



Frozen in time: life in the face of chronic care cutbacks

Kathy Cook

In brief

Kathy Cook won the \$750 first prize in *CMAJ's* 7th Annual Amy Chouinard Memorial Essay Contest. The deadline for entries to the contest, which is designed to stimulate interest in medical writing among journalism students, is June 1. Entries should be forwarded to the news and features editor. In her winning essay, Cook explores the frustrations and quality-of-life issues that arise in a chronic care institution that is trying to operate in the midst of serious funding cuts.

A balding, elderly woman in a wheelchair reaches out as we pass in the lobby of the St. Vincent's Pavilion and mumbles something. She looks up sadly and her plump face deforms slightly. She begins to speak incomprehensibly and I ask her to repeat herself. "I've been waiting for so long," she says, grabbing my arm to ensure that I won't walk away.

I hope that someone will step in to help her, and me. The lobby of this chronic care facility near downtown Ottawa is filled with a half-dozen patients in wheelchairs, and they're ignoring us. The receptionist finally looks over. "I told you the bus will be here in 15 minutes," she tells the woman. "You're just going to have to wait."

By now I'm late for my interview with a severely disabled man who has lived at this hospital for half of his 40 years. I wonder if he gets tired of waiting too.

A paralysed woman who manoeuvres her wheelchair by blowing in and out through a straw shares my elevator. When I get off at my floor, I'm greeted by a faint smell of urine, mixed with antiseptic.

Alone in his electric chair

Finally I arrive at Room 512, home to Frank Kilgour. He's waiting in his electric chair, and his intelligent blue eyes sparkle as he smiles — it's as if he is laughing without sound. He's here because of major brain damage suffered June 30, 1978, after he lost control of his car on a gravel road near Eganville, Ont., some 150 km west of Ottawa. He remained in a coma for most of the next year. Doctors told his mother he probably wouldn't survive. If he did, they said, the catastrophic injury would leave him in a permanent vegetative state, unable to think or move.

But Kilgour was a strong young man with a brown belt in karate and bronze cross in swimming, and he did survive.



Barbara Sibbald photo

Frank Kilgour and his mother Helen at St. Vincent's: home for half his life

His mother, Helen, says he was a licensed pilot and an excellent piano player. Her son just looks at me, still smiling. He wanted a career as a commercial pilot, but because his eyesight was less than perfect he enrolled in an aircraft maintenance course in Toronto. He completed one semester and was home for the summer when the accident rewrote his future and landed him at St. Vincent's.

Kilgour is a prisoner of his battered body. He can't talk, and although he can smile and chew his food he has next to no ability to move his body. It took several operations just to give him limited mobility in his left index finger and his knees. But he has no trouble thinking.

For someone with enough time, Kilgour will share his thoughts. It's a long, labourious process. To communicate he points to letters on a piece of bristol board that always accompanies him. His spelling is impeccable.

He also uses a computer. Although his finger isn't steady enough to press the proper keys, a sensor on his right knee allows him to slowly pick the letters for the words he wants.

In his years here, Kilgour has revealed himself as a talented, if slow, writer — he spent 6 years writing a short story about the day he received his pilot's licence, 20 years earlier. The colourful piece was eventually published in his hometown newspaper, the *Eganville Leader*. He did not mention his current situation.

His mother has decorated his half of the hospital room



like his old room in Eganville. The badges he earned as a Boy Scout are displayed, and his framed pilot's licence is on the wall. He has a television set, a stereo, hundreds of music tapes. With his working finger he can touch a large button by his bed that controls either the TV or stereo. His favourite show is *Star Trek*; he prefers country music.

Helen Kilgour first noticed that he was showing signs of comprehension 3 years after his accident, and it was she, and not doctors, who reinitiated communication by creating a board with letters and numbers on it.

Although she still lives in Eganville, she has rented a small apartment in Ottawa so she can spend half her time with her son. A widow, she feeds her son his dinner 4 times a week and sits and talks with him for hours on end. When she can, she takes him home to Eganville for an overnight stay. Because she is unable to lift her 6-foot son on her own, she can't keep him for long. "Frank never complains though," she says. "He understands that I have to bring him back."

Time passes slowly for her son, and she wishes there were more activities for him. "I don't know what he'd do without his music," she says. He goes to physiotherapy twice a week, but shows little interest in recreational activities many of the other patients enjoy. Helen Kilgour says he needs more stimuli to keep him interested in life. She wishes there were more people willing to spend time sitting down and talking with him. That's a common wish at St. Vincent's.

"We need to fight"

A few floors away, 39-year-old Randy Romain sits in front of his computer. By pressing his elbow down repeatedly on a large button, he writes letters using Morse code. He uses his lips to dial a call on his speaker phone. And since he can't see the computer screen, he has an adapter that verbally relays his email messages to him in an odd computer voice.

