



# Patient Power

## Living and Dying With Dignity

**Cherie Rineker**

Myeloma Patient, Author and Blogger

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**Andrew Schorr:**

Hello. It's Andrew Schorr from Patient Power, and once again we're with a friend of mine who we've interviewed many times, Cherie Rineker. And, Cherie, thank you for being with us once again. Thank you.

**Cherie Rineker:**

Hi. Good afternoon. I brought my glasses for you, Andrew.

**Andrew Schorr:**

Yeah, there you go. That's a positive woman and the smile. But for our audience, we're going to talk about a really tough subject. And if you are newly diagnosed or have begun treatments that's working for you, you don't want to watch. Because we're going to talk with Cherie about the many, many lines of treatment that she's had, that some worked for a while, some didn't work at all, and where she is now, and some decisions she's made about herself that aren't for everybody.

And we're talking about how do you want to go out of this world, really, when you have a serious condition, in Cherie's case, multiple myeloma. So, Cherie, today you're on pain medicine, right?

**Cherie Rineker:**

Yeah.

**Andrew Schorr:**

And it's been a big issue for you. How many lines of therapy have you had?

**Cherie Rineker:**

I'm currently still trying my 16th line. It had not worked, and I ended up in the ER, and now we're giving it another shot. We're not sure if it's working. The numbers have really shot up in the last month and so has the bone pain and the tumors and the lesions and everything.

**Andrew Schorr:**

And how many trials have you been as well?

**Cherie Rineker:**

I think I've only been in two or three, the CAR-T being the main one, and there is a trial possibility in the pipeline. But we're discussing it. We're not sure—I said at this point whatever I do I want to do with a decent quality of life. That's my main thing at this point. The quantity hope is kind of out of the window, so we're talking adding maybe some months or maybe six months, so it's all about quality for me right now and my family.

**Andrew Schorr:**

And, Cherie, you're how old now?

**Cherie Rineker:**

I'm 51.

**Andrew Schorr:**

And you've been living with multiple myeloma how many years?

**Cherie Rineker:**

Since I was diagnosed at the age of 44. November, it will be seven years.

**Andrew Schorr:**

All right. So it's been quite a journey. How many hospitalizations during that time, do you think?

**Cherie Rineker:**

Gosh.

**Andrew Schorr:**

Countless.

**Cherie Rineker:**

An average of four to six ER visits and usually end up in the hospital, per year. It's been a tough—I know there's people with seven years and being on their first or second line of treatment. I was on four different treatments before my first stem cell transplant nine months in.

**Andrew Schorr:**

Right. So as we put this in perspective let's just take a look at Cherie's situation. A woman who's hopefully at different times, you know, had hope in many different therapies including one of the most experimental, CAR-T, chimeric antigen receptor T-cell therapy, and unfortunately her myeloma, the plasma disorder she's had that's affected her bone and caused significant pain, fatigue, it's kind of blown through that.

And while you still are trying one more thing you've made a decision by becoming a resident of the state of Colorado where they have a death with dignity law. You've actually made that part of your plan if need be, right?

**Cherie Rineker:**

Correct, yeah. When I relapsed from CAR-T, which I really considered my miracle drug, I went in complete MRD-negative remission. You and I did a show about that. I was thrilled. I considered myself cancer-free, chemo free, and to the day a year later I was about to step in front of 500 doctors and scientists talking about my success, and four hours earlier I got the news that I had relapsed. And it was devastating.

And over the next month I just did not see myself being able emotionally to handle the same stress I'd handled for the previous seven years. I had just battle fatigue, I call it, pretty severe PTSD, not only for myself but for my husband and for my daughter. And so I went up to Colorado, became a resident, read the law, found a doctor and put that in order as an insurance policy because as a myeloma advocate I have spoken at length to widows and widowers and seen the downhill trend when you get to my place when even something like this fails.

And most people choose to go from treatment to treatment ending up in a pretty horrible death, and I just didn't think it was right for me, especially not for my young daughter who is pretty traumatized from it all and also just our whole home situation that we live in. So it was a difficult choice that I discussed with my family and my children, very difficult, but we all decided this was going to be the best way.

**Andrew Schorr:**

Now, we should say, Cherie—and thank you for sharing something that's very, very personal and controversial—but there are many states where this is not allowed in any way. Doctors have no option to work with whatever paperwork and

decision-making can go with it to help people, basically allow them to die without suffering, okay? And Colorado is one of the states. There are a few others. There are others that are considering it, but for our viewers, we recognize that this may be, say, we're taking away all hope, and that is not our intent.

This is something that some patients like Cherie consider after going through many treatments. And you've kind of adjusted your thought. Your hope had been like see your kid graduate from college.

**Cherie Rineker:**  
Right. Right.

**Andrew Schorr:**  
You've reoriented your expectations.

**Cherie Rineker:**  
Yeah. I mean, right as we speak I'm working very hard on finishing my second book, which I've changed the title a bit. It was going to be Pilgrimage toward Health, Keeping Hope Alive, but now I'm calling it again A Pilgrimage without End, Keeping Hope Alive. And the message of hope for me now is to absolutely live these last months to its fullest, to live it very conscientious, very purposeful. So I fill up my days with a lot of stuff. Obviously that helps keep my mind off what is really going on, but also just loving life and loving my relationships with my daughter and my friends and stuff.

So, listen, none of us are going to get out of here alive, and I just really kind of know the timeline. So to stick your head in the sand at this point and just being in denial can actually end up making the end of your life much more miserable, as I have heard from others who have continued fighting beyond when they should have.

