

TRANSCRIPTION

cpsi Canadian Patient Safety Institute
iscp Institut canadien pour la sécurité des patients
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[0:00:09] My story about Chris's experience, which I think is more common than most people are prepared to acknowledge, is a story of failures to intervene at the appropriate time, which has resulted in some personal suffering, but also a great deal of cost to the health care system that could have been avoided with good primary care. Chris was always very happy, always cheerful. As a child, they used to call her sunshine because she was always smiling. And she was like that right through her life until the very end, really.

[0:00:47] Chris first had a problem back in the mid-eighties. She had a thyroid cyst. We were referred by the family doctor to a surgeon who removed the cyst, but also that part of the thyroid on one side of her neck. And he told us that she would have to, as a result of having half a thyroid out, would have to take Synthroid for the rest of her life.

[0:01:13] About six months after the operation, the doctor's office rang up to ask her to go in for a blood test. And she said she didn't really need it because she felt perfectly well. And that was the last we heard of it until the mid-nineties when she was rushing to go out and she was jumping her feet in her sandals and she tore off her toenail, but she didn't notice that she had torn it off until she got back and took the sandals off. And we realized that not feeling the fact that you'd torn a toenail off was probably quite serious.

[0:01:56] Eventually, we found a general practitioner who agreed to take her on. He was a very capable young man, but he realized that this is indicative of something serious, and he sent her off to see a neuropathies and an endocrinologist, and they eventually found that she was hypothyroid. She'd also develop diabetes and diabetic neuropathy. In other words, the nerves in her legs and feet had just been killed off, and that's why she didn't feel the toenail coming off.

[0:02:28] Now, it was only at that point, some ten years after the initial operation, that I found out that if you've got a thyroid condition, you're supposed to be going in for tests every six months to monitor the status of it. And while the doctor's office did ring us six months afterwards, they didn't explain the purpose and the risk of not taking these tests. And Chris felt perfectly well.

[0:02:59] The next step in this story is in late 1999, Chris felt there was some minor swelling of her foot, and she said she felt a pricking sensation in her foot. By this time, this

excellent young GP that we'd found had quit and so she was without a general practitioner again. But we had an appointment with her, a regular appointment with our endocrinologist shortly after she noticed these symptoms. And so when we went to see the endocrinologist, we told him about this and he said, "Oh, well, don't concern yourself. It's just a secondary condition of neuropathy." And she said, "Well, shouldn't you take an x-ray because I've got this pricking feeling and I shouldn't have any feeling at all in my foot?" And he said, "Oh, don't worry about it."

[0:03:52] And it gradually got worse. And then she started developing diabetic ulcers and they started to treat her with intravenous antibiotics, which worked. The ulcers cleaned up and off she went again, still with some sensation in her foot. But then the ulcers came back. So she had these repeated treatments with intravenous antibiotics, and the ulcers kept recurring.

[0:04:22] And so the diabetic clinic nurse got involved. She said, "Just take her into ER at the teaching hospital." So we did. And once the x-ray was produced, she got to see the infection specialist who, without looking at the x-ray, just looked at her foot and said, "Oh, you've got a shark on foot [ph]." Now, what a shark on foot is, is it's a compound fracturing of the bones in the foot. And it results because you've got diabetic neuropathy. So the infection specialist in the ER referred to the orthopedic surgeon. The orthopedic surgeon was telling me that she absolutely had to have a hospital bed because if this wasn't treated, if she didn't get off her feet and got treated immediately, she risked losing the foot altogether.

[0:05:14] But about 18 months after the shark on foot incident, she developed another infection in one of the toes. The orthopedic surgeon said she would certainly have to have the toe removed. But in 2008, after I'd retired and we'd moved to Niagara, she again got diabetic ulcers on the shark on foot. And so we went into hospital through ER and they found she developed sepsis as a result of the infection, which they cleared up with no problem, but they couldn't get the infection out of the bone. So they decided she'd have to have a foot amputated. And that amputation was done.

[0:05:59] But she still was cheerful and smart until mid-2011. It was around mid-August. She first showed some signs of confusion, but she was very reluctant to go and see the doctor. I did persuade her to go. He explained to her that she probably had either Alzheimer's or had had a mini stroke, or she could have a urinary tract infection, which is called UTI. And so one morning, her blood sugars were so low and she looked so ill, I just called ER and they took her in and they diagnosed her with UTI. But she did get better and she was fine for about a week after she'd finished with the antibiotics, and then she started to show symptoms which were quite different. It's so difficult under those circumstances. I mean, there were some days when I thought she was getting better and then the next day she would be, you know, in really bad shape and just stare into the air.

[0:06:58] And the hardest thing was I wasn't there when she died. She died about 5:00 in the morning of heart failure, apparently. And one of my medical relatives in Europe made some reference to UTI and the danger of sepsis following UTI. So I looked this up on the net, and apparently, people of Chris' age – she was 75 five days before she died – are particularly susceptible to UTI, particularly if they have diabetes or other chronic conditions. And she'd been seen by at least eight doctors who all not considered the possibility of sepsis.

[0:07:44] So I asked to see her nephrologist and he agreed to see me. And, hard pressed as he was, he nevertheless spent almost an hour. He got the hospital records for her and went through them diligently. And he said, yes, she almost certainly did die of sepsis.

[0:08:07] The biggest lesson I think I've learned from Chris' experience is that the doctors failed to really involve Chris in her own treatment. They've got to try and anticipate your ignorance and tell you what you need to know, encourage you to ask questions, encourage you to get involved. You've got to do it one step at a time and explain what you think. Everybody knows the fundamentals, but you have to be able to do this to help patients understand their condition and what they should be doing.

[0:08:42] One of the other observations I've got is that once somebody is diagnosed with chronic conditions at the primary care level, they should not, as Chris was for quite some time, be left without a family doctor, but they should be assigned to family doctors who are knowledgeable and experienced in dealing with those conditions.

[0:09:11] In addition to that, I would say that once having made a mistake, the health care system should have a protocol in place to make sure that they don't make, as they did in Chris' case, repeated mistakes.

[0:09:30] I think her upbringing was a little old-fashioned, hence her insistence on being elegant. I used to tell her even when she was in the wheelchair, because she used to say to me, "Aren't you embarrassed by taking me to a restaurant in a wheelchair, you know, with a foot off?" I said, "Embarrassed? Why should I be embarrassed?" I said, "I'm really proud of you, that you just carry on." She was a really very active person until she got the shark on foot. But that was the other great thing about it. She never let this sort of change her attitude. She just accepted that she couldn't do these things and did what she could and was happy doing it. She was quite inspiring.

[0:10:08] You have to believe that the system can be changed both from the inside and the outside and keep fighting, because without that, we are not going to make it better. Just accepting the situation as it is and trying to struggle on is not enough.

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