

## S1E3 – Activist

### Transcript

**Terri:** [00:00:01] So there's the story. A lot happened in my life because of that. I'm no longer married to the same person and my son still struggles. If he sees me catch cold, he's afraid something's wrong, something's going to happen. The big mistake here was, I'm not stupid. I was running a business school. I'm a businessperson. But I totally panicked when I got sick and I left it up to everybody else. I stopped following my instincts. I stopped asking questions. I put my health care in their hands. And that's a mistake. Humans make errors. And we have instincts and gut feelings for a reason. Did you want to ask questions or do you want me to just keep going?

**Narrator:** [00:01:03] The Canadian Patient Safety Institute presents *Patient*, a nonfiction medical podcast about the people trying to fix modern health care from the inside out. My name is Jordan Bluman [ph]. There are easier ways to make an activist than what happened to Terri Savo [ph]. And we're going to tell that story in just a second. But while a lot of people right now rightfully are thinking about health care and the kind of health care systems that we want, that jump from paying attention to taking action is a really big one that a lot of us struggle to make. We care, but we don't know what to do with all that caring. So we're going to tell the story of someone who made that jump. Her path is not necessarily one you'd want to follow because it involves a lot of hardship and a lot of loss. But it tells us something about the relationship between experience and activism. That story starts in a school: Terri's school, but not a school that she went to.

**Terri:** [00:02:20] I owned one.

**Narrator:** [00:02:21] You owned a school?

**Terri:** [00:02:22] Yeah. It was an awesome opportunity. I worked at a business school that was doing bad practices and it was shut down by the governing body for private colleges. And during the shutdown, they asked for my input on what was happening, et cetera. And the commission came up to me and said, "Gee, we could really use a school out here." And I laughed and said, "Sure, you could. You're not looking at me, are you?" Next thing you know Aboriginal Business Canada was contacting me and offering me a grant and the Tale'awtwx Aboriginal Capital Corporation was contacting me, offering me a fabulous business loan for which only half I had to pay off. And anyway, before I knew it, I owned a school. It was a quick lesson in everything to do about business. It grew quickly. I had great staff, but I was working six or seven days a week. My son was two and a half when I opened this school, so I had a family and a home and a

school and I was working pretty hard. So unfortunately, I got sick. Do you want to ask questions or do you want me to just keep talking?

**Narrator:** [00:03:48] You can keep talking.

**Terri:** [00:03:50] Yeah. I was 43 years old. Both my mother and my grandmother had died at the age of 36 and 40 respectively. We knew they died of heart failure, so I was quite aware that I had a history there. I made sure all my doctors knew the history whenever I changed doctors and moved and whatever. And I was well-entrenched in the idea that they would remember that every time they saw me. So after about five years of running full steam, I went away for a retreat with a colleague. And Friday night we arrived and I got sick; I was delirious. I spent the weekend running hot and cold, not knowing where I was. And Sunday afternoon, I woke up and thought, "Oh, that was a horrible flu." I got dressed and came home and went back to my normal routine.

[0:04:56] During that following year, things started to happen. I started getting gaining a lot of weight. I was sweating a lot, something I didn't do a lot. I wasn't a big sweater. So I was sweating a lot. I had a lot of chest congestion. I was slowly getting more and more tired. I was very fatigued. And I was seeing my doctor regularly, so it was being misdiagnosed all the time. She sent me everywhere. I went to see a gynecologist at one point.

**Narrator:** [00:05:31] That word Terri used, "misdiagnosis," doesn't really cover it. What followed was a saga and misdiagnosis. "You're allergic to your dog. You're going into pre-menopause. It's smoking. You're congested. You need more exercise. You're working too hard. You're just getting older." Every possible answer under the sun.

**Terri:** [00:05:52] But never the fact that I had this horrendous heart history with my grandmother and my mother both dying before they were 40 of heart failure. So it was totally missed until I finally told the doctor after three visits in one week that tapping my back and tapping the front of me and the back of me wasn't enough; "I think I need a chest X-ray."

**Narrator:** [00:06:20] Terri insists on getting an X-ray and reluctantly, her doctor orders one.

**Terri:** [00:06:24] She said, "I don't think you need one. I think you just need to stop working so hard."

**Narrator:** [00:06:28] Terri gets the X-ray and is then told to go get an EKG, which is a test that records the electrical activity of the heart using electrodes placed on the skin.