Romain, a thin, bearded man from Buckingham, Que., first had difficulties with balance when he was 15. He started going blind at 20 and by age 23 was in a wheelchair. Four years later, he could no longer use his hands.

Because of his rare neuromuscular disorder — he could not supply the correct name for his disorder, but said it was related to an enzyme deficiency — St. Vincent's has become his permanent home. For the past 2 years he has been president of the Residents' Council. "We need to fight constantly to get what we need," he says.

With more than 500 chronic care beds, St. Vincent's is the largest chronic care hospital in Eastern Ontario. Operated by the Sisters of Charity, it has been struggling to provide adequate care while coping with a series of funding cuts over the last 5 years.

Romain says many patients are unhappy about the level of care. "The care is always rushed," he says. "The nursing staff don't have time to spend an extra second with us, and they're very stressed because they're overworked."

Family physician Frank Knoefel says the hospital is struggling to maintain a good quality of life in the face of declining funding and heavier workloads. Not only has funding been cut, he says, but acceptance criteria for chronic care patients have been made more rigid.

"For us, changing floors is like moving to another town."

Under current rules, many of the chronic care patients now at St. Vincent's would not have qualified for admittance. They would be deemed long-term patients and, as such, would qualify for only a fraction of the funding —

and medical services — available to chronic care patients.

Five years ago the hospital received the same funding for lower-needs chronic care patients, such as those with Alzheimer's disease, as it did for someone with more severe medical needs, such as a patient with multiple sclerosis. This meant that the hospital could shift money to where it was needed most, says Knoefel.

When older patients die now, says Knoefel, their beds are filled with patients who have much heavier medical needs. "Today you admit someone who has a feeding tube and wounds that need to be dressed and changed so many times a day, plus all sorts of therapy requirements. So we're replacing a patient who was receiving light care and we're not getting more money — we're getting less money. Every day we bring in someone who has heavier needs than the person who left. That is our fundamental problem."

Knoefel says the hospital is also affected by Ontario's chronic nursing shortage. St. Vincent's no longer has an adequate nursing pool to rely on when a staff nurse is sick, and this means it has to call an agency. "A nurse who comes here for a shift once in a blue moon can't provide the same service because she doesn't know the patients. They have 8 hours to look at a care plan and try to figure out what needs to be done."

"This is my home"

Romain is also fighting against the multiple moves patients have to endure. "It's our home here," he says, "and we get used to people. We don't want to have to move around. For us, changing floors is like moving to another town. And the nature of our care is so private that I don't like strangers caring for me."

Knoefel says the incessant cuts mean the hospital has had little choice but to reorganize several times to improve efficiency. Despite the many difficulties, Romain considers himself fortunate because Janet Burns, his girlfriend of 2 years, is often able to help him. An attractive woman with bright blue eyes, she arrived at St. Vincent's 3 years ago. Her mother had determined that she could no longer care



for Burns, who has multiple sclerosis, at home. Not long after she arrived, she met Romain in the hospital's garden.

Although Burns is also confined to a wheelchair, she is more mobile than Romain because her arms are stronger and her eyesight is good. "She's my seeing-eye dog," he says. In their electric chairs, they're a mobile pair — she takes him shopping, and they recently took in a movie. "As long as it's a movie with lots of dialogue, I can enjoy it," explains Romain. And they recently went out for some Thai food with a friend, who helped feed Romain.

But despite some good times, Burns finds the hospital a stressful place. She's looking for an alternative. "It's hard to live here. There's a lot of noise. The people here cry a lot — they yell a lot. My nerves are shot."

From morning to night there's the constant noise of clanging trays and ringing phones, mixed in with screaming and moaning. Patients with head injuries sometimes yell all night or day, often without being aware they are doing this.

Burns has heard about co-op living for certain patients, and is hoping she will be accepted. "I can still transfer in and out of bed by myself," she says, rather proudly. "But

my mother doesn't want me to go to a co-op. She doesn't think I can make it."

At St. Vincent's she's sharing a room with her fourth room-mate, having already endured the slow deaths of 3 elderly female patients. "It can get very sad sometimes. I see their health deteriorate, and their families coming in to see them. And then they die."

Burns wishes she could be placed with other people like herself, or at least people in her age group — she's in her 30s — but she thinks odds of this happening are shrinking. "They have to make the workload even. It takes more time to care for someone with MS than someone with old age."

Burns often feels guilty if she asks for extra help; normally she can't even get her hair combed. "They have to cut corners with us [and] if anything goes wrong, then they don't get their breaks or suppers," she says. "Sometimes they get mad at us, but it's not their fault. It's almost inhuman what they expect [staff] to do."

Kathy Cook is a second-year student in the master's program in journalism, Carleton University, Ottawa.

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