

TRANSCRIPTION

cpsi Canadian Patient Safety Institute

iscp Institut canadien pour la sécurité des patients

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Patients for Patient Safety Canada

[0:00:10] I'm here to tell the story of my delayed diagnosis of colorectal cancer, which occurred as a result of a series of miscues and mistakes and omissions made along my diagnostic pathway. I presented to family physicians with alarm symptoms of colorectal cancer. I saw four doctors, one, two, three family physicians, and a general surgeon. Each one missed, belittled the symptoms I presented with, and so a diagnostic endoscopy that should have happened within 60 days, by best practice standards, happened in 661 days.

[0:00:44] I had gone on a trip to Scotland with my mother and sisters, and my mother had had colorectal cancer about ten years before. So that's why we were in Scotland. We were celebrating my mother being ten years free of colorectal cancer. Just prior to leaving on that trip, I noticed that I had started to have rectal bleeding. And so I booked an appointment with the doctor and the day I got back from my trip to Scotland – I'd been continuously bleeding for three weeks throughout the holiday, which was disturbing to me – and when I saw doctor number one, doctor number one was a locum for my regular family doctor who I'll call doctor number two.

[0:01:21] So, doctor number one, I saw right away. And doctor number one said, "Oh, not to worry, this bleeding is likely the result of an antibiotic you'd taken about a month previous. It's just an antibiotic reaction. No need for follow up, no need for return appointment." And the symptom went away.

[0:01:45] But then it came back. After about a month and a half, it came back in October at the beginning of October. And I went then to see doctor number two was my regular family doctor. Someone who had been my family doctor for 15 years at the time. And so with doctor number two, by then, the symptom had progressed beyond mere bleeding onto I was actually – and this is kind of gross – but I was shedding skin too, like I was actually bleeding skin. So my intestinal surface was being sloughed off as the cancer was developing. And I told her that. She documented it in her EMR. I reminded her of my immediate family history of colorectal cancer. And she said, "Yes. Yes, I see that." But she said, "Well, I suspect that this is just an antibiotic reaction."

[0:02:38] She wrote a letter to a general surgeon who I'll call doctor number four. And in that letter to doctor four, it was a letter that said, in essence, "Rectal bleeding. Please assess." She didn't say anything about my family history. She didn't say anything about my symptom severity, which was quite advanced by that time. And she didn't say anything about the nature of the bleeding, the stage of the bleeding, any other aspect of it. So, you

know, blood mixed with stool is an alarm symptom for colorectal cancer that merits immediate endoscopy, well, at least within 60 days by all practice standards. But without correct guidance, specialists are not going to know that.

[0:03:18] So when I went to see doctor three, I had a positive cancer screening tests on record, and seven months, by now, of bleeding and serious symptoms. So I said to him again, you know, I have this family history, I have these significant symptoms, I have all this. And his response was, "Well, you know, you need to have a colonoscopy. Colonoscopy needs to be done by a specialist. I'll check with doctor number four to see what's going on with that." And of course, because he's my colleague, I think, "Oh, great, I'm finally in the care of someone who's going to do something for me and help me." But I was wrong about that because doctor three did nothing at all. He forgot to take action.

[0:04:07] And somehow, in the EMR, his EMR, the instruction to follow up with the surgeon was checked off as having been completed, when in fact it was never completed. So neither he nor his secretary nor anyone in the office ever made any attempt to contact the surgeon at all.

[0:04:26] Meanwhile, the referral that had been sent by doctor number two went to doctor four's office. And this came out later. The College of Physicians and Surgeons did an investigation into my care. And one of the things that was revealed in the course of that investigation was that doctor four, general surgeon, it had been her practice for many years, as many as 20 years, to have her receptionist triage her referrals for endoscopy and for other things.

[0:04:49] The best practice standard for when a person comes into a family physician's office with alarm symptoms of colorectal cancer, which are going to be deficient anemia, rectal bleeding with blood mixed with stool, dark red bleeding, any of these features, all of which I had, it should be 60 days. From the day I walked into a family physician's office with alarm symptoms of colorectal cancer to the day I received a diagnosis of a stage three, possibly stage four colorectal cancer, was 669 days. So almost two years. It was two years from the day I went to doctor number one to the day I was getting chemo, radiation treated, that was two years exactly.

