

TRANSCRIPTION

cpsi Canadian Patient Safety Institute
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[0:00:06] My patient safety story is not a simple one. I lost my father at the age of 62 in 1973 due to cancer. I lost my best friend due to cancer at the age of 62 at the end of January of this year. My impetus for getting involved in the patient safety movement was really my father's death and the very difficult time he had, the very inadequate care he received, and the very unsafe care he received.

[0:00:50] My friend Lorraine and my father, Ken, both wanted to die at home. My father was a hunting, fishing, good old boy. He loved to laugh. He loved to cook. He made the turkey stuffing for all of our neighbors because once they tasted his, they insisted on his coming over to help them make theirs on Christmas Eve. He was full of life. He loved his work. And until his final illness, he never missed a day of work. He was a very hale, hearty fellow. The thing he loved best in all the world was gardening.

[0:01:36] My father had had some symptoms in December of '71 and was followed up with some diagnostic tests, found to have a bowel cancer. By June, he began to experience extreme bone pain in his legs and in his spine, and it was pretty clear that this pain was going to continue until he died.

[0:02:03] My dad wanted to die at home and my mother and I tried to make that possible for him. Homecare was really in its infancy in those days. They did things like shave my father so he would be more comfortable, and they would dress his ulcer and ultimately show my mother how to administer morphine injections during those last four weeks. But really, home care was not the fully-developed system we think of it being today. My aunt came and together, we did our very best to make him as comfortable as we could. But there were so many aspects of his care that we didn't understand.

[0:02:51] When he was at a point when he could no longer turn in bed, we didn't realize that he could get a terrible pressure sore just by that immobility. And that's what happened. He had a huge ulcer at the base of his spine, which was itself very painful. So I just can't tell you how – we wanted to honour his wish – but how terrible we felt that he was suffering so much. And it was heartbreaking to see how badly controlled his pain was. He was offered aspirin and 292s until four weeks before his death, which occurred in June of 1973. And only for the last four weeks of his life did he receive morphine, which allowed him to get some pain relief.

[0:03:49] My friend Lorraine's death was peaceful. The entire period leading up to her death, those five plus weeks were calm, happy, peaceful, accepting, and there was some fun. My best friend died at the end of January of this year. She had terminal cancer, knew well in advance that she wasn't going to survive this particular condition, and wanted to die at home. With Lorraine, it was so different. First of all, she knew she wanted to be at home, but knew that she was going to be followed home with a team, a team that included her family doctor, who was also the head of palliative care in the region, a team of nurses, which included – because it was over Christmas and New Year's – pretty much every nurse, I think, that worked in that particular system. She had metastasized uterine cancer following a hysterectomy and her bowel was totally blocked, which meant that she couldn't eat food anymore. She couldn't she couldn't go to the bathroom. And she was hooked up to quite a bit of equipment while she was in bed.

[0:05:22] She had a pain pump that she could augment when needed. She had a gastric tube which kept her from having overwhelming nausea. And she was on several other kinds of medications which were used to control her symptoms. And I was really carefully instructed in how to administer those injections and how to observe really careful hand hygiene.

[0:05:53] It sounds strange, but I'm very proud to say that she had no infection when she died. She had no skin breakdown when she died. She was pain-free when she died. And that, I think, is an extraordinarily uplifting experience following what had been such a difficult journey with my father. And she was very funny and very full of life, right to the end.

[0:06:23] She was initially receiving TPN, which is a feeding that goes into a PICC [ph] line, an intravenous feeding. But she was told by her doctor, there will come a day when you will say, "I don't want this anymore." And she came to that day and she said, "I don't want this anymore." And we all felt that we had permission to say, "Okay."

[0:06:49] What I would like the health care system to know about my two experiences of death and dying are that people need choices about how and where they die, and they need information to help keep the patient safe. I want the health care system to be more humane, more empathetic, kinder. We're all human beings. We all deserve to have the best possible death. And we know now a lot more about how to make that happen. It's not easy because it's very time-consuming and it's very hard on the heart. But ultimately, it's so rewarding to see that you can make a difference in someone's life at a crucial time in their passage.

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