

Five Years to a Cure

Category: Stories

written by Ellen Diamond | August 24, 2012

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Recently, while reading a post in an online chat group for people with chronic lymphocytic leukemia (CLL), I spotted an intriguing comment. At an important conference, a world-renowned hematologist had referred to a “five-year timeline” for a cure.

This took me back fourteen years, to when I’d just been diagnosed with CLL. There was a Gilda’s Club near my workplace; I’d always passed it quickly on my way home. Now I found myself stepping through the doorway to hear a top specialist talk about my disease.

I recall his closing words: “Give me five years, and I’ll give you a cure.”

As desperately as I wanted to believe this pronouncement, I felt reluctant to pin my hopes on it. Fourteen years later, my skepticism remains.

I’ve heard many CLL experts make similar predictions, but despite great advances in research and treatment, no one with CLL has ever been cured. I’ve never doubted the doctors’ sincerity and good intent, but at times I’ve felt quite angry at their willingness to raise their audiences’ hopes in this way.

Given the facts, how can they make these pronouncements?

Part of the reason, I believe, is that when doctors and patients use the word “cure,” they mean very different things.

For doctors, “cure” appears to mean a point on the timeline of scientific research at which all of the obstacles to effective treatment have become manageable, and so, therefore, the treatment should succeed.

As a patient, I define “cure” as the moment when I’ll be told that my CLL has been destroyed, in all probability never to return. Quite a difference!

Although the word “cure” is heard more and more frequently at workshops and conferences, in reality the best treatment outcome is a kind of detente, with the disease driven into remission for longer or shorter periods of time.

The gold standard of treatment has been the FCR regimen, a combination of two chemotherapy drugs, fludarabine and cyclophosphamide, and one biological agent, rituximab. This triple-whammy, when used as a first-line treatment, produces the best total-remission rate and the longest remissions. But, like every chemotherapy, it has serious downsides as well.

When first facing treatment, three years after my diagnosis, I was terrified of FCR. The stronger the chemotherapy, I felt, the more aggressive the remaining CLL cells were likely to be when the disease returned. I also

feared that stronger chemo would wreak more damage on my immune system. After doing some research, I chose not to go with FCR but instead to use only fludarabine, the most effective anti-CLL agent of the three. I also opted for fewer treatment cycles.

My doctor did not object, and I felt vindicated by the results. Although my CLL never went into remission, it retreated, and my quality of life remained good both during and after treatment. My swollen lymph nodes, though unsightly, were not painful, and I only required treatment when they hindered the functioning of my bladder, lungs or stomach.

Two more rounds of treatment followed, with the nodes coming back faster each time. After three years, I'd run out of the less aggressive options and was considering FCR. Then I learned of a trial using a promising, less toxic combination—fludarabine and thalidomide. In December of 2003, I began the regimen, with a very successful outcome: my CLL went into a complete remission and has stayed there so far.

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Eventually the disease will come back, I know. But in the meantime, I've developed a “timeline” of my own. While researchers have continued to hone their therapeutic weapons against CLL, I've been learning how to live with it.

In fact, my life is much better now than it was fourteen years ago. The lessons I've learned have given me a better, more positive outlook and made me more resilient and adaptive.

I've learned that compromise is not same as giving in or giving up. Though the periods between treatments have not signified a cure, they've given me time to continue growing and changing, and I've made the most of it.

I've learned that fear, and my fright about feeling fear, were preventing me from making peace with the facts of my “new” life. I remember waking up one morning and feeling absolute terror, because the lump in my abdomen was making it more difficult for me to take a deep breath. All the worst thoughts came crowding in—and yet, only a short while later, the fear had passed and I was making breakfast. A few such experiences have taught me that even terror will pass, and that the thoughts it inspires are no more “true” than my other

thoughts; they only seem that way.

I've also learned that I can survive medical mistakes—even potentially harmful ones. During the trial, for instance, I had some fifteen CT scans to chart the regimen's effectiveness. Since then, it's emerged how harmful the scans' radiation can be. According to reliable studies, I'm now at some risk of developing a new cancer because of these scans.

Initially I felt deeply hurt and angry at my doctors for exposing me to such risks. But somewhere along my timeline I let go of most of the worry and all of the anger. The odds are still in my favor; for me, the glass is still very much half-full, not the opposite.

Perhaps the best lesson I've learned is that I do not require perfect health to be happy.

Simply growing older might have taught me that, but having leukemia has done it sooner.

Nowadays, when I hear a doctor mention a five-year "cure" timeline, I no longer react with cynicism or anger. I'm grateful beyond words to the brilliant, dedicated doctors whose work has brought CLL so near to being a manageable, nonfatal condition and who have given thousands of us precious years in which to live our lives.

When it comes time for my next round of treatment, my oncologist will no doubt express enthusiasm for the wonderful new non-chemo approaches. On her timeline, these represent a gigantic step forward.

I may need to tell her that, somewhere along my own timeline, I've lost the need—even the wish—to be cured.

About the author:

Ellen Diamond holds MA degrees in counseling and social work. Now retired, she occupies her time with singing, playing piano and writing as well as spending time with her family members (when she can grab them) and her friends. Ellen is an active member of the senior program at the 92nd Street Y in New York City. Her father died of CLL at age forty-three, and another close relative is now facing treatment for it.

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