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Bringing Clarity to Blood Cancer

**Understand your diagnosis, learn the terms you
need to know, and meet your treatment team**

You've Been Diagnosed With Blood Cancer. Now What?

A diagnosis of blood cancer can come as a surprise.

But the more knowledge you have, the more confidently you can move forward. This brochure can help you communicate with your healthcare team and participate in treatment decisions. People who participate in their treatment decisions report higher levels of satisfaction with their care and can have improved health outcomes.

Don't hesitate to ask your healthcare team if you need or want more information.

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Every patient's journey is different, but here is what yours may look like:



Step 1

Understand your diagnosis

- Know your main diagnosis and subtype
- Ask if a test for genetic tumor markers is needed
- Ask if your cancer needs treatment



Step 2

Discuss treatments with your doctor if necessary

- Find out what treatments are available
- Consider how different treatments may impact your daily life
- Ask if a clinical trial is appropriate for your type of cancer



Step 3

Actively participate in your treatment

- Understand how your treatment will fit into your daily routine
- Learn what you can do to get the most out of your care

Understanding a Blood Cancer Diagnosis

Step 1

Understand your diagnosis

Step 2

Discuss treatments with your doctor if necessary

Step 3

Actively participate in your treatment

What is blood cancer?

Blood cancer can happen when your body makes too many white blood cells or makes white blood cells that are abnormal.

There are 3 main types of blood cancer:

- **Leukemia** is found in your blood and bone marrow. It is caused by the rapid production of abnormal white blood cells
- **Lymphoma** affects the lymphatic system. The 2 main types of lymphoma are Hodgkin lymphoma and non-Hodgkin lymphoma
- **Myeloma** is a cancer of the plasma cells

In addition to a main type, your blood cancer may also have a subtype. Doctors can classify blood cancers into subtype using various tests. It is important to understand your subtype, as this can play an important role in deciding the best treatment for your diagnosis.

Your blood cancer may be either indolent (slow growing) or aggressive. If your cancer is indolent, your doctor may advise a “watch-and-wait” approach. If your cancer is aggressive, you may need treatment sooner.



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Understanding a Blood Cancer Diagnosis (cont'd)

Step 1

Understand your diagnosis

Step 2

Discuss treatments with your doctor if necessary

Step 3

Actively participate in your treatment



Questions you may have at diagnosis:

- What type of blood cancer do I have?
- What is my blood cancer subtype?
- Do I need a second opinion?
- Do I need to begin treatment?



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Your doctor may use some of these terms at diagnosis:

Aggressive: A tumor or disease that spreads, grows, or forms quickly.

Bone marrow: Soft tissue at the center of most bones where blood cells are produced.

Genetic tumor marker: A substance found in tissue, blood, bone marrow, or other body fluids that may be a sign of cancer or certain benign (noncancer) conditions. A tumor marker test is usually done with other tests, such as biopsies or imaging, to help diagnose some types of cancer. It may also be used to help plan treatment.

Indolent: Describes a slow-growing type of cancer.

Lymphatic system: Removes excess fluids from your body and produces immune cells.

Plasma: White blood cells that produce disease- and infection-fighting antibodies in your body.

Red blood cells: Cells that carry oxygen to other cells in your body.

Watch-and-wait: Monitoring of a condition without receiving treatment until symptoms appear or change.

White blood cell: A type of blood cell that helps the body fight infection and other diseases.

[Click here for additional terms >](#)

Understanding Treatment Options

Step 1

Understand your diagnosis

Step 2

Discuss treatments with your doctor if necessary

Step 3

Actively participate in your treatment

There are many treatments for blood cancer. These questions can help you explore options with your doctor.



Questions to ask before starting treatment:

- What types of treatments are available to me?
- Why are you recommending this treatment?
- What are the goals of this treatment?
- How will I know if the treatment is effective?
- What side effects might I experience with this treatment?
- What is a clinical trial and could it be right for me?
- Can you explain the difference between a research hospital and a local cancer center?
- What happens if the treatment does not work?



Here are some terms that may be used when discussing treatment options:

Bone marrow/stem cell transplant: A procedure in which healthy blood-forming stem cells are infused into the body to replace bone marrow that isn't producing enough healthy blood cells.

Chemotherapy: A treatment that uses certain drugs to stop cancer cells from multiplying, either by killing the cells or stopping them from dividing.

Clinical trial: Also known as a clinical study, this is a type of research study that tests the risks and benefits of new medical approaches in people.

Immunotherapy: Therapy that uses the immune system to help the body fight cancer.

