

## **Track 1: Introduction: Living with Chronic Myelogenous Leukemia**

### **Narrator**

Welcome to the *Cancer Survival Toolbox*<sup>®</sup>, an award-winning program brought to you by the National Coalition for Cancer Survivorship, or NCCS. The *Toolbox* is a FREE set of self-learning audio programs developed by the NCCS along with the Association of Oncology Social Work, the National Association of Social Workers, and the Oncology Nursing Society. NCCS is the oldest survivor-led cancer advocacy organization in the US, advocating for quality cancer care for all Americans and empowering cancer survivors to advocate for themselves. To order additional copies of this *Toolbox*, call 877-NCCS-YES (877-622-7937) or visit <http://www.canceradvocacy.org/toolbox>.

This program, which is supported by a grant from the Centers for Disease Control and Prevention, focuses on chronic myelogenous leukemia – or CML – what it is, how it’s treated, and ways to cope with this treatable cancer. It gives you tools that can improve your abilities to cope with CML and its treatment. It is written by cancer survivors and healthcare professionals, and can help both those with a recent diagnosis, and those who have been living with this disease for some time.

You can use the information on this CD along with programs from the original *Cancer Survival Toolbox* for access to additional resources. If you were just diagnosed, you may want to listen to the original *Toolbox* programs on “Communicating” and “Finding Information.” The topic “First Steps for the Newly Diagnosed” might also be of help. While CML can occur at any age, it’s most often diagnosed in people over 60; this group might find the program, “Topics for Older Persons” helpful. You can also refer to the resource booklet that comes with this CD for information from other sources, including national leukemia organizations.

Before we move on, let’s discuss the term “cancer survivor.” At NCCS, our view is that any person diagnosed with cancer is a survivor – from the time of diagnosis and for the rest of his or her life. You can also use the term “patient.” Throughout this program, we use cancer “survivor” to mean anyone

dealing with CML, including the person with the disease, family members, and family and friends who are caregivers.

There are four major forms of leukemia. Two are acute—acute lymphocytic leukemia—ALL—and acute myelogenous leukemia—AML. Two are chronic—chronic lymphocytic leukemia—CLL—and chronic myelogenous leukemia—CML. Acute leukemias grow rapidly. Chronic leukemias advance slowly.. Each year, around 5,000 people in this country are diagnosed with CML.

Over the past decade, clinical trials and other research have added to what's known about CML, and treatment options have increased. More and more people are living well with CML. This program focuses on things that have helped survivors, family members and friends cope and get the best possible outcomes from treatment.

**Eduardo:**

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

**Evelyn:**

When I learned I had CML, I panicked, thinking I might die very soon. But my hematologist said based on my blood tests there was a good chance that with treatment, my disease could go into remission.

**Dan:**

I used to play golf but now I'm short of breath and just too tired.

**Kim:**

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

**John:**

The uncertainty, turmoil, and treatments are harder on my family than on me. Fortunately, we learned about support groups and education programs for all of us. There are all kinds of resources for these tough times.

**Rick:**

I'm still not sure I understand fully what CML is. They call it cancer but it's in my blood. I thought cancers were tumors.

**Bruce:**

I noticed I was sweating a lot, even when I wasn't doing anything. It took a couple months to figure out what was wrong.

**Ken:**

I was so surprised when my doctor said I had CML. I was feeling fine and hadn't been sick.

**Narrator**

As you've just heard, when some people are diagnosed with CML, they have no symptoms. Others might have general symptoms that could also be caused by other health problems. The absence of clear-cut symptoms and the fact that some symptoms are like those for other illnesses are reasons for the time it takes and the number of tests needed to pinpoint a diagnosis of CML.

Since CML can have different symptoms, it can be difficult to understand. Some basic knowledge about bone marrow, types and function of blood cells, and chromosomes—especially the Philadelphia chromosome—can be useful. The booklet that comes with this CD, which has diagrams and graphics describing how CML is diagnosed and treated, can be a good resource.

Let's hear from Bruce—what it's like to live with CML, and what effects his cancer and treatment have had.

**Bruce**

I'll probably need some form of treatment for the rest of my life. Anyone faced with CML must not only manage normal everyday activities, but also be aware of problems that can come up and know what to do. My wife and I are now pretty good about arranging medical visits, 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, the infusion center, support groups, these sorts of things.

**Narrator**

We learn from Bruce that CML is serious; that he may need treatment throughout his life, and that symptoms can be managed with self-care and medications. Bruce's been living with CML for many years. It's likely he'll always have CML, yet it's well controlled by medications. He makes sure to follow up with his doctor for ongoing monitoring—to see how effective his treatment is and if he needs to change his treatment plan. It's important to notice Bruce credits several resources for the help and support he and his family receive.