6 Steps From a Cancer Patient on Being Your Own Best Advocate

Jennifer White, an Atlanta-based cyber security consultant diagnosed with chronic lymphocytic leukemia, shares her tips on advocating for the best care.

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Life is like a Mad-Lib, and Jennifer White is taking control of what she can fill in the blank spaces.

The Atlanta-based cyber security consultant was diagnosed with chronic lymphocytic leukemia (CLL) in January 2019. In July of that same year, White, a Boston native, came to Dana-Farber. She currently comes to Boston four times a year for visits.

For White, there is nothing more important as a cancer patient than being your own biggest advocate. She believes that her constant questions, search for second opinions, and knowledge of her own body has tremendously affected her journey.

Here are her words of advice to other patients who may be going through a similar journey, as well as words of wisdom about cancer prevention.

Get your physical every year.

White had no symptoms when she was at her yearly physical. Finding out about her CLL diagnosis was nothing short of total shock, after it was discovered that her white blood cell and lymphocyte count was much higher than the normal range.

“My doctor came in and said, ‘Hey listen. I don’t want you to be mad at yourself. I don’t want you to be mad at me, but I’m 99 percent certain you have CLL,’” she recalls.

Looking back, White sees how the data from her past physicals were valuable: They helped her doctor recognize the potential warning signs of CLL, and for Dana-Farber to conclude Jennifer had been dealing with CLL for five years. Without that information, White notes she still might not know she had cancer.

Treat your cancer as a business problem and build your team.

“I think a lot of times, people tend to treat things differently in their personal life than they would if

it was a business problem or a task they're given at work," White says. "Sometimes, people in general don't feel they have the power to ask a question of a doctor."

When she was diagnosed, White focused on the task of creating her team.

"This is my team that I'm building; I'm going to be the one that manages this team," White says. "I need to find my quarterback and my players and bring them all together."

The team is not only made up of the doctors and nurses that work with White directly, but her friends and family, who play a crucial role in supporting her.

Be okay with not understanding the 'why.'

White couldn't understand how she was diagnosed with CLL. However, that type of thinking proved to be fruitless for her.

"The 'why' is in the rear, but I have the control to live positive and look positive in the outcome of what is ahead," she says. "Control what you can control, don't let it control you."

However, letting go of the "why" and staying positive is not easy. In fact…

It is a journey to positive thinking.

"You get sad about it, but you have to figure out how to find the positive," White says. "I don't have control over my blood fighting CLL, but I am a fighter."

Finding the positive, White says, is something that takes time.

"It's almost like grief. There's no one size-grief fits all. Your cancer journey can't be defined by a playbook. It's going to be different from everybody's," she says.

When White finds herself struggling, she holds onto the goodness of others — such as the people who donate money to cure cancer or leave her a kind word.

"I consider them part of my team; we're all in it together. Sharing my story has been the most vulnerable thing I have ever done, but then I think 'you're fighting cancer, you got this,'" White says. "The response and support I have received keeps me positive and lets me control my own narrative."

Validate your sources.

Once she was diagnosed, White got caught in a whirl of CLL-related Google searches and other online "noise" that left her feeling confused and defeated.

White's remedy is to instead research selectively, and to go beyond just Google research. It is also about getting second opinions about treatment.

Treatment isn't always initially necessary for CLL patients. Before she went to a Dana-Farber specialist, another doctor told her White was on the verge of needing treatment, when this was far from the case. This is one of the reasons White believes in patient self-advocacy.

"Think big. If you were accused of a crime, you would get the best criminal attorney you could," she notes. "Cancer is no different. You just have to look at it the same way. Find the best doctor you can."

Lastly, White's number one piece of advice boils down to one simple truth:

Find your journey and how you're going to take it and just be you. That's it.

During her first appointment with Jennifer Brown, MD, PhD, White sat for over an hour as her questions got answered.

"She can put things in a perspective that I understand," White said. "It's so much more than a doctor-patient relationship. She just has a very comfortable way of asking the right questions."

From joking with nurses, to receiving in-depth email updates, White says she has experienced a whole new world during her "watch and wait" at Dana-Farber.

"I've got a Rolls Royce in Dana-Farber, and that speaks to everybody from the garage attendant to the CEO and everything else that permeates through there," she says.

White cannot control the fact that she has CLL. Like a Mad-Lib, that part of her story is predetermined. However, through her vocalization, her outlook, and determination, White is picking up the pen to create a story that is all her own.

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