Oral anticancer therapy: Treatment given by mouth to help kill specific cancer cells or stop them from dividing.

Radiation therapy: Use of high-energy radiation to kill cancer cells and shrink tumors.

Stem cell: A type of cell that develops other cells; for example, blood-forming stem cells create blood cells.

Targeted cancer therapy: A type of treatment that targets specific proteins that control how cancer cells grow, divide, and spread.

[Click here for additional terms >](#)

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Your Treatment Team

Step 1

Understand your diagnosis

Step 2

Discuss treatments with your doctor if necessary

Step 3

Actively participate in your treatment

When you start treatment, a team of specialists will provide care and offer support and guidance throughout the process. Your team will depend on the type of cancer you have.

Here are some team members you may meet:

Hematologists are physicians who specialize in treating blood disorders. Hematologic oncologists (sometimes referred to as a “heme-onc”) focus on treating blood cancers.

Infusion Nurses specialize in giving medicine and fluids to patients. Specifically, they give these through an intravenous (IV) line, central line, or access port.

Nurse Practitioners/Physician Assistants have advanced training in diagnosing and treating illnesses and support physicians in their practice. In some states, these advanced practitioners can prescribe treatments and medicine.

Oncology Nurses specialize in treating people who have cancer.

Oncology Nurse Navigators offer individualized assistance to patients, families, and caregivers to help with decision-making and overcoming barriers in the healthcare system.

Pathologists are physicians who specialize in identifying different types of cancer by studying cells and tissues. Pathology results can inform oncologists about the type of cancer and how fast it is likely to grow and can guide treatment decisions.

Pharmacists are healthcare providers who are medication experts. They work with your doctor to ensure you’re receiving the correct medicines and the right dosage strengths.

Radiation Oncologists are physicians who have special training in using radiation to treat cancer.

Radiologists are physicians who use imaging tests to help make an accurate diagnosis for many types of cancer. Imaging tests include things like X-rays, CT, MRI, and ultrasound that examine organs and other structures inside the body.

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Starting Your Treatment

Step 1

Understand your diagnosis

Step 2

Discuss treatments with your doctor if necessary

Step 3

Actively participate in your treatment

How will my treatment fit into my daily life?

Knowing what to expect can help you manage your schedule so you can focus on treatment.



Questions to ask after starting treatment:

- Where will I receive my treatment?
- How often should I receive treatment?
- Will I be able to work while receiving treatment?
- How can my caregivers and family be involved?
- How and when will you monitor my progress?



Your doctor may use some of these terms as you begin treatment:

Infusion: Also known as intravenous infusion, this is a method of putting fluids, which could include medication, into the bloodstream.

Infusion Center: A medical center where infusion/injectable medications are administered.

[Click here for additional terms >](#)

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Continuing Your Treatment

Step 1

Understand your diagnosis

Step 2

Discuss treatments with your doctor if necessary

Step 3

Actively participate in your treatment



Everyone responds to treatment differently. Keep asking questions to help you get the most out of care and understand what your experience may be.

- Is my treatment working?
- How can I manage side effects?
- When should I alert my healthcare team about a side effect?
- Are there any foods I should be eating while on treatment?
- Can you recommend a safe exercise program for me?
- Where can I turn for help with financial concerns?
- Where can I turn for emotional support?
- What additional support resources are available to me?



Your doctor may use some of these terms as you continue treatment:

Blood cell counts: The number of red and white blood cells and platelets in the blood.

Complete response: When all signs of cancer disappear as a response to treatment. Also known as a complete remission.

Partial response: A decrease in the overall size of a tumor or the extent of cancer in the body. This is also known as a partial remission.

Refractory: A condition or disease that does not respond to treatment.

Relapse (Recurrence): The return of a disease or the signs and symptoms of a disease after a period of improvement.

Remission: When the signs and symptoms of cancer disappear or decrease.

Stable disease: Cancer that is neither decreasing in size nor getting worse in severity.

[Click here for additional terms >](#)

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Additional Blood Cancer Terms You May Hear

After a blood cancer diagnosis, you will begin to encounter medical terms that may be unfamiliar. Use this glossary to help you understand your disease and communicate with your healthcare team.

Acute disease

A disease that starts fast and/or progresses quickly.

Advanced

Describes cancer that has spread from where it started to other nearby tissues or distant parts of the body.

Biomarker

A molecule found in blood, other body fluids, or tissues that may be used as a sign of a normal or abnormal bodily process, or of a disease. Biomarker testing may be used to help plan treatment, find out how well treatment is working, or predict whether cancer will come back or spread to other parts of the body.

