Freestanding hospices ease pressure on physicians, hospitals, MD says

Features

Chroniques

Anita Elash

Anita Elash is a freelance writer living in Toronto.

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In brief

ONE OF CANADA'S NEWEST HOSPICES, located in Oakville, Ont., was designed to help dying patients live and die peacefully. Another of its important roles is to help family members cope with the uncertainty and loneliness that surrounds a death in the family. "There are so many people out there without support," says its founder, Margaret Anderson.

En bref

LE PLUS RÉCENT ÉTABLISSEMENT DE SOINS PROLONGÉS AU CANADA, situé à Oakville (Ont.), a été conçu pour aider les patients en phase terminale à vivre et à mourir paisiblement. Il a aussi pour fonction importante d'aider les membres de la famille à vivre l'incertitude et la solitude entourant un décès dans la famille. «Tellement de personnes dans la communauté ne reçoivent aucun soutien», affirme la fondatrice, Margaret Anderson.

The story of Ian Anderson's death from colon cancer doesn't differ much from thousands of others. He died in November 1990 at his home in Mississauga, Ont., lying in the bed where he had spent the previous 3 months. Anderson's wife Margaret, who had devoted herself to feeding, bathing and medicating her husband throughout his illness, spent the day at his bedside, uncertain of where to go for help.

There was no doctor, no nurses, no one to explain what would come next. It was a wrenching experience, and one that Anderson decided she would some day help other families avoid. "I felt very isolated," she says. "I felt very helpless. I felt very much alone. And I realized it should not happen that way."

The result is Ian Anderson House, Canada's newest privately funded, freestanding hospice and the only