

Track 1: Introduction: Living with Chronic Lymphocytic Leukemia

Narrator: Welcome to the *Cancer Survival Toolbox*[®], an award-winning audio program brought to you by the National Coalition for Cancer Survivorship – or NCCS for short. With a grant from the Centers for Disease Control and Prevention, NCCS created this special program that focuses exclusively on chronic lymphocytic leukemia (CLL) – what it is, how patients with CLL are treated and managed, and ways to cope with this diverse, and increasingly treatable blood cancer. You can listen to this program alone, or you can use it along with the original *Cancer Survival Toolbox*[®] to help you deal with the challenges of cancer. If you recently received a diagnosis of CLL, you may want to listen to the *Toolbox* programs on “Communicating” and “Finding Information” from the original program. The topic “First Steps for the Newly Diagnosed” might also be a good addition to the information offered in this program. While CLL can occur at any age, it is generally diagnosed in an older population, that is, over 60 years of age. Some of you might find the program, “Topics for Older Persons” of particular interest. In other words, you have access to many more resources by combining the information in this CD with the companion programs in the original *Cancer Survival Toolbox*[®]. You can also refer to the resource booklet that comes with this CD for more information from many other sources, including national leukemia organizations.

But before we go on to the next topic, let’s discuss this term “cancer survivor.” At NCCS, we feel that everyone diagnosed with cancer is a survivor – from the moment we are diagnosed until the day we die. Of course, you can also use the familiar term “patient.” But we will often use cancer “survivor” throughout this program to mean anyone who is dealing with CLL.

There are four major forms of leukemia. Two are acute - acute lymphocytic leukemia - ALL - , and acute myelogenous leukemia - AML - The other two forms of leukemia are chronic - chronic lymphocytic leukemia - CLL- and chronic myelogenous leukemia CML. Acute leukemias grow

rapidly and develop in cells that are not fully formed (or mature). Chronic leukemias advance slowly, which allows the development of more mature (functioning) cells. Each year, around 5,000 people in this country are diagnosed with CML. About 15,000 people are diagnosed with CLL, making this form of leukemia three times as common as CML.

Depending on a person's signs and symptoms of the illness, their diagnosis might be CLL or SLL - Small Lymphocytic Lymphoma, or a combination of both. The diagnosis of SLL is used when the disease affects mostly lymph nodes and other parts of the lymphatic system; the diagnosis of CLL is made when mostly bone marrow and blood are affected. Sometimes, the diagnosis is both SLL and CLL (SLL/CLL), meaning that lymphatic system, bone marrow and blood are equally involved. CLL and SLL are really similar and they are managed in the same way. For this reason, we will use the term "CLL" for the remainder of this program.

Just in the past decade, clinical trials and other research findings have added to what is known about CLL, and the number of effective treatment options has increased too. More and more people are living well after the diagnosis of CLL. This module of the Cancer Survival Toolbox focuses on CLL and measures that have helped other people diagnosed with CLL, family members and friends, cope with this form of cancer and to get the best possible outcomes from treatment.

Voice #1:

My blood counts change all of the time so I'm always anxious about what happens next. My daughter looked up clinical trials on the Internet.

Voice #2:

My diagnosis was made after some abnormal blood test results popped up during a routine physical exam. I had not noticed any symptoms at all. When I learned that I had CLL, I panicked, of course, thinking that I might die very soon, but when I met with the hematologist, he said that based on the blood tests, there was no need for chemotherapy or other treatment for CLL right now.

Voice #3:

I feel so completely tired and no amount of sleep seems to help. I used to play golf twice a week but now I'm short of breath and just way too tired.

Voice #4:

I have trouble carrying the laundry up from the basement anymore. My legs buckle underneath me and I can't seem to make it up a flight of stairs without stopping to rest.

Voice #5:

I think that all the uncertainty, turmoil, and treatments are harder on my family than they are on me. Fortunately, we learned about support groups and education programs for all of us. It really helps to know that there are all kinds of resources to help us through these tough times.

Voice #6:

I am still not sure that I understand fully what CLL is. They call it a cancer but it's in my blood. I thought cancers were always tumors.

Voice #7:

I had a swollen lymph node in my neck for several months. The doctor kept prescribing antibiotics for an infection.

Narrator:

As you've just heard, when some people are diagnosed with CLL, they have no symptoms at all. Others might have a few general symptoms that could also be caused by other health problems. The absence of a clear-cut set of symptoms and the fact that some symptoms are like those for other illnesses are reasons for time it takes and the number of tests needed to pinpoint a diagnosis of CLL. It is a type of cancer that can be hard to understand. To help you learn about CLL, some basic knowledge about bone marrow, and about types and functions of blood cells, is going to be useful. So, we will start there.

Also, we suggest you use the booklet that comes with this CD. Look at the diagrams and pictures that describe how CLL is diagnosed and treated.

To learn more about this disease, let's hear first hand from Sam what it is like to live for several years with CLL, and how living with CLL and having treatment has affected him.

Sam: I will probably need some form of treatment for the rest of my life. Anyone faced with an illness like CLL must not only manage normal everyday activities, but must also be aware of the problems that can come up and know what to do. My wife and I are now pretty good about arranging medical visits – sometimes with several doctors, getting prescription refills on time, and submitting insurance claims. We also find and arrange for caregiving and support with other agencies, such as home care, and the infusion center, the support group, these sorts of things.

Narrator: We learn from Sam that CLL is a serious disease; that he may need treatment throughout his life, and that symptoms can often be managed with good self-care and medications. Sam has been living with CLL for several years now, and he is certainly a long-term cancer survivor. It is likely that Sam will always have CLL – yet he lives for periods of time when the disease is well-controlled. It is important to notice that Sam credits several resources for the help and support he and his family have gotten after his diagnosis of CLL..