

Paths to Recovery – The Journey Continues

TRANSCRIPT

Narrator

More than a decade ago, we met two blood cancer survivors and members of their care team. They discussed their diagnosis, treatment, and their ups and downs as they continued along their Paths to Recovery.

We visited them again to see where their paths had taken them and talk about how they adapted and thrived along the way. Join us for an update on where the road has taken them and their journey ahead.

Previous 2010 video footage:

Sheriff Todd

Multiple Myeloma survivor

Basically, what I do right now is I just live one day at a time, and I don't really worry about what's going on in the future. My main concern is to try to live the best life that I can live today with hopes that, of course, tomorrow will still be around.

Edward A. Stadtmauer, MD

Section Chief, Hematologic Malignancies

Roseman, Tarte, Harrow, and Shaffer Families' President's Distinguished Professor

Penn Medicine, Philadelphia, PA

A decade or so ago, we hoped that maybe half of the patients would respond to therapy, and people would live a number of years. Now we expect 90–95% of people to respond beautifully to therapy and for people to live decades with the disease.

Sheriff Todd

My life has changed a lot over the years. I can tell you that. When I was first diagnosed, I was originally told that if I had not gone and gotten my stem cell transplants, there was a good chance that I would only have about two months to live. And I was very blessed to be able to go down to the University of Penn and to get some fantastic care. And during that time period, my life was kind of up in the air because of the fact that I really didn't know whether or not I was going to be around to see my kids grow up, yet alone, graduate high school, graduate college, get married, have children. So, my life has been blessed.

Previous 2010 video footage:

Laura

Acute Lymphoblastic Leukemia survivor

It was like ok, well just fix me and let me get on with my life. Not knowing that when you have a disease like this it's not like the flu, where you're going to get better and then you're done. It's ongoing. Maybe I'm in remission now, but all these other issues are still with me and here it's almost 10 years later, almost. So, it's a new normal as they say.

Lissa Parsonnet, PhD, LCSW, OSW-C

Psychotherapist/Consultant

For a lot of people who have been fortunate enough to be healthy and vibrant and fit and also to be able to control their lives, a cancer diagnosis is a major assault to their sense of self. As human beings, we are all vulnerable, obviously, but we're not in touch with that until we have to be. I think sometimes that we kind of go through life with a cloak of immortality. We all go through life as if it

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will go on forever. And then cancer comes along, and it just tears the cloak off. And for most, people do survive cancer and they get their cloak back, but it's kind of tattered and torn and it just doesn't feel the same. You get your cloak back, but it never fits right. It never fits the same as it used to.

Laura

There have been ups and downs, of course. Ron was – when I was so sick – he was my rock, and he took care of many things besides the house and just making sure I was okay.

Ron

Laura's husband

It's still sometimes hard for me to look back and realize what we've been through as a couple and as a family. It was tough, but we stuck with it. And I think we're both in a great place and stronger for it.

Laura

And now I feel more normal normal; not a new normal. And it's just, I think my age normal because it's 23 years, almost 23 years since I was first diagnosed. So, my new normal, I get tired at night. Is that because of leukemia? I don't think so. And I used to know my different tireds, my “mommy tired,” my “leukemia tired,” my “low blood tired,” and my, “oh my gosh, I'm 63 now, I'm tired.” So, that's my new normal now. And I accept it.

Sheriff Todd

The milestones, the neatest things: seeing all three of my kids graduate high school; all three of my kids graduating college; all three of my kids getting married. I myself took the opportunity to become ordained, and I was able to marry my son. And most recently I had my fourth grandchild. Never thought I'd see any of that. It's been a long road, but amazing.

Coping: During and After Cancer

Dr. Stadtmauer

My goal is to get patients through the therapies as well as they can because you can have the most brilliant therapy and the most amazing treatment, but if the patients can't tolerate them, then it's as if it doesn't exist. So, it's really important to listen to the patients, and it's very important for the patients to talk to their physicians about what type of symptoms that they're having. And the disease itself can cause symptoms. Multiple myeloma in particular is a disease that can affect so many different parts of your body. It can affect your bones. It can affect your blood counts. And so people can be tired and fatigued or have pain. Fortunately, the way that many symptoms get better is with successful therapy. So, getting the treatment will frequently make those symptoms better. But in addition, we have lots of great supportive care to help with that.

Sheriff Todd

Struggles. There were many struggles. I mean, I could tell you from the first time, just dealing with Dr. Stadtmauer, just before the first stem cell transplant, he said to me, “Sheriff, I'm going to bring you this close to death with chemotherapy and everything that we have to do in order to kill all those cells, but then I'm going to bring you back.” What he did for me was tremendous, but that didn't come without struggles.

Lissa

Depression and anxiety is more prevalent in the cancer population than it is in the general population. But even with that, most cancer patients don't become clinically depressed. They become sad. They experience a normal reactive anxiety to something that would make any of us

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anxious. I think the anxiety tends to kick in very quickly. It's kind of a panic reaction, "oh my God, my life is threatened." That's a stress. And anxiety is a common reaction to stress.