**Terri:** [00:06:37] And when I went for the ECG, they smiled and handed me an envelope and said, "Could you walk over to the hospital and check in there with one of the doctors?" So when I got there, they were waiting for me. They put me in the emergency and said, "You're in heart failure and we don't know what's wrong."

**Narrator:** [00:06:57] Turns out it wasn't allergies.

**Terri:** [00:07:00] So they brought my family in and told my husband and my child that they weren't sure they could do anything with me, that there was a good chance I could pass away, but that they would try to stabilize me and see what's going on. So they did.

**Narrator:** [00:07:18] They stabilized her. It took three months for Terri to be referred to a cardiologist, three months where she was wondering if she could move or breathe. Three months of waiting and waiting and waiting.

**Terri:** [00:07:38] Really, there was no information for me on what stage I was at, what I should be doing or shouldn't be doing. I just waited. And eventually I went to the cardiologist who gave me the goods and said, "You're on a heart transplant list. Your heart's been damaged."

**Narrator:** [00:08:00] They ran the gamut of tests to see if Terri was suffering from a viral infection of the heart, which she wasn't. However, during that examination, they did find out that there was scar tissue all over Terri's heart, so they started giving her medication.

**Terri:** [00:08:15] So I was very lucky. They treated everything with a fairly new treatment. They gave me beta blockers to slow my heart down. They gave me ACE inhibitors to lower my blood pressure. They put me on very high doses of diuretics to get the water out of my system that I had built up. And within two years, my heart had mended and my heart efficiency went back to 58%. It's a really rare occasion for that to happen. Most people pass away or by that time, if they aren't improving over that little bit of time, they're going to need a heart transplant.

**Narrator:** [00:08:54] Terri was going to live, but for the remarkable good that these medications were doing in getting Terri's heart rate back up to something close to normal, they were also having another side effect, a side effect that defined that period of time for Terri: For nearly two years, Terri was basically asleep.

**Terri:** [00:09:15] And I went to sleep. And I mean, I went to sleep. I was in bed probably 22 hours out of 24 a day.

**Narrator:** [00:09:24] That's Terri in a 2011 video interview she gave on her experience.

**Terri:** [00:09:28] And the only reason why I even got up was because my son was home from school. If I wasn't dressed and sitting up looking like mom, he was scared.

**Narrator:** [00:09:40] So this became the question: Terri is recovering. Her heart efficiency is creeping up thanks to the medication she's on. When she was first admitted, it was about 20% in a healthy person's around 60 and the drugs were getting her there, but they were also putting her to sleep. 22 hours a day in bed; it's impacting her family. So the cardiologist made a call about weaning her off of the drugs, slowly, still monitoring her. And it was in this moment during this handoff from one doctor to another when the trouble booted right back up again.

**Terri:** [00:10:13] The cardiologist decided that she would wean me off some of these heavy drugs so that I could have a life and stop sleeping all the time. So she sent information to my doctor about weaning me off these drugs but never taking me right off of them – there was a bottom line – but monitoring my condition to ensure it didn't change. The cardiologist passed me off back to my GP, basically said goodbye to me and good luck and the GP took over. What happened there was the GP didn't monitor my health properly. Apparently, my blood pressure was going up in increments every time I saw the GP. And at one point, the GP was away and I saw her partner, and her partner reduced my meds again, which were lower than the bottom line. So not only was my health deteriorating, but my meds were deteriorating to lower than they were ever supposed to. And this wasn't caught until I started to gain weight again and decided I needed to be back at the cardiologist. So I returned to the cardiologist and she checked me over and said, "You're in heart failure. What happened? Why wasn't anybody monitoring you?" And back I went on all the drugs. And to this day, I'm still on all of them. You know, you just fight the fatigue. Now you get used to the drug and you carry on.

**Narrator:** [00:12:01] Which is one of those things that people say that is much, much easier said than done. Terri had come full circle. She'd gotten worse, then she'd gotten better, then she'd gotten worse, then she'd gotten better. And the question now is what she was going to do with that experience.

