

‘I know I’m going to have a good death’: Why palliative care matters

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A month ago, Francis Young was lying on a gurney in the corridor outside an overflowing ER, dying, slowly and mercilessly. Racked with pain from untreatable stomach cancer that had spread to his liver, the 85-year-old former truck driver had stopped eating and had given up.

His nursing home wouldn't take him back because he was too sick; the hospital would not admit him because they had no bed and no treatment to offer; and, with his wife suffering from severe dementia and institutionalized, he

had no family nearby to offer care.

"Then this angel came along and asked me if I wanted to go to palliative care," Young recalled. "I said, 'What the heck. I don't want to die alone in a hallway.'"

Thanks to a referral from a compassionate ER nurse, he ended up at the [West Island Palliative Care Residence](#), a hospice in Kirkland, Que., that has a reputation as one of Canada's best – a model for how end-of-life care should be delivered.

The 23-bed facility (spread over two sites) offers each resident a private room with plenty of room for visitors, comfy common spaces and first-rate palliative care.

"This place is about life, not death," says Teresa Dellar, the executive director who founded the residence in 2002.

A long-time social worker at Lakeshore General Hospital, on Montreal's West Island, she was frustrated that, at end-of-life, patients were "shipped downtown" where they were lonely and it was difficult for family to visit. Dellar was particularly touched by the case of a single mother with cancer who was unable to see her three young children in her final days.

"Ethically, I couldn't send people away any more. It was creating too much hardship and heartbreak," she said.

Dellar enlisted the help of Russell Williams, who was then a member of the Quebec National Assembly, and they began fundraising.

"I thought we would find a sugar daddy with a \$1-million," Williams said. "What we got was much better: community support." (Williams, who is now president of Rx&D, Canada's Research-Based Pharmaceutical Companies, remains a strong supporter of the charity, as do a number of drug companies located nearby, notably Pfizer.)

Like virtually all hospices, the West Island Palliative Care Residence depends on charitable donations to operate. It has an annual budget of \$4.3-million, with \$1.3-million coming from the province and \$3-million from donations.

The reluctance of governments to fund palliative care is puzzling. About two-thirds of Canadians die in hospital, where a bed costs about \$1,000 a day to operate; a palliative-care bed costs less than half that amount. In Quebec, the provincial government provides \$165 daily per bed in palliative-care funding. In hospitals, patients also pay extra for private and semi-private rooms (between \$40 and \$300 daily depending on the province). In the hospice, there are no fees at all, despite the mounting costs to provide care.

Over the residence's 12 years of operation, hospice care has changed considerably, Dellar said. In theory, patients with less than three months to live are eligible for admission; but, in practice, patients live in the residence only an average of 18 days before dying.

"Patients now come here later and sicker, so the care is much more intense," Dellar said.

At the outset, 98 per cent of palliative-care patients had terminal cancer – in large part because disease progression is fairly predictable and cancer patients are good advocates. Increasingly, however, the hospice is seeing more patients with end-stage cardiovascular and renal disease, and with conditions such as ALS and multiple sclerosis.

Pain control is the overriding goal, to ensure patients' final days are comfortable and they are able to spend them with family and friends. And the atmosphere is surprisingly upbeat. There have been seven marriages on-site, countless birthday parties and, increasingly, patients are organizing their own wakes before they die.

What distinguishes palliative care in the residence from the end-of-life care in hospitals is follow-up. Every family gets follow-up care – counselling from psychologists and social workers – for a year after the death of a loved one.

"If you don't do the follow-up, they end up in the ER themselves," Dellar says. Her belief is that if you don't offer bereavement services, it's not really palliative care.

There is no talk of physician-assisted death or euthanasia at the residence. "That's an important issue but it's not our issue," Dellar says. "Palliative care is not euthanasia. We actually extend life – and improve quality of life – we don't hasten death."

Francis Young is a case in point. He was at death's door when he arrived but, once the medical staff got his pain under control, his appetite returned, his mood perked up and his condition stabilized.

"I actually feel great," he said. "But I'm not crazy. I know I'm full of cancer and when I put my head down on the pillow every night, I don't know if I'll be here tomorrow."

To the amusement of staff, Young has decided to spend his final days raising money for the hospice. He has no money himself but greets visitors at the door with a Montreal Canadiens-emblazoned tin can and hits them up for donations.

"I don't want to die but it's going to happen, so this is where I want it to be," he says. "I know I'm going to have a good death."

That, in a nutshell, summarizes the philosophy of hospice care. As Dellar notes, at hospitals, the morgue is usually hidden away, at the back door, next to the dumpster. The symbolism is telling.

"Here we don't have a morgue and we don't have a back door. Everyone comes in the front door and they leave through the front door."

They are afforded as much dignity in death, as in life.