrounding the spinal cord or to administer anticancer drugs to either prevent or treat leukemia or lymphoma of the coverings of the central nervous system. The doctor will first use a local anesthetic, and then insert a needle between two vertebrae in the lower part of the back. Fluid samples are collected in sterile tubes and examined for evidence of leukemia or lymphoma. This procedure is also called a “spinal tap.”
**Lymph Nodes.** Small bean-shaped organs around the body that are part of the body’s immune system.

**Lymphocyte.** A type of white blood cell that is part of the immune system and fights infection.

**Lymphoma.** A cancer that starts in a lymphocyte, usually in a lymph node, but may start in a lymphocyte in the lymphatic tissue of the marrow, gastrointestinal tract, spleen, skin or other sites. The disease results from the uncontrolled accumulation of malignant lymphocytes.

**Marrow.** A spongy tissue in the hollow central cavity of the bones that is the site of blood cell formation. When marrow cells have matured into blood cells, they enter the blood that passes through the marrow and are carried throughout the body.

**Mucositis.** A complication of some cancer therapies in which the lining of the digestive system becomes inflamed. Mucositis can occur anywhere along the digestive tract from the mouth to the anus. Often seen as sores in the mouth.

**Mucous Membranes.** The inner lining of cavities such as the mouth, nose and sinuses. These linings require new cells to be made to replace those that drop off. This replacement is a normal process and keeps the lining intact and moist. Radiation therapy or chemotherapy drugs that block cells from dividing prevent the replacement of lost cells. The linings become dry, defective, and may ulcerate in patients who receive such treatment. This change can be painful, such as when ulcers develop in the mouth. These painful, ulcerating lesions are referred to as oral “mucositis.” Anal ulcers can also develop. The loss of what is referred to as the barrier function of mucous membranes permits microbes to enter the tissue or blood and often leads to infection.

**Myeloma.** A cancer of plasma cells (derived from B lymphocytes) that begins in the bone marrow. The cells secrete chemicals that stimulate the overactivity of bone-dissolving cells, called “osteoclasts,” leading to osteoporosis and brittle bones that fracture easily. A form of myeloma involving multiple marrow sites is the most common type of the disease. Some cases of myeloma progress very slowly. They may be referred to as “smoldering” or “indolent” myeloma.

**Nadir.** The approximate point when the cells in the blood are at their lowest number, based on the drug used. One drug may have a nadir of 7 to 14 days. This means that 7 to 14 days after the beginning of chemotherapy, the numbers of the white blood cells, red blood cells and platelets will be at their lowest point. Once this period is over, the blood counts usually will rise to safe or normal levels.

**Neutropenia.** A below-normal concentration of neutrophils, a type of white blood cell.
Neutrophil. A type of white blood cell. Neutrophils and monocytes are the two main microbe-eating and infection-fighting cells in the blood.

Ommaya Reservoir. A device inserted under the scalp with a tube leading into the fluid channel that bathes the brain. It is used to inject drugs into that fluid. The technique is used for patients with leukemia or lymphoma that involves the covering of the brain so as to get adequate concentrations of the drug to that site.

Petechiae. Pinhead-sized sites of bleeding in the skin. This type of bleeding results from a very low platelet count. The small punctate hemorrhages are frequently seen on the legs, feet, trunk and arms. They evolve from red to brown and eventually disappear. They stop developing when the platelet count increases.

Pharyngitis. The medical term for an inflamed or sore throat. “Strep throat” is technically a streptococcal pharyngitis. Pharyngitis is usually caused by a bacterial or viral infection.

Platelets. A type of blood cell that helps prevent bleeding. Platelets cause plugs to form in the blood vessels at the site of an injury. “Thromocyte” is a synonym for platelet and is often used as the prefix in terms describing disorders of platelets, such as thrombocytopenia (too few) or thrombocythemia (too many).

Radiation Therapy. Treatment with x-rays or other high-energy rays.

Red Cells. A type of blood cell that carries oxygen to all parts of the body. In healthy people, red cells make up almost half of the blood.

Remission. No sign of the disease and/or a period of time when the disease is not causing any health problems. The terms “complete” or “partial” are sometimes used with the term “remission.” Complete remission means that all evidence of the disease is gone. Partial remission means that the disease is markedly improved by treatment, but residual evidence of the disease is present. Long-term benefit usually requires a complete remission, especially in acute leukemia or progressive lymphomas.

Risk-Adapted Therapy. Treatment based on one or more patient and disease factors that can affect how individuals respond to treatment. Risk-adapted therapy is designed to maximize benefits of treatment and minimize toxic side effects and long-term effects.

Risk Factor. A factor that may increase the chance that a person will develop a disease or condition. For example, cigarette smoking is a risk factor for lung cancer.

Stem Cells. A type of cell found in marrow that makes red blood cells, white blood cells and platelets.

Subcutaneous Injection. An injection into tissue right under the skin.
Targeted Therapy. A type of medication that blocks the growth of cancer cells by interfering with specific targeted molecules. Targeted cancer therapies are generally less harmful to normal cells than chemotherapy, which affects cancer cells and other normal rapidly dividing cells.

Thrombocythemia. The number of platelets in the blood is too high.

Thrombocytopenia. The number of platelets in the blood is too low.

Thrush. A fungal infection of the mouth, tongue or throat known as “oral candidiasis.” A specific fungus called “Candida” is the cause. It is usually manifested by white patches of fungal colonies on the surface of the oral tissues and may be painful.

Toxicity. The degree of side effects from administration of drugs or radiation therapy. Drug toxicity may range from mild and tolerable to life threatening. Toxicity may also be transient or longstanding. Since most therapy that is directed at injuring and killing cells is nonspecific, normal tissues are often affected along with cancer cells.

White Cell. A type of blood or immune cell that helps the body fight infection.
More Information

Free LLS Publications include

- Acute Lymphoblastic Leukemia
- Acute Myeloid Leukemia
- Blood and Marrow Stem Cell Transplantation
- Blood Transfusion
- Chronic Lymphocytic Leukemia
- Chronic Myeloid Leukemia
- Each New Day: Ideas for Coping with Blood Cancers
- Financial Health Matters
- Hodgkin Lymphoma
- Myelodysplastic Syndromes
- Myeloma
- Non-Hodgkin Lymphoma
- Understanding Clinical Trials for Blood Cancers
- Understanding Lab and Imaging Tests

Visit “Suggested Reading” at www.LLS.org/resourcecenter to see helpful books on a wide range of topics.

References

Bath C. Options for preserving fertility should be considered early to maximize the likelihood of success. The ASCO Post. April 15, 2012 Vol. 3 Issue 6.


Notes
REACH OUT TO OUR INFORMATION SPECIALISTS

The Leukemia & Lymphoma Society’s (LLS) Information Specialists provide patients, families and healthcare professionals with the latest information on leukemia, lymphoma and myeloma. Our team consists of master’s level oncology professionals who are available by phone Monday through Friday, 9 am to 6 pm (ET).

Co-Pay Assistance
LLS’s Co-Pay Assistance Program helps blood cancer patients cover the costs of private and public health insurance premiums, including Medicare and Medicaid, and co-pay obligations. Support for this program is based on the availability of funds by disease. For more information, call 877.557.2672 or visit www.LLS.org/copay.

For a complete directory of our patient services programs, contact us at 800.955.4572 or www.LLS.org
(Callers may request a language interpreter.)
Our Mission:

LLS is a nonprofit organization that relies on the generosity of individual, foundation and corporate contributions to advance its mission.