**Terri:** [00:12:16] So there's a lot of fingers I could point there. My GP, when I phoned her, I was really upset and said, "Why were you not monitoring this?" And she had asked me every time she took my blood pressure, "Have you had a coffee or have you had a bad day?" And, "Yeah, I had a coffee or yeah, you know, my son wouldn't get ready for school, so I yelled at him today." And all of that was an excuse for why my blood pressure is up rather than my blood pressure is up and it shouldn't be. You should be able to live your day-to-day life and not keep having your

blood pressure going up and carry on going up. And when I told her that, she said, “Well, it's not all my fault. You should have been looking after that, too.” And it was a huge awareness program. It's like, “Me? You're the doctor.” So there's the story. A lot happened in my life because of it. I'm no longer married to the same person.

**Narrator:** [00:13:28] And that's right about where we met up with Terri.

**Terri:** [0:13:31] My son still struggles...

**Narrator:** [0:13:31] You see, I wasn't there, so I obviously don't know, but Terri's turn from finger-pointing to problem-solving was... Let's just say that it didn't waste any time. And it stands to reason with what we know about her personality. Terri is a businessperson. She owned a school. She's a natural-born problem-solver. She wanted to turn the experience into something productive. Her experience of being a patient was trying beyond the illness itself, and so she saw those gaps in the system that she couldn't help but want to patch. So like any good problem-solver, she sought out to find the best collaborators. She reached out for help.

**Terri:** [00:14:12] Getting involved in Patients for Patient Safety Canada was mainly because I wanted to make sure doctors didn't make those mistakes anymore. When I was sick, I was sick mentally, physically, emotionally. And you know, it was a low time. And my marriage was changing; my business, obviously, life totally dropped out. At some point, I just I got up and said, “I don't want to live like this anymore. I'm negative. It's all the bad things. Somehow I've got to make this positive again. You know, I can complain all I want about how the system did me wrong; or I can help change it. And I don't know where to start with that, but somehow I've got to help change it.” And you know, I read the newspaper one day and there was a young lady who had had harm done to her in Nanaimo, and she decided, at her own expense, to put on a conference and call in whoever she could in the medical system to listen to her. And she just wanted them to hear her.

**Narrator:** [00:15:29] Terri started attending conferences and meeting people, and those people heard her asking insightful questions about what it means to be a patient. And after a while, Terri starts being asked for her perspective as a patient, being asked to attend conferences, being asked to talk to health care practitioners.

**Terri:** [00:15:46] And so after a while I started saying, “You know, if you ask me to participate, if you involve me, maybe I have something valid to talk about. And maybe then I'll also understand where you're coming from.” So from there, I heard about the Patients for Patient Safety Canada, and they were on some higher-level things and some of the stuff they were

doing. So I joined Patients for Patient Safety Canada. And when I was interviewed as a member, I spoke a little bit about that, about not wanting to point blame at doctors and wanting to actually effect change and definitely affect culture. And we were starting to emerge into electronic records and I was excited about electronic records, meant everybody had access to your health history and that would make life easier, et cetera. So I did a few speaking engagements and got some tremendous feedback from the medical profession where I spoke and wasn't now pointing the blame, but was now talking about partnering and talking about listening to the patient and working together as a team. And I had so many people, after both the times I spoke, come up to me and say, "This makes me feel wonderful. This is what I want. As a medical professional, this is what we all need."

**Narrator:** [00:17:32] What patients and practitioners need. Not blame because it feels righteous and not apathy because the problem feels big; the dialogue. Two people talking. Which, for a patient going into a room with a doctor in it, probably means asking questions. Over the course of this mini-season, we keep coming back to this specific topic, of questions. It's a huge idea in the world of patient safety. The five questions you're supposed to ask your care provider. Which again, for those of you that have followed us through the season, are a kind of a formal list embraced by organizations all over the world as a way to understand what it means to go on or come off of a medication. Precisely what Terri went through. So we're going to turn it over to someone who can tell us about those questions and how advocates like Teri think that the right questions can keep people safe.

**Chris:** [00:18:24] Yeah, and I think they're non-threatening questions, too. Often people are afraid to ask. Many people wouldn't say when their doctor walked into the room, "Did you wash your hands before you touch me?"

**Narrator:** [00:18:34] That's Chris Power, CEO of Canadian Patient Safety Institute.

**Chris:** [00:18:37] We all should say that, but it feels like almost confrontational. And so most people wouldn't say that to their health care provider. But I think these questions, they're nonthreatening. They're general, but they will give you such great information yourself to hold on to, to help keep yourself safe.

