



# Patient Power

## Patient Advocate Discusses the *Medical Aid in Dying* Movement

**Carol Preston**  
CLL Patient and Advocate

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### **Carol Preston:**

Hello, everyone. This is Carol Preston, and thank you for joining me on Facebook Live. When last we chatted a couple of weeks ago, I brought you up to date on a year-and-a-half's worth of activities and mostly good activities since I was blindsided by that second cancer, a soft tissue sarcoma.

Today I want to focus on Medical Aid in Dying and here's why. With Patient Power and we who are patient advocates, and really all of you out there are patient advocates as well and care partners, we talk a lot about staying well, good quality of life, using the best great treatment as a bridge to the next great treatment. But the reality is that every once in a while at least I start thinking about what if the disease races faster than the treatments that become available? And that's where the issue of Medical Aid in Dying comes in.

Why am I that interested? Because this past winter and early spring I was a legacy leader, which is a very euphemistic term for a senior intern in Annapolis, Maryland, during the legislative session. And I worked in the office of one of my state legislators from my district and was lured or reeled in by the Medical Aid in Dying issue, which was very, very big in Annapolis this year.

And because I am a several-time cancer survivor and because I have had communications experience, I was asked if I would testify both before the State House, the House of Delegates and the Senate, which I did, not in prime time but I did add my voice to those who support Medical Aid in Dying as well as giving some television and radio interviews. So it was really my privilege to extend a hand, to extend my hand to talk about this important issue because as much as we all want the C word to happen in our lives, the cure word, whatever the malady, the reality is that none of us will be here forever, and again I needed to think about how far along am I and how far along are the treatments that are going to keep me going the way I want to keep going.

So Medical Aid in Dying in Maryland became a very passionate issue of mine, but it also became a very passionate issue for just about every citizen in the state of Maryland. Now, for those who are not familiar with the issue, and I think most of you are, there are nine jurisdictions, eight states and the District of Columbia, which have Medical Aid in Dying provisions. Maryland would have become the first state below the Mason Dixon line had it passed, and I'm not telling tales and I'm not giving away the ending when I say it did not pass. It passed in the House of Delegates. It did not pass in the Senate.

So with nine jurisdictions already supporting Medical Aid in Dying, what made it so difficult in Maryland? And I have to say as a citizen it was very, very disappointing to me, because I may never use that prescription, which is really what it is, and you really have to jump through a lot of hoops to get it. Approvals by three doctors, both written and oral, and really there are family considerations involved with that.

So for me it was a crushing defeat, but in taking a look at the demographics of Maryland you begin to get a clearer picture why. The state is 30 percent African-American, a much higher percentage of African-Americans than many of the states which have passed Medical Aid in Dying, including Washington State, Oregon, Vermont, Montana, and also it is a heavily Catholic state. And there are passionate arguments on both sides of the issue, but in the end it was just not meant to be for these demographics.

So why is something like that important to me? Well, I've given you one reason, because however the end comes at some point the disease may outpace the treatments. But the other thing is the doctors already have at their disposal what one of my physician friends refer to as a wink and a nod, and they actually have ways of helping patients die.

The problem is, the challenge is that they're not legal. I mean, technically they are legal, but the morphine dosage can be upped, there are all kinds of ways to help patients die. But wouldn't it have been nice at least from this patient's perspective to have the option to have the comfort level of knowing that the prescription in my hand may sit there by my bedside forever, I may never choose to use it, but I sure would have taken great comfort to know that I could choose my end-of-life option rather than having the state or the government decide for me.

Nobody wants to be in pain interminably, nobody wants to be lying, you know, in a bed like a vegetable. These are very personal decisions. This is not the only issue like that. We all know that there is at least one other, and there are other issues as such. So for the State of Maryland anyway, Medical Aid in Dying is not to be this year.

But as much as I relish and embrace life, quality of life, keep track of the next treatments for my CLL, chronic lymphocytic leukemia, and hopefully the sarcoma will not come back, I have to be a realist and think about what's next. What's next may be to go to another state. What's next may be to do nothing. But I think that is an issue we all need to consider. We need to think about it. We need to figure out for ourselves what's going to work for us, our families, our communities and our states.

I wanted to share that with you because my experience in testifying and in writing and talking about Medical Aid in Dying, and I would love to hear from you as to your perspective and what you think about this particular issue. If you're for it, how do we move it forward? And if not, it is important for me to hear all sides to find out why.

Thank you so much, everyone, for sharing these few moments on Facebook Live with me. This is Carol Preston wishing us all to stay well.

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