Biopsy

A procedure where a piece of tissue or a sample of cells is removed from the body so it can be tested in a laboratory.

Chronic disease

Chronic diseases are defined broadly as conditions that last 1 year or more. They also require ongoing medical attention or follow-up.

Chronic lymphocytic leukemia (CLL)

A cancer in which too many immature lymphocytes (white blood cells) are found mostly in the blood and bone marrow. Sometimes, cancer cells are found in the lymph nodes and the disease is called small lymphocytic lymphoma.

Circulatory system

The system that contains the heart and the blood vessels and moves blood throughout the body.

Computerized tomography (CT) scan

A 3-dimensional (3D) view of tissues and organs. It's also commonly referred to as a CAT scan, computed tomography scan, computerized tomography, or computerized axial tomography scan.

Concurrent conditions

When you have more than one health condition at a time.

Diffuse large B-cell lymphoma (DLBCL)

A term used to describe a group of fast-growing B-cell non-Hodgkin lymphomas (NHL) in which the cancer cells look large when viewed under a microscope. DLBCLs are the most common type of NHL and are marked by rapidly growing tumors in the lymph nodes, spleen, liver, bone marrow, or other tissues and organs.

Additional Blood Cancer Terms You May Hear (cont'd)

Disease progression

When a disease continues to worsen in extent or severity.

Duration of response

For patients who responded to treatment, the length of time from when treatment started to either disease progression or death. In clinical trials, duration of response may be used to measure how well a treatment is working.

Fatigue

A feeling of being extremely tired, weak, heavy, or run down, or having no energy. This side effect is common with many cancer treatments, including chemotherapy, immunotherapy, radiation therapy, bone marrow transplant, and surgery.

Follicular lymphoma (FL)

A type of B-cell non-Hodgkin lymphoma that is usually indolent. The tumor cells grow as groups to form nodules. There are several subtypes of follicular lymphoma.

Genetic mutation

Changes that happen to the DNA sequence during cell division when cells are making copies of themselves.

Hemoglobin

A protein in red blood cells that carries oxygen to other cells in your body; often abbreviated Hgb or Hb.

Hodgkin lymphoma (HL)

Also called Hodgkin disease, this is a cancer of the immune system in which a type of cancer cell called the Reed-Sternberg cell is present.

Lymph node

A small structure that is part of the immune system. Lymph nodes contain immune cells that help the body fight infections and disease.

Magnetic resonance imaging (MRI)

A noninvasive procedure that takes detailed pictures of areas inside the body. This may be used to help plan treatment, diagnose disease, or determine how well your treatment is working. Also called nuclear magnetic resonance imaging (NMRI).

Mantle cell lymphoma (MCL)

A typically aggressive type of B-cell non-Hodgkin lymphoma that usually occurs in middle-aged or older adults. It is characterized by small- to medium-sized cancer cells that may be in the lymph nodes, spleen, bone marrow, blood, and gastrointestinal system.

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Additional Blood Cancer Terms You May Hear (cont'd)

Minimal residual disease (MRD)

This defines the small number of cancer cells present in the body during or after treatment. Also called measurable residual disease.

Multiple myeloma (MM)

A cancer of the plasma cells that's generally identified by the cells becoming cancerous and growing out of control.

Myelodysplastic syndromes (MDS)

These syndromes can occur in your bone marrow when the cells that create blood cells become abnormal. These syndromes are considered types of cancers.

Myeloproliferative neoplasm (MPN)

This is a type of cancer that occurs when your body produces too many blood cells, including red blood cells, white blood cells, or platelets.

Neutropenia

This is a condition in which you have a lower number of neutrophils (a type of white blood cell) than normal in your blood, which could put you at a higher risk for infections.

Non-Hodgkin lymphoma (NHL)

A large group of different types of cancers that affect white blood cells. There are many different types of NHL; some are fast growing (aggressive), while others are slow growing (indolent).

Overall response rate

A measure used in clinical studies to assess how well a treatment may be working. Overall response rate reflects the percentage of patients whose cancer shrinks or disappears after treatment.

Overall survival

The length of time beginning at diagnosis or start of treatment that a person diagnosed with cancer is still alive. In clinical trials, overall survival may be used as a measurement to see how well a treatment works.

Platelet

Cell fragment that helps to stop bleeding. Platelets are also called thrombocytes.

Positron emission tomography (PET) scan

A type of nuclear scan that usually uses radioactive sugar to identify cancer cells. Different cells in your body can take in different amounts of sugar. Because cancer cells grow more quickly than others, they are more likely to absorb more radioactive sugar and thus be more easily identified during your scan.

