

Patient Power

Why Watch and Wait? Understanding CLL Disease Development

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Andrew Schorr:

So, Dr. Menashe, I went four-and-a-half years with no treatment. There are other people who have gone an extended time with no treatment. How do you tell people that? Dr. Sharman was saying people think of—let's say if a woman were diagnosed with breast cancer or if somebody were diagnosed with another solid tumor, we'd say, "We need to start treatment with this week, next week, next months," and you're telling people, "We're gonna watch it."

Dr. Menashe:

Right. Well, I think people have to understand what the natural history of the leukemia. So, for example, which is a common presentation for people who might just come with an asymptomatic lymphocytosis, they might have a 13q abnormality, which is, if you look at a graph, the survival is not especially for people who are older, dramatically different than someone the same age without that.

So, just giving information about the natural history of the disease is critical and then you balance that with what will treatment do. Right now, there is no known treatment that will be useful now versus later on that could change going forward.

Andrew Schorr:

Right now, in other words, it doesn't seem like there's a penalty for waiting, in many cases.

Dr. Menashe:

Right. Or if there was a very easy treatment that would have a high rate of benefit, you might consider it, but right now, even very effective treatments still have significant toxicity risk for someone who can do well for years and sometimes decades.

Andrew Schorr:

Okay. So, Dr. Choi, there was a woman who did a listsery, just an email group years ago on acor.org, a CLL listsery. Bridgette, we were talking about her. When I was first diagnosed in 1996, she got on the phone with Esther and myself, and her words—I'll never forget it—she said, "Chill out." Chill out. Then it was four-and-a-half years of they say watch and wait. We were saying watch and worry, but just go on with your life.

So, Dr. Choi, when you tell people that, during that time that we're waiting, research is going forward. Like some of the things you're working on, they may pop during that time, right?

Dr. Choi:

Yeah. Certainly, I should say it's much easier said than done to chill out. Even when we're not recommending treatment with medications, I think we still recognize that as your doctors and your care team, we can help keep you healthy, help look for infections and make your quality of life as good as it can be and make you as strong as you can be before you need treatment.

But in that time also, probably behind the scenes, many people are analyzing trends in your blood work. We're always looking for patterns of growth of your lymph nodes. Then at centers like UCSD and across the country and around the world, people are also probably studying the leukemic cells that are taken from the blood of patients with CLL and trying to see if we can correlate that with how things go in the future.

I think there's a lot to learn even during those times when we're not treating you, both as your care team and also for researchers.

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