[0:05:26] Months go by. And then the day comes when I do go for this scope. And this tumor that is seen is almost entirely circumferential, huge bulging, bleeding, tumor, bleeding so much that it's bursting its own blood vessels, it's growing so fast. And yet, doctor four who sees this tumor on endoscopy does not tell me about it. Sends me home telling me, "Well, there's a growth there," but she doesn't tell me. And I'm on the very brink of obstruction. So only a tiny little bit of ability to get the digestion through there, and this huge, huge – by then, it was the size of a grapefruit. This was its final measurement. So I eat normally over those eight days, eight days 'til she finally tells me it's cancer. I eat normally over those eight days because I don't know not to. I don't even know that I've got a lethal disease.

[0:06:25] So eight days later, she tells me, and yet, doesn't give me any guidance around what to do about a tumor like that. By the time I get to radiation, the radiation oncologist said, "Oh my God, you have an x-ray here. You have eight days of digestion that hasn't made it past that tumour. You're going to need an emergency permanent colostomy in the next 24 hours." And fortunately for me, within those 24 hours, I was able to arrange a consultation with an expert surgeon who said, "Look, I can keep you alive. You've got to do exactly what I tell you to do over these next five days. I'll get you to radiation, and radiation will shrink that cancer down to a safer size."

[0:07:02] One of the things that my cancer doctors told me later, they told me that the symptoms I had initially presented to doctors one, two, and three had been those of an adenoma or a precancerous state. Had I had timely investigation, I might have missed cancer altogether. I wouldn't have had to undergo any of those things, apart from a polypectomy or some kind of surgical removal of whatever was going to develop into cancer, which is a day surgery. It's an easy thing.

[0:07:29] Colorectal cancer is one of the most preventable cancers there is. It's right up there with skin cancer of being highly preventable. I would not have had to go through chemo. I would not have had to go through radiation. I ultimately had to have two surgeries. I would have avoided all the many complications I experienced and all the rest of it. I was off work for two years. And there's all the income that we lost. There's all the time we lost as a family. There's all the harm done, not just to me but to my family as well.

[0:08:03] It was totally devastating. It was devastating on all levels. It's devastating to learn you have cancer at all under any circumstances. But to find out that you've lost your chance against it. It cost me so much in terms of my life and my family and everything. And all of that was entirely preventable. It was entirely preventable had any one of them done their jobs. And one of the things that became clear in the College investigation is that each doctor assumed some other doctor would take responsibility for the case. So in the end, none of them did.

[0:08:35] My sister's a Buddhist and she gave me Buddhist prayer flags to tie to my backyard fence. You know, as the wind blowed across the open dikes, which is an open field in my backyard, it would blow the flags towards the house as if the prayers were coming in through the house. And there were prayers being given from the community and good thoughts and support all round.

[0:08:53] The flags eventually got quite tattered in the wind from that, but they were, many times, a sort of source of strength or solace. When, at one point, the government phoned me to say, "We are refusing to allow you to have this medication you're lobbying for," and I went to the window and pressed my head against the cold glass and just looked out, and there's the prayer flags blowing towards me. And I'm thinking, "I need those prayers. I really need those prayers right now."

[0:09:20] The way I've chosen to kind of live my life after these events is to really, really get into patient advocacy on many levels. And so I've been very, very active with Cancer Care Nova Scotia, ultimately serving on as many as six expert working groups aimed at improving standards of cancer care. So that's improving standards relating to the treatment of cancer, but also to patient engagement, patient education, all kinds of other things. It is possible for even the most harmed person to sit down and discuss things dispassionately, sensibly, going over the research literature, whatever, to kind of take health care in the direction it needs to go.

[0:10:01] So I think doctors are often very afraid of patients at all, in terms of patient engagement, but particularly afraid of harm to patients, but they don't need to be because we are people who have the passion to make a difference. And it's the passion that's going to turn things around in some of our systems.

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