## **TRANSCRIPTION**

## cpsi Canadian Patient Safety Institute iscp Institut canadien pour la sécurité des patients Johanna Trimble VANCOUVER, BRITISH COLUMBIA

[0:00:06] This event began in 2003. It involves my mother-in-law, Fervid Trimble, and she was a resident in a seniors complex living in her own apartment. Pretty happy and healthy.

[0:00:22] I want to tell you a little bit about Fervid. She was raised in an absolutely dirt-poor wheat farm outside of Chinook, Alberta. She lived there for a few years with her family. And I've seen pictures. They were poor. They moved eventually to I think it was Idaho. And Fervid managed to put herself through university in Moscow, Idaho, at the University of Idaho. She got a master's degree in business. This was back in the early '40s, and she put herself through school with a master's degree. So this is the kind of woman we're talking about. She was a force to be reckoned with.

**[0:01:00]** She felt very ill with this flu and ended up, in fact, getting dehydrated. And my sister-in-law, Cathy, took her to the emergency ward. They found she was, in fact, dehydrated but didn't have pneumonia, gave her fluids, released her, and she was free to go back to her apartment. However, she was still feeling pretty weak and couldn't really get her breakfast and lunch and get down to the dining room for a meal, so they decided to send her to the health care centre, which was attached to the seniors' residence complex.

[00:01:35] We expected that she would be there for just a few days of recuperation. That's what they led us to expect. And instead of her coming home to her apartment in a few days, what actually happened is she started getting a lot worse. And when I say worse, I mean in terms of, cognitively, sometimes we would arrive to visit Fervid and we'd find her in her bed, apparently asleep in the middle of the day, and we could not wake her up. It was not a normal nap. We honestly could not wake her. And she seemed to sometimes be delirious, coming in and out of consciousness. We know she was hallucinating. She was telling us stories about going into Seattle with her husband, who was dead and had died several years ago. Sometimes she didn't recognize us. She was making strange arm movements. She was having coordination problems.

[0:02:35] We found this very confusing because Fervid had never shown any signs of having any dementia, Alzheimer's. I mean, she was a very bright, with-it woman.

[0:02:47] We began to suspect that maybe she was on more drugs since she'd been admitted to the health care centre. And we were able, because my sister-in-law, Cathy,

has power of attorney, were able to get the list of drugs. Because I've done a lot of research before and I have a library background, I've also done a lot of drug research before because I never will take anything or do anything without researching it first, if it's my own health or a family member. And I've done this for other elders in my family. I was able pretty much to figure out that there were two drugs that affected serotonin in the brain, and these were likely causing something called serotonin syndrome. And that, actually, is a syndrome that can be fatal if it's not caught in time. If it's caught in time and the drugs are taken away, the person can recover.

**[0:03:40]** With a lot of these residential care facilities, there will be a psychiatrist that works with specific residential care homes and they will come through and meet with the staff and look at the clients that are having any kind of psychological problems. The big problem for us, looking back, is that these psychiatrists, they do not know the people they're talking to. All they see is the state they're in right now. And with Fervid, that was delirious, hallucinating, and so on. He didn't know her baseline, which we, as the family know, we knew she was having no mental difficulties. We didn't believe she was depressed. We believed that she was rightfully mourning the loss of her life and her society. She was a very involved person in her community, was the floor captain of the residents, had a book club. She was mourning the fact that she was now in a room in what effectively was a hospital.

**[0:04:43]** We realized that we were not medical people and there was no way we could just run in and demand that they stop all the drugs. I have enough knowledge to know that some drugs have to be tapered. Some might be, in fact, lifesaving.

**[0:05:01]** We met with the floor team for that floor of the health centre. We were close to the end of the meeting and my husband conducted the meeting because he is a skilled conflict resolution professional. I tend to get hotheaded so I thought it was best that I do the research, he speaks. By the end of the meeting, the medical staff actually had drawn their own conclusion that it would be a good idea to direct deletion of especially the new drugs that we had indicated could be causing serotonin syndrome and to really take a good look at what she was on, what she needed, and what might just, in fact, be causing the quality of her life to deteriorate.

**[0:05:43]** In Fervid's case, once the drugs were removed, the ones we were most concerned about, it took, I'd say, somewhere between maybe three and six weeks for her to come back, cognitively, right back to normal, as sharp as she ever was.

[00:06:02] We were really happy to have the Fervid that we knew back, but it was not totally a happy ending because Fervid had been bedridden by this time for months. And when a frail elder is bedridden, they lose about 5% of their functioning muscle strength for every day they're in bed. So what happens is, if you do not address these medication problems quickly, that person will spend weeks, months in bed, and they're not going to be able to get up again. They're not going to be able to be discharged back to their

apartment, back to independent living, because they won't have the function to be able to look after themselves. So although Fervid was wonderful and she was great and she was back, she pretty much needed a wheelchair now. Maybe four or almost five years later, after this medication issue had been worked out, she had gotten *C. difficile*. She'd had recurrences. She was getting very weak, but she was still cognitively right there all the time.

[0:07:07] And something happened to us as a family. I can only say that I think Fervid knew that she wasn't going to be there very long. And we started having these incredible conversations with her. It's like, nothing was talked about except what was the closest thing in everybody's heart. And it's not the kind of family conversation you're used to having.

**[0:07:35]** After Fervid died in 2008, I spent about a year feeling incredibly frustrated. I really wanted to do something about this problem that I saw as a problem with medicine for elders, the way we care for elders. Everyone has the best intent, but we're not doing it the right way. We have to look much more carefully at how we're treating frail elders who have half the liver function and half the kidney function that somebody under 75 has.

**[0:08:10]** It's very important to involve the family. Families have to understand that they may have to ask to give input. I would hope that the medical system will start asking for input more from families and caregivers. But if they're not, then as a family, do it respectfully, but give your input on your frail elder. Let them know how they usually are. Tell them if there's something happening you don't understand. Try and get an answer. I feel totally inspired to go forth and see that these kinds of things don't happen to other people and their family members, and to give other people a chance to have those kinds of discussions with an elder, a loving elder who is not cognitively impaired and overmedicated and confused and hallucinating, but is right there for you.

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