Progression-free survival

The average length of time after the start of treatment in which a person is alive, and their cancer does not grow or spread.

Additional Blood Cancer Terms You May Hear (cont'd)

Reimbursement specialist

Someone who works with insurance companies and medical billing staff to manage the billing and reimbursement processes.

Specialty pharmacy

A pharmacy that provides specialty medications to people with complex, chronic conditions.

Systemic

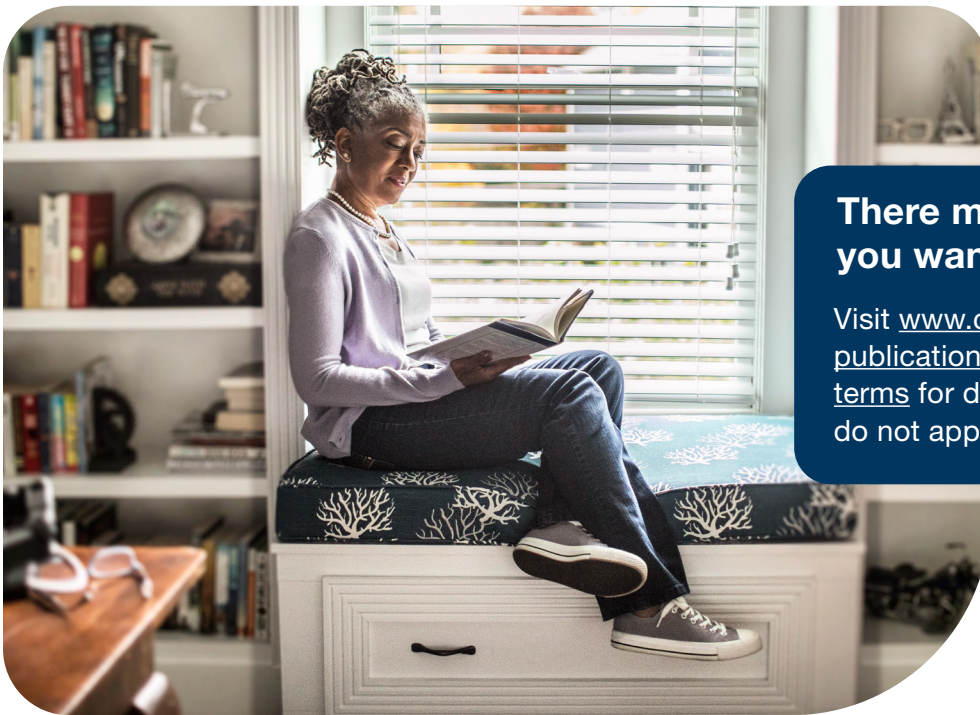
Describes a disease or a treatment that can impact your entire body. For example, cancer can be a systemic disease; chemotherapy would be an example of a systemic treatment.

Tumor grade

A description of a tumor based on how abnormal the cancer cells and tissue look and how quickly the cancer cells are likely to grow and spread. The manner in which each type of cancer is graded is different; however, they all are used to help plan treatment and determine prognoses.

Waldenstrom macroglobulinemia (WM)

Also known as lymphoplasmacytic lymphoma, this condition is a type of non-Hodgkin lymphoma in which cancer cells create large amounts of abnormal proteins called macroglobulins.



There may be other terms you want to learn about

Visit www.cancer.gov/publications/dictionaries/cancer-terms for definitions of terms that do not appear in this list.

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Support Organizations for People Living With Blood Cancers

You may feel you need support as you move through treatment. Fortunately, patient advocacy groups are available to you and your loved ones. Advocacy groups offer:

- Support
- The latest news
- Links to co-pay assistance foundations
- Clinical trial assistance



CancerCare
www.CancerCare.org



Blood Cancer United
(formerly The Leukemia & Lymphoma Society)
www.bloodcancerunited.org



Lymphoma Research Foundation
www.lymphoma.org



Multiple Myeloma Research Foundation
www.themmrff.org



National Comprehensive Cancer Network (NCCN)
www.nccn.org/patientresources/patient-resources



CLL Society
www.cllsociety.org

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Support Organizations for People Living With Blood Cancers (cont'd)



American Cancer Society

www.cancer.org



NMDPSM

www.nmdp.org

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Managing Finances

If you have been prescribed a treatment, you may have questions about your financial options.

Health insurance coverage can help make treatment more affordable. Medicare and Medicaid can also offer assistance for those who qualify.

Consider researching the pharmaceutical company associated with your treatment. Some pharmaceutical companies, like AstraZeneca, have programs that provide people with assistance to help them pay for their treatments.



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