Chronic Lymphocytic Leukemia (CLL)

Chronic Lymphocytic Leukemia (CLL) is a cancer of blood cells called lymphocytes. The body has two types of healthy lymphocytes. They are B-lymphocytes and T-lymphocytes. Each type has important roles in our immune system. Your immune system works to protect you from infection. It is the B-lymphocytes that lead to CLL.

CLL is characterized by building up of an excess amount of these malignant B-lymphocytes (CLL cells) in the blood, bone marrow, lymph nodes, and other lymphoid organs like the spleen. This is a disease that primarily affects older adults.

CLL is divided into three risk groups: low-risk, intermediate-risk, and high-risk. Your stage helps your treatment team learn about the likely course of disease (prognosis) and helps them plan your treatment.

**Low-Risk Chronic Lymphocytic Leukemia (stage 0):**
People with low-risk CLL have a high white blood cell count. This high count is likely found during routine blood work, as patients with low-risk CLL often do not have any leukemia symptoms. Low-risk CLL has an excellent prognosis (likely course of a disease) and often requires no therapy at all other than observation.

**Intermediate-Risk Chronic Lymphocytic Leukemia (stage 1 or 2):**
People with intermediate-risk CLL can have
- Swollen lymph nodes, liver and/or spleen
- an increased lymphocyte count in their blood

People at this risk may be asymptomatic (showing no symptoms) at diagnosis. Because they might not show leukemia symptoms, their disease may have been found because their doctor found one or more swollen organs noted above. Intermediate-risk CLL has a favorable prognosis and often requires no therapy other than observation. Patients may require treatment due to very enlarged lymph nodes or symptoms related to the disease.

**High-risk Chronic Lymphocytic Leukemia (stage 3 or 4):**
People with high-risk CLL have Anemia (low red blood cells) or thrombocytopenia (low platelet count) due to crowding of the healthy bone marrow by CLL cells. They can also have an increased lymphocyte count in their blood and swollen lymph nodes or spleen. Some patients do not have any symptoms. Other patients can have enlarged painless lymph nodes, fatigue-related anemia, or bleeding or bruising related to low platelets. High-risk CLL requires treatment.

**What are the symptoms of Chronic Lymphocytic Leukemia?**

Many people with CLL do not have symptoms. People with CLL who have symptoms usually notice their symptoms very slowly. Common symptoms include:

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- Fatigue, tiring more easily
- Shortness of breath in everyday activities
- Swollen lymph nodes (in neck or armpit), usually painless
- Infections
- Weight loss for no clear reason

Leukemia symptoms may be vague and can also be caused by other illnesses. Call your treatment team if you have any of these symptoms.

**How is Chronic Lymphocytic Leukemia diagnosed?**

- Full medical history by your doctor
- Full physical exam with attention paid to enlarged liver and spleen
- **Blood tests:** Complete Blood Count (CBC) to check the number of white blood cells, red blood cells and platelets in your blood. Learn more about understanding your blood counts.
- **Blood Cell Test:** a test on the blood cells where the blood cells are stained with a colored dye. The cells are looked at through a microscope. It is also called a blood smear.
- **FISH:** a test called fluorescence in situ hybridization (FISH). FISH looks at genes or chromosomes in cells to see if there are any changes. Samples of cells from blood can be used.

**What is the Treatment for Chronic Lymphocytic Leukemia?**

Treatment can help manage CLL. Your treatment team hopes that your treatment will lead to a normal life expectancy. There are many ways to manage CLL. Leukemia treatment can consist of:

**Observation** – when a doctor observes a patient’s condition and does not prescribe drugs or other treatments. The doctor monitors the patient with physical exams and blood tests. Side effects caused by the disease, for example infection, can be treated. People with low- or intermediate-risk CLL or slowly spreading CLL may be followed with observation if they have no significant symptoms. This is because treatment for asymptomatic early stage disease has not been shown to be better than observation alone.

**Chemotherapy** – drugs given to destroy leukemia cells. Chemotherapy may be given by mouth or into a vein (IV). There are many different types of effective chemotherapy in CLL. The choice depends on balancing risks of efficacy with the risk of side effects. Chemotherapy is usually combined with immunotherapy (see below).
**Immunotherapy** – drugs given to tell the immune system to destroy leukemia cells. These are targeted drugs against leukemia that are usually given IV, but sometimes given by mouth. These drugs are usually combined with chemotherapy, but may be given alone.

**Targeted therapy** - a type of treatment that uses drugs to attack cancer cells by interrupting the chemical pathways within the leukemia cells that cause the leukemia cells to grow and survive. These are usually given as pills, and have been shown to be highly effective in CLL.

In addition to the treatments above, new types of treatment for CLL are being tested in clinical trials. You can enter a clinical trial anytime during your leukemia treatment.

**Clinical Trials**

Clinical trials are research studies of new drugs, new combinations of drugs or already approved drugs being studied to treat patients in new/different ways. They may include new drug doses or new ways (schedules) to give the drugs. Clinical trials are run under strict guidelines. Their purpose is to help find out whether new cancer treatments are safe and effective or better than the standard (current) treatment. At Massachusetts General Hospital, there are several clinical trials open for the treatment of leukemia and lymphoma that use the latest in cancer treatments.

If you have any questions or would like to speak with one of our physicians, please call the Center for Leukemia at Massachusetts General Hospital at 617 724 4000.