

TRANSCRIPTION

cpsi Canadian Patient Safety Institute
iscp Institut canadien pour la sécurité des patients
Dennis Maione
Patients for Patient Safety Canada

[0:00:10] This is my story of a more than 20-year journey through health and health care, through sickness and the heroes and villains that were part of my journey. I have a genetic predisposition to cancers, something called Lynch syndrome, specifically MSH2 variety. So when I was 27, I had my first cancer. That was 1992. And again when I was 42, I had a second cancer. That was 2007. And the nature of my cancers mean that doctors don't always know what to do with me. For everybody who has Lynch syndrome, at least the MSH2 version like I have, 80% chance over your lifetime of having at least one colorectal cancer. Most of them show up early when docs aren't looking for them because we don't start screening until 50, 55. And that's because typical spontaneous colorectal cancers take a while to develop. People with Lynch, they're fast.

[0:01:09] I was living in Regina the first diagnosis in 1992. I had been married for less than a year, didn't have a doctor because I was going to school there. So I went to a walk-in clinic. Took six weeks to figure out what I had because the guy – and reasonably so – wasn't looking for colorectal cancer in a 27-year-old. He finds this mass, sends me to a specialist. I sit down in front of the specialist and he looks at my reports and he says, "Well, how the hell did you get this?" I said, "Well, I don't even know what I've got." He says, "Well, it looks like you got a mass. Let's do a biopsy. We'll check."

[0:01:45] So we did a biopsy in his office and a week later he calls. "Come down to the hospital where I am. Bring your wife." The surgeon is on one end of the table. He's closest to the door and he has us sitting on the other. And he says, "You've got cancer. I'm going to have to give you a colostomy. As a result of the surgery, you're going to be impotent. And don't bother getting a second opinion, because I've consulted with all the cancer care docs here in Regina, and this is the way to go." He treated me like I was a disease. Here's this thing. We're going to get rid of it. And you ought to be overjoyed because I'm going to remove this cancer from you.

[0:02:15] And I phoned a friend of mine in Saskatoon, a doc, and I said, "This is what I've been told." He says, "Come on up. I have someone who can look at you." And it was a really different experience. I sat with this man and he drew me a picture of my large intestine. He did a manual exam. He said, "Here's where the tumor is. You know, I can't guarantee a different result, but you have a long life ahead of you and nothing I'm going to do is going to grow back."

[0:02:45] My surgery took two hours longer than it was supposed to. Everybody in the waiting room and the waiting area are all worried. They said there was a couple of times when he just about gave up, did the colostomy because he cuts everything and gets the tumor out and he tries to get his hand down into my pelvis. And men's pelvises are narrow and he's fighting with this piece of skin that he's trying to pull out and reattach. And he said, "I just kept thinking. I just kept thinking about this guy on this table and the life that he had ahead of him," and how he wasn't going to give up until he couldn't do anything more. Yeah, he removed a tumor from me. He sewed me up. Best surgeon I ever met. He did more healing by touching me and telling me it was going to be okay than – anybody could have cut me. Anybody could have taken the tumor out. But he did something there, something that made him the hero for me.

[0:03:45] When I was first diagnosed with Lynch syndrome, I already had kids. What they found is that people with stage two cancers who get adjuvant chemotherapy who have Lynch do worse if they have chemotherapy than if they don't. Oh, that's troubling. Meantime, I'm meeting with my with my oncology doc and he says, "Yeah, we're going to start you on this oral chemo." Armed with this paper, we come into my oncologist's office and say, "Look what we found. We found this stuff." "Not clinically relevant," he says, Do tell. What do you mean? "Not clinically relevant?" So no matter what we did, what we got was, "Talk to the hand. Not clinically relevant, not going to engage you." I didn't want to be my own oncologist. All I wanted was somebody to talk to me like I had some sense, like I had some clue, like I could read, like I could look at charts and see that five-year survival rates were different, and I wanted to talk to somebody. Not a chance.

[0:04:49] So now we go back to this hero-villains contrast. I have had maybe 30 minutes in total of interaction with him over the past almost ten years. My impression of him, he's a villain. I can't say that. I can't say that that is the intrinsic quality of him. But somehow, that's him for everybody, but that's him for me. That's him for me because he wouldn't engage with me. I was a frightened patient with no sense for what I was supposed to do, and I just wanted somebody to walk me through the process, to tell me that it wasn't ridiculous for me to think the things I was thinking. Maybe I'm different. Maybe there's something about me, my genetics, my biology, my physiology that makes treatment different from me. That's what I wanted. And I couldn't get that from him.

[0:05:39] My wife is not going to have this. So she starts to do an investigation. They find more articles. She wants a second opinion. We've asked my oncologist whether or not there are experts in Lynch in Canada. Is there a centre of excellence, a place where people go? "No." Well, we find it. It's Princess Margaret Hospital in Toronto. They have a hereditary cancer group there. Oh.

[0:06:15] Go in to see my oncologist again. Can we give this doc a call? "No, what would be the point?" Well, the point might be that an expert could tell us. "No, not doing that." I could get drugs, I could get chemotherapy. I could get follow-up every six months, every year. I could get that. I could get CT scans. I could get all of those things. But I couldn't

get engagement. It wasn't about expertise. It wasn't about treatment. It was about him engaging me as a human being with some sense for myself, for some sense for who I was and what my body was like.

[00:06:53] Well, we finally got everything all in order, flew to Toronto, sat down with the doctor who had written the paper. We talked to him, and I said, "What do I do?" And he said, "Well, if it was me, I sure wouldn't take chemo." That was it.

[0:07:10] And without my wife and the work that she did, I wouldn't have found out any of this stuff. I'm smart, but I'm not smart as her. And I'm tenacious, but I'm not as tenacious as her. And so for me, really, the strength comes in the people who surrounded me in my experience.

[0:07:31] I joined Patients for Patient Safety Canada because it was a way for me to do advocacy in a larger sphere than what I was doing. I have only a small network. I can talk to people. I've been able to walk a couple of people through the experiences that I had. But my area of reach might be 100 or two. With patients for Patient Safety Canada, the reach is bigger. Each of us that has a story can tell our story to a wider audience nationally, perhaps even bigger than that. We can mentor new docs better than we're doing. We can teach them better.

cpsi Canadian Patient Safety Institute
iscp Institut canadien pour la sécurité des patients
PATIENTS FOR PATIENT SAFETY CANADA
PATIENTS POUR LA SÉCURITÉ DES PATIENTS DU CANADA

FIN