And I never heard one widow say we should have fought harder. The answer was always we shouldn't have fought that hard in those last six months to a year. And I listen. I listen to people and I really learn, and so that's my choice. So life doesn't have to be hopeless just because we know we're going to die because, Andrew, I hate to break it to you, but you're going to die, too. Everyone's...

**Andrew Schorr:**  
...it's a one-way trip.

**Cherie Rineker:**  
Right. So if we—I'm really—in my book and in the talks that I give now I would like to—I tell people I've befriended death in the sense that I just recognize it's part of life. It's what I'm going to do. I've lived a dignified life, and I want to die a dignified death.

**Andrew Schorr:**  
Cherie, thank you for sharing that. So for our listeners and there are people, we've done some other discussions about this, people say, well, there you are at Patient Power, you're taking away our hope. That is not it. It is, so Cherie has had hope 16 times with different medicines, and even though in her particular cancer, multiple myeloma, there's been a lot of progress, drug approvals, many clinical trials, it doesn't work for everybody. And so for whatever reason for Cherie now she's going to give it one last shot with her doctor, right, Cherie?

**Cherie Rineker:**  
Right.

**Andrew Schorr:**  
And see if that works and hope for that, but if it doesn't you have a plan. You've taken back control.

**Cherie Rineker:**  
Right. Right. Yeah, you're absolutely right. And, you know, I've participated in trials, and trials don't always end up good either. People die on trials. So I was speaking to my friend Dana Holmes yesterday, and she actually told me—I asked her if I could say this—she said, you know, what you're doing with death with dignity is really just taking on another line of treatment in a sense, and the treatment being easing into death versus having a rougher end.

And so we're talking about a possible trial. It's straight—how do you say it?—from mice to men, so it's very, very risky. And I still haven't quite decided do I want to do it because that might not go pretty at all. But I may do it.

But if that doesn't work then the death of dignity would just be another line of treatment. I just would know the outcome, which would be easing myself out of this world. I've always promised my followers that I'll give you the good, the bad and the ugly, and I concentrate on the good, and I always end on a good note. And even now with this—I mean, I cry sometimes but I live my life full of joy and gratitude. So it's part of the conversation, you know.

**Andrew Schorr:**

Well, Cherie as you know, at Patient Power we reach people with many different cancers, whether it's advanced prostate cancer or lung cancer or breast cancer or leukemias and myelofibrosis like I have, whatever it is, it's something I could face myself, of course. And so each of us will come with our own personal values and the discussion like you've had with your family. We will look at the laws as they exist in the state where you live or the state where you choose to relocate. You did.

**Cherie Rineker:**

Right.

**Andrew Schorr:**

And then you have your options on—I have a friend with advanced prostate cancer who made the same decision in California. It was really tough for all of us. It was tough for his wife. But he thought about it, discussed it and said that was his choice. For someone else and some other people watching you may say I would never do that, or my religion, I don't believe in it, and that's okay. But, Cherie, you are comfortable with the plan you have.

**Cherie Rineker:**

I got a lot more peace once I put this plan in because I knew how too many friends of mine had died and what those last weeks looked like, and I was scared to death of that. I have been in situations where I'd been at MD Anderson on a morphine pump every eight minutes, and the pain was just not controlled when I moved. So I knew that story of, no, we'll get you comfortable was—certainly had not been true several times in my case through this.

And as far as the law goes, I've been telling friends that I really don't believe this should have anything to do with politics because until you walk into this situation how can you be part of this conversation? I believe me and my doctor are consenting adults. We're discussing about it in a consenting way. This is not a slippery slope. You can't be depressed. This can't be a quick thing. You have to have less than six months. There has to be two doctors that have to say that you're sane, basically. And then there's a waiting period.

And so once the doctor who knows your history, who knows your suffering, who knows your limits as you do yourself agrees with you upon this decision, then why should the rest of the world really have anything to do with this? It's to me an intimate choice.

And if you have a doctor who doesn't agree with it and you really want this, then you can find—a doctor should not be forced to make this decision either, you know. But it is a decision you can discuss with your family, but ultimately I believe your family should share your wishes as a dying patient. I think I take precedence in this choice of my life over everybody, and I'm very grateful I have a family that agrees with me.

**Andrew Schorr:**

Cherie, I can't thank you enough for sharing this. I know this will spark a lot of discussion, and we all welcome that. I know you are all over social media. You welcome that. But in the end, this is a personal decision. Cherie is sharing hers, following the rules in Colorado with the doctors that she has consulted with.

And, Cherie, I mean, on my side I hope this last medical offering will bring you some relief because I want you to be around for a long time but not suffering, no matter what. And I also—I don't know. You know, this is a tough discussion, but I want to thank you for sharing so personally so many times with us, and I want to see that you finish that book, okay?

Cherie Rineker:

Well, thank you. And I just spoke with my doctor in Colorado last week, keeping in touch with him, and he himself said he follows me online. He read my book, and he wants me to finish my second book. And he said, Cherie, I hope two years from now we'll still be discussing this, and I hope you're still going to be around. So nobody's pushing for me to end my life. I am suicidal. I don't want to bail out. I'm not quitting. I am a hell of a fighter. Nobody could accuse me of not having tried, but there is a time when you have to start facing that part of your reality.

**Andrew Schorr:**

Cherie Rineker, thank you so much. I'm giving you a hug, okay?

**Cherie Rineker:**

Thank you, Andrew. It's a pleasure.

**Andrew Schorr:**

Bye-bye. Andrew Schorr with Cherie. Knowledge and this personal decision-making can be the best medicine of all.

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