

# TRANSCRIPTION

**cpsi Canadian Patient Safety Institute**  
**iscp Institut canadien pour la sécurité des patients**  
**Theresa Malloy-Miller**  
**Patients for Patient Safety Canada**

**[0:00:09]** My story starts certainly with Daniel, my son Daniel, in January of 2003. At that time, he was just, you know, a regular teenager, very bright. Just finished application to university. It was just after New Year's Eve. He looked like he had a cold. And that was a Saturday. And then by the Sunday, he was really sick and he was throwing up every 45 minutes. And he just wasn't getting better.

**[0:00:46]** So by the Monday morning he was sicker than – because he's a normal, healthy kid. He was sicker than we'd ever seen him. And I had sort of done, you know, everything I could think to do. So we went to emerge in the local hospital. They saw him really quickly and they felt he was dehydrated and they did some blood work and thought he had enteritis. And he had a really high heartbeat of 140 beats a minute. And the physician in the ER came back and he checked it because that's unusually high. And I asked him about it and he said, "Oh, it's probably just part of dehydration." And Daniel's still throwing up.

**[0:01:34]** And we never did hear about the blood work. And I just assumed, well, if they didn't tell us, it would be fine. We went home and then the next day, he got worse. His breathing started to get really unusual and he was up for all the next night. We went back to the emerge. So this was Wednesday.

**[0:01:59]** So we went in and the attending physician saw him again quite quickly. They did more blood work and they decided that he had hepatitis. A medical student came by and was interviewing him. And by this time, Daniel just didn't want to talk to anybody anymore. And the medical student said, "Have you gained weight in the last couple of days?" And Daniel looked at him and said, "I've been throwing out for three days. What would you think?" But the medical student didn't explain why he'd asked that. And we just thought, "Oh, gee, that's a really curious question to ask."

**[0:02:45]** So this just kind of carried on. They were giving him fluid. His blood pressure was going up and down, his temperature. And we kept asking, you know, "What is going on?" And they said, oh, I think the equipment's not working. So they would change the blood pressure machine, got a different thermometer.

**[0:03:05]** So then they decided to admit him to the pediatric inpatient floor. So we went and chatted with the nurse and said, "We're thinking we're going to go for a little while, just get a little bit of sleep, and we'll be right back in the morning." And she said, "Oh, don't

worry, there's lots of docs around. He'll be fine." And we'd been home only a couple of hours and the phone rang and it was the hospital saying, and the nurse said, "We've moved Dan to the intensive care unit. You know, don't worry. They just have better equipment. We want to help him with his breathing." And she said, "Don't rush, he's fine."

**[0:03:37]** And so we raced to the hospital. And we got there and as we were coming in the ER doors, there was someone waiting for us, which we thought was kind of unusual. So we get into the intensive care unit and a resident meets us and she says, "It doesn't look good." And I just said, "Oh, what is going on?" And she didn't really say much more. And so she leads us to where Daniel is, and they're trying to resuscitate him at that point. I think we're just yelling out, "Daniel, you know, you got to come through this." And they sort of took us away and that was it. He was just gone.

**[0:04:30]** And it was like someone just had ripped our insides out and threw them on the floor. And it was just done. They gave us a little wooden box with his stuff in it. And we walked out of the hospital and it was bright and sunny and people were coming in with their kids. Finally, the senior attending physician, as we were leaving, he came and he said, "You know, we think he had myocarditis, which is a heart infection." We couldn't believe that this healthy kid in three days could be gone.

**[0:05:04]** So we started to read about myocarditis and read about dehydration. And we just had a ton of questions. We had heard nothing from the hospital. We got Daniel's hospital file. And the weight gain that the medical resident had recorded was there, and it just didn't seem to go anywhere. It was noted on his chart that he was in renal insufficiency, and they hadn't shared that with us. And it just went...

**[0:05:38]** And the culminating thing was in the ICU, a nurse had cautioned – there was a resident. There was no attending physician there; there was a resident. And a nurse had cautioned him twice about – he had elected to give Dan a sedation to insert an arterial line. And the nurse said, "We don't have a detectable blood pressure on Daniel. Are you sure that's a good idea?" And she recorded that. She cautioned him twice. And he went and had and did that. And we looked at the effect of that medication is to increase respirations and slow the heart rate and essentially put him into heart failure. And the effect of that drug is three minutes. And after they gave it, three minutes later, he had a cardiac arrest. And so that was the final straw.

**[0:06:26]** After reading his file, I think before, we were destroyed. And after that, we were furious. We were not doing this as research for a lawsuit. We desperately needed to understand what happened to our healthy son and why he was gone. And we knew we couldn't get back, but we thought we could help to make sure that this wouldn't happen again.

**[0:06:49]** To have that validation, to hear that that was not okay, that's not the service we aspire to give to people, so it gives meaning to Daniel's story and it gives hope that they

will now have the energy to look to do something different. So they talked about the things that they had done differently, that they had a standard protocol for children who came to the ER, and if there were abnormal blood values, they had to be repeated before the child was discharged. They had a standardized protocol for fluid resuscitation for children. They increased the charge nurses, which I don't really know which charge nurses, but they did in the ER to just promote communication between physicians and nurses. They standardized the blood pressure machines and they reviewed the sedation guidelines. They set up a module about myocarditis and reviewed that with medical students and residents and nursing students and staff just to make that visible.

**[0:08:00]** So the director of nursing, from that point, she took it as a project of her own to set up a patient safety conference, which would be the first in London. And she asked us to speak at that conference. And it was received very well. And from that point, I joined the planning committee for the conference. And most recently, I was invited to join the corporate quality council for the hospitals, because they would like to have a patient representative on all their quality councils that they're starting out. So they've come a long way.

**[0:08:41]** The message from Dan's story – and I think it comes back to respectful communication – that in so much of those few days, we felt we were asking lots of questions, but it was like asking questions in a fog. There didn't seem to be a system set up that was ready to listen to what the family had to say. And as we worked through the all of the reports, the College complaints that we did, I got that sense that nurses felt that they were saying the same thing. “We weren't being listened to.” And in health care settings, there has to be a system that supports everyone to feel respected, and then to have the confidence to communicate what needs to be communicated.

**[0:09:35]** Daniel, he was just an amazing kid that my husband, Tim, and I always knew that he was smarter than us, and that the only edge we had was experience. He had a large group of friends. He would help them with their homework, played competitive hockey, played lacrosse, he played soccer, he played electric guitar, and he always wanted to play the drums, which we had kind of discouraged. Daniel's a big part of our life, and so we carry Daniel's story and we're quite happy to do that. And he's always going to be our son.

**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