**Alice:** [00:18:53] My name is Alice Watt. I'm a medication safety specialist at ISMP Canada. I'm also a clinical pharmacist as a hospital pharmacist.

**Narrator:** [00:19:02] Alice worked on the five questions during their creation a couple of years back?

**Alice:** [00:19:05] Well, I think for patients, it gives them the right words and the phrases they can use. Sometimes when you're at a doctor's office, you feel pressed for time, and having a list of questions prepared for you encourages them to ask the questions and talk about what they want to understand. It starts a two-way conversation and encourages everyone to be more involved with their health care and take more accountability and responsibility for their health care.

**Chris:** [00:19:32] They are, you know, "What changes? Have any medications been added, stopped or changed and why? And should we continue? What medications do I need to keep taking and why?" Then the question, "What's the proper use? How do I take my medications and for how long?" Then the monitoring question of, "How will I know if my medication is working and what side effects do I watch for?" And then the whole follow-up, "Do I need any more tests and when do I book my next visit?" So those five questions have been translated into many, many different languages, are being used all around the world, and are getting great press, and we're thrilled about that because questions do save lives. We know that. And, you know, in Canadian health care, we still have a huge deference to physicians and to nurses and to our pharmacists. Many of us think they know best and so we don't feel that we should be asking questions or we don't even think about asking questions, but it's so critically important for us to understand. I think we all have those stories where our grandparents or our parents or somebody we know, we say, "What medications are you on?" They say, "I don't know, it's a blue pill." You say, "Well, what is it for?" "Well, I don't know. The doctor just told me I should take it." We as individuals, we so desperately need to know what the medications are for, what their side effects are, why we're taking them, how long we should be taking them, because medications are the number one harm that happens to patients. When medications are missed, when the wrong medication is given, when there are side effects that people don't know about. So it's really critical for us to be asking those questions. And we think these five questions are easy ones for people. We can have them on a little sheet of paper. You can have them in your wallet, wherever you are, so that when you're having any interaction, you ask these questions and help keep yourself safe.

**Narrator:** [00:21:28] You can find those at [Patient Safety Institute.ca](http://PatientSafetyInstitute.ca).

**Terri:** [00:21:33] I did take a year off to find out who I was. I really needed to stop being the patient person for a while. My son was in university and I needed to stop being a mother and I needed to just run away and find out who I was. And it was the best thing I ever did. And I came back and started a consulting company.

**Narrator:** [00:22:00] Terri started a business and she put herself back out there. And over time as things began to quiet down...

**Terri:** [00:22:06] And so there's less work and I thought, "Oh, this is a good time to get back to Patients for Patient Safety Canada." And it just so happens they were looking for a new chairperson, so I offered up my services and I'm really happy to be back. It's great to be involved again.

**Narrator:** [00:22:24] Which brings us here to our conversation with Terri. Not Terri, the patients; not Terri, the activist; not Terri, the mother; not Terri, the wife. Terri.

**Terri:** [00:22:36] A girlfriend of mine has a townhouse condo sort of thing in Arizona. And I had helped her out through a difficult time. And she said, "I wish I could pay you back in some way." And she came up one day and she said, "Would you like to come to Arizona and hang out?" And I said, "How long can I go for?" And she said, "As long as you want. The place is yours for the year." We get lost in being a wife and a mother or a husband and a father, and we get lost in our mortgages and our positions and our jobs. And it was just perfect timing. I got my motorcycle license at 57. I bought a motorcycle. I became a new person. I just went out, you know, just did a few things that I probably never would have done before and just figured out who I was. Here I am.

**Narrator:** [00:24:09] This season of *Patient* was produced by the Canadian Patient Safety Institute. As we wrap up this little three-episode season, I just want to thank anyone and everyone we spoke to. Your insights were enlightening and your stories were honest and humbling. If you want to learn more about the world of patient safety, we just barely started dipping our toes into this season. And to find out how you can help keep patients and people safe, visit [Patient Safety Institute.ca](http://PatientSafetyInstitute.ca). *Patient* is produced by Scott Winder, Cecilia Bloxham, Carla Horam and myself, Jordan Bluman. Thanks for listening.