I don't know that it ever stops, but it dissipates. At the beginning, it's kind of like you have a radio on and at the beginning the radio is on and the volume is blaring and it's all you can see and hear. And when I think about cancer, you can never turn the radio off, but you can turn it down. Over time, you can turn the volume down. But one of the times that it goes back up again is when treatment stops and all of a sudden you're not seeing doctors and nurses regularly. So, you're not being monitored, and you have to go by how do you feel. So, termination of treatment is definitely a psychosocial crisis point with anxiety, confusion, and sometimes depression. Over time, the radio volume goes way down, but I think most people will say at every checkup, the volume kicks up. After five years, it doesn't kick up as much as it did after the one year, but you can't turn it off. The radio never goes all the way off.

Laura

A year after being medically better, it hit me emotionally what I had gone through. So, I needed to talk to someone to sort out my feelings. And she let me know that my feelings were normal, and she validated them.

Sheriff Todd

There were difficult times. There was depression. There was anxiety. There was pain. There was uncomfortableness. There was no sleeping. There was constant tears, and all that stuff going through your mind, not knowing who to believe, what to believe, reading this, reading that. Yes, you have to overcome those struggles. No, it's not easy.

Lissa

There is no one right way to cope with cancer. There's no wrong way. If you get from here to there with a cancer diagnosis, you've done it right.

Sheriff Todd

You do have the support. There is support out there. You might not feel their support out there. People may look at you and they may not understand that you need help. Sometimes you need to reach out for that help and then that help will be there.

Lissa

So, I think it's really important for people to communicate with the people in their environment. Because most people have at least one person who really wants to help them but doesn't know how. There are people in this world who are very isolated. COVID pointed that out a lot. And it's not unlike what people go through when they have cancer and they're immunocompromised or they're just too sick and depleted to socialize and to just have the encounters that we have at work or at Starbucks or wherever we go and talk to people. People lose that, and they become very isolated. And those people are more likely to get depressed.

Looking to the Future

Dr. Stadtmauer

Well, we're so fortunate now with all the developments over the last decade that we have so many options for therapy. In many ways the newer therapies have less side effects and more effectiveness than the old therapies, and therefore we're thinking long-term, we're thinking of how are we going to design a treatment that has a low likelihood of giving some crippling side effect that's long-term, while maintaining a long, healthy life.

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Sheriff Todd

I've had some good times; I've had some bad times. I've had my cancer come back a couple times. I've gone through many rounds of chemotherapy and radiation. It's been struggles here and there.

Dr. Stadtmauer

We're perfectionists. We're constantly trying to tinker with the current therapies, make them better, make them better in terms of their effectiveness, make them better in terms of their side effects, and ultimately to improve the duration and the quality of life of the patients with these diseases. Participation in clinical trials is the way we do this.

Sheriff Todd

I was given some options by Dr. Stadtmauer. I had the opportunity to get involved in clinical studies and also the possibility of an experimental drug that was out there. I responded very, very well to those studies, which I know not only helped myself, but helped others.

Laura

Even though I may be cured or free of the disease, as they say, there are still instances where I think I have it again, that it's come back. And so that's a time when I would definitely need to talk to Lissa to sort out my feelings. Why am I feeling that it's back? I have a pain in my shoulder. Could just be a pain in my shoulder. But little things like that. And just to kind of ease the fear and taking those positive steps. Well, go to the doctor. Go see your doctor. Go get a blood test if you're that scared.

Lissa

Cancer is never really behind a person. It's never really over. The medical treatment is over, the disease process is over for many, many people, whether it's cure or remission or disease-free. The medical part of cancer is over, but people are forever changed. So, the cancer medical experience ends, but the cancer journey, as they say, never really ends because people are changed and people carry that with them.

Dr. Stadtmauer

I am very happy when I see a patient that I treated a decade ago who's doing well. I mean, what could be a better positive reinforcement of what you've been doing? I really have them come back to make me happy, but it also gives me a good opportunity to reinforce what they've been through, and to really make sure there isn't any long-term side effect of something that is happening that I can help with.

Sheriff Todd

I do talk to a lot of people that have been diagnosed recently. I try to give them the good roads, the bad roads, the good signs, the bad signs. One of the things I have to tell them right off the bat and I tell the family is Dr. Stadtmauer said to me the one day, he said, "Sheriff, I have to tell you this. It's going to get a lot worse before it gets better." A lot of people don't want to hear that, but it's good to know ahead of time so that you recognize that fact.

Laura

In the scheme of life, how many years you have, what I went through. I mean, it was a huge deal as you know, it changed all of our lives. But in the scheme of life, it's a bump in the road. You're going to get through it.

Sheriff Todd

Every day is a new day. That's the key. Every day is a new day. And it all depends on how you yourself treat that day. And the one thing you need to really remember too is we're always talking

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about the patient, but it's also the caregivers. It's also those people that are out there that are behind the scenes that all the time are there that give us that strength, that give us that motive, that give us that hope to continue to move forward.

Laura

I couldn't have gotten through that period of my life when I was so sick without this guy sitting next to me. I said he was my rock, and he still is. It's pretty awesome and special. And I don't take any of it for granted.

Narrator

For more information about myeloma, leukemia, or other blood cancers, as well as disease, treatment, support information, and resources, please contact an LLS Information Specialist at 1-800-955-4572 or visit us on the Web at www.LLS.org/InformationSpecialists.

We welcome your feedback!
Please complete the evaluation for this program at
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