



## Dan's Story: My Experience With CAR T-Cell Therapy

**Dan Symes**  
Powerful Patient

**Jodi Symes**  
Care Partner

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**Andrew Schorr:**

Hello and welcome to Patient Power. I'm Andrew Schorr. It is a thrill for me to introduce you to someone who has benefited from the leading edge of medical science, and it's really taken them from death's door to getting back to a full life. And joining us now from Boston to hear their story is Dan Symes, lives outside Boston in Amesbury, Massachusetts, and his lovely wife, Jodi. Thank you both for being with us.

**Dan Symes:**  
Glad to be with you.

**Jodi Symes:**  
Hi.

**Andrew Schorr:**

Okay. Thank you. So, Dan, here you are, 66 years old, and you're working back as a project manager in the construction development world. But going back to when you were 61, you were diagnosed with non-Hodgkin lymphoma, and over a few years you got to be a pretty sick guy, didn't you?

**Dan Symes:**  
I did. I was almost not here. I spent a lot of time in a wheelchair being pushed around by my wife.

**Andrew Schorr:**

And they told you at one point after they tried a lot of medicines that you had just a short time to live. What did they say?

**Dan Symes:**

That's correct. They—we finally asked the question because nothing they were doing was working, and said—they basically said at the hospital we were at there was nothing else. They had no other treatments for us, and without the correct treatment we had a few months left.

**Andrew Schorr:**

Jodi, this is like a hopeless situation for you and Dan. You have four kids. Must have just seemed like you were at death's door.

**Jodi Symes:**

It was it was a pretty awful day. I'll never forget that day. We—as Dan said, we hadn't asked the question about time, but it felt like it needed to be asked that day and certainly not the answer we hoped for.

**Andrew Schorr:**

Okay. Well, ladies and gentlemen, this is a happy story to this point in that your doctor at that medical center in Boston said, well, there's this doctor at another medical center who might have something for you. You went across town, and they tried a bunch of things, and there were clinical trials. You had a time when it still wasn't working, right? You had a lifeline but not an end goal, right, Dan? And there was kind of a waiting game.

**Dan Symes:**

That's correct. We were on a waiting list for the trial that did eventually cure me. And while we were waiting to get on, you know, become number one on the list, we tried two other trials that really weren't doing anything either.

**Andrew Schorr:**

All right. But let's tell the story of the trial that worked, chimeric antigen receptor T cells. Now, you had gone from having non-Hodgkin lymphoma to more aggressive disease, diffuse large B-cell lymphoma. You were having bleeding. You had all kinds—you were getting transfusions. You were in a wheelchair, I understand in and out of the hospital.

So okay, so with CAR-T cells my understanding is they make a drug out of your T cells. They take your T cells, make a drug out of it, and eventually give it back. So what was that whole process like, Dan, for you?

**Dan Symes:**

It's, I don't know, it's strange because obviously you're hoping for the best. When you get accepted, finally get accepted into the trial because, you know, they've got to do all of the tests, echocardiogram, CAT scans, PET scans, you know, everything to make sure that you're healthy enough. Then you, excuse me, then you go and they take your T cells out, which is kind of a crazy science fiction-type thing where they put an IV in both arms, they've got a machine with a bunch of wheels and plastic hoses just spinning around, and stuff drops in a bag. And then it goes off.

Back to—we're in Boston and went back to Seattle, and then it becomes a waiting game where they give you, say, four to six weeks it will be back. And during that time they give me—they were giving us what they call salvage chemo, going in almost weekly for different things, which kind of fools you a little bit, because you get it, and you feel really great for like three days, and then it goes away, it's gone.

**Andrew Schorr:**

But eventually...

**Jodi Symes:**

Just a quick aside.

**Andrew Schorr:**

...sure.

**Jodi Symes:**

Dan said "us" a couple times. Just to be clear, he's the one who had the treatment. I think he says us, because it's something we definitely did together. I was there with him.

**Andrew Schorr:**

Absolutely. Jodi, I'm sure you were there every step of the way.

So the cells come back.

**Dan Symes:**

Yes.

**Andrew Schorr:**

A drug made out of your T cells, and they're put in. What happened and how fast?

**Dan Symes:**

It's like it's anticlimactic. It's funny because at that point I had been in the hospital for four days because they do a depletion chemo for three days before you get your cells back, and so then on the fourth day the cells are coming. And I had a nurse in my room literally like for three hours setting all this stuff up. It was like an operator room when they were finished.

They come in, they set up an IV, and they come in with their little syringe and they go pfft. They squirt it in, and that's it. Then everybody stands around and stares at you for half an hour, and they take your blood pressure every 10 minutes. They go out in the hall, they wait another 20 minutes, and they come in and they do it again, and it's all over. And I go what was all this for?

**Andrew Schorr:**

What happened?

**Jodi Symes:**

You were in the hospital for 10...

**Dan Symes:**

I was in the hospital for 10 days, and that being because the criteria is you can't have a fever for three days before they let you out, and I kept, I just kept hitting these little low-grade fevers. I'd be like, you know, I could get up to 101, I'd be 101-and-a-half, and so it extended out to 10 days. But at the end of 10 days, I could get out of the bed and walk, which, I mean walk for a distance, which I could not do when I get there 10 days earlier.

**Andrew Schorr:**

You'd been in wheelchairs.

**Dan Symes:**

Yes. My wife literally pushed me into the hospital, and like I tell everybody, it was slow, it wasn't pretty, but I walked myself back out.

**Andrew Schorr:**

Wow. So, Jodi, as a family member, and you've been with him every step of the way, do you see this as a miracle of modern medicine?

**Jodi Symes:**

Yes. The simple answer is yes. I know that if we were living in a different time we wouldn't be sitting here talking to you tonight. I think we are the beneficiaries of modern research, clinical trials and people sitting in labs years ago saying years ago, hey, I think this might work if we could just figure out how to do it.

So I do see it as not only—not as much a miracle. It's just a reward for so much hard work by so many bright people. We're really—we really know how lucky we are.

**Andrew Schorr:**

Right. It's a celebration of science, and you as a spouse and Dan there with us and back to work, and now you have this 2-year-old granddaughter, the light of your life, Lyla...

**Dan Symes:**

Yep.

**Andrew Schorr:**

...and you get to celebrate with her. So, Dan, looking back on this, how grateful are you, and what's your hope for the future?

**Dan Symes:**

I'm extremely grateful. You know, if you had asked me a year ago I would have told you I'm not going to be here, you know. And now we're going to retire in the spring and we're going to do all the things that you planned on your whole life that weren't going to happen. Incredibly grateful.

**Andrew Schorr:**

Wow. And you had a scan not too long ago and I understand now, of course you've gone, you're recovered from the infusion, the CAR-T, and your body had been ravaged with the cancer, so you're dealing with that, but basically there's no evidence of disease, right?

**Dan Symes:**

There is nothing. And that was at 14 months. Well, they say, you know, you want to ask how fast it works. Thirty days after the infusion you get—because of the trial you don't see very much in real time, so 30 days after the infusion I had a scan, a PET scan, CAT scan, and we had an appointment. It was the first time that you ever saw anything in real time, and they put up the scan from three days before I got the infusion and the scan from 30 days after, which was two days before, beside each other.

And the scan three days before the infusion, I was—my abdomen and halfway up my back was just one entire bright light. You couldn't, you know, you couldn't even—there was no separation between tumors or anything. It was just one giant tumor. And they put up the new scan, it was dark. There was nothing. It was absolutely dark. You wouldn't even think it was the same person.

**Andrew Schorr:**

Wow. And the point is that's remained I think what the doctors called durable. In other words, this has been lasting now, right, for how long? For maybe months.

**Jodi Symes:**

Well, it's 16 months now.

**Dan Symes:**

Yeah. It's 16 months now. It was 14 months at my last scan when everything was still perfect.

**Jodi Symes:**

And every time he has an appointment, the doctor walks in the office, shakes his hand, and says, complete remission, my friend. He leads with that so we don't sit there waiting on pins and needles because as any cancer patient knows, even though you're hopeful and you're optimistic you just want them to tell you it's clear.

**Andrew Schorr:**

Right.

**Jodi Symes:**

That the scan is clear.

**Andrew Schorr:**

Well, all I can say is from all of us, from me and all of us watching, we wish that long term. Go retire. Go do all those things you want to do together. You look like a wonderful couple, and celebrate Lyla and your children, have more grandchildren, and only good times. And hopefully when you go in for those checkups they shake your hand, still nothing there, go about your life. That's all of us, what we want. I want to wish you all the best and thank you. Jodi, thank you for being the care partner that Dan needed I'm sure and still needs.

**Dan Symes:**

Oh, yeah.

**Andrew Schorr:**

And, Dan, all the best to you, buddy. It's great to see really someone in the flesh, if you will, who has benefited from, as Jodi said, all the hard work that I'm sure many people in medicine have been working towards for so many years.

**Dan Symes:**

Incredibly smart people.

**Andrew Schorr:**

Yeah. All the best to you. Dan and Jodi joining us from Amesbury, Massachusetts, and this is the kind of stories we love to tell, and we hope we can tell it with many, many more people.

I'm Andrew Schorr reminding you that knowledge can be the best medicine of all.

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