

The tragedy of dying alone

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CHARLA JONES/TORONTO STAR FILE

The tragedy of dying alone SARS forced families to stay away from elderly patients Daughters demand answers about treatment of their fathers

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When the SARS crisis hit last spring, visitors to Toronto-area hospitals watched the doors clang shut.

To the frightened patients locked inside and their anxious families outside, those doors might as well have been prison gates.

Suddenly, families could no longer visit their sick, elderly and often frail relatives who didn't have SARS, but needed help and couldn't understand why everyone had disappeared from their lives.

In their place, all the patients saw were strange figures, garbed in masks, gowns and gloves, peering down at them. The usual hospital routines went out the window, tuck shops were closed and volunteers disappeared.

Linda Rumble's nightmare began when her 81-year-old father, Evan Herriott, who suffered from diabetes and multiple sclerosis, was taken to Scarborough General Hospital to have both his legs amputated above the knees on April 16, at the height of the first SARS outbreak.

After his surgery, he was put on a floor normally used for doctors' offices, because SARS patients occupied the regular surgery floor. There were no television hook-ups

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and he couldn't reach a radio placed on the windowsill by his daughter. He felt totally alone.

When he was discharged two weeks later to the veterans' home where he lived, Rumble discovered a small bedsore he had developed earlier was now much bigger.

It took her almost three weeks to get an appointment with a specialist, and by then "it was the size of a crater," she said. The cavity in his back was roughly the size of the palm of a man's hand.

He went to Scarborough Centenary Hospital for emergency surgery in mid-May, just as the second SARS outbreak hit.

Rumble wasn't allowed to visit her father, even on his 85th birthday. He returned to the veterans' hospital on May 28 but never recovered from the infection and died June 22.

Jan Nichols' father was a relatively healthy 85-year-old man who lived on his own, drove a car and was looking forward to his usual summer at a cottage near Peterborough. But he postponed the trip to have a routine hernia operation at Oshawa's Lakeridge Health Centre on May 22, the day before the second SARS outbreak.

He was scheduled to come out the next day. Instead, he died there a month later. Nichols still doesn't know why.

Both families know that hospitals were under extreme pressure during the two SARS outbreaks. But they feel they were treated badly, the rules weren't consistent and their parents would have lived had they been allowed to be with them.

They and several other families made their heartfelt case to last fall's SARS Commission, headed by Mr. Justice Archie Campbell. The commission's interim report is scheduled to be released this spring and the final report is due in December.

Rumble spent two days in hospital with her father before his amputations, showing the nurses how to change the dressings on his legs, "doing everything for him," she says. But when she showed up at 6:30 a.m. the day of his surgery, she wasn't allowed into the hospital. She and her sister sat between the two sets of glass doors in

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Scarborough General's main entrance all day, trying to get information through a security guard. She never did talk to the surgeon, despite repeated requests.

Throughout her father's ordeal at the hospital and the veterans' home, his family was told only one family member would be allowed in if death was imminent, and if the facility was closed to visitors, nobody would be allowed to say a final goodbye.

"To deny seniors this basic right is simply wrong," Rumble adds.

If she had been there, she says, she would never have allowed him to be discharged without having his bedsore examined.

Rumble says she doesn't blame hospital workers who were in an impossible situation. While she understands why visitors couldn't be allowed into SARS units, she says visitors should have been allowed elsewhere.

"It was sinful to put families through that," she says. "To deny a patient a family member present when death was imminent was to deny them their basic right to die with dignity and love."

Appearing before the SARS Commission was hard, she says, "but I had to do it. I had told my dad they could learn from something like this and I promised I would do something."

Jan Nichols' father, John Milne, developed a fever the day after his hernia surgery.

Even though there was no reason to suspect him of having SARS, "he was treated as a SARS suspect," Nichols says. "We were never actually told what was wrong with him other than some form of pneumonia."

He was eventually put on a ventilator and his family was ordered to wear protective masks, gowns and gloves when they visited him. They did visit the cardiac care unit, often several times a day, until the nurses complained they were using too many gowns and masks.

"Sometimes we would just go to his glass door and wave to him and give him comfort and reassurance from there," Nichols recalls.

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Then two SARS patients were admitted to the hospital, which "seemed to put the fear of death into the staff," and any sense of normalcy disappeared, she says.

Sometimes they were allowed to visit for five minutes, sometimes half an hour. One day, a security guard told her sister she couldn't go in at all unless she could prove her father was going to die within 24 hours.

On June 10, the family was told there was no hope and Milne was taken off the ventilator.

"For the last 17 days of my dad's life, he never felt human contact," the daughter says. "For a man who always reached for someone's hand to hold, whether it was his daughter's or one of his 10 grandchildren, all he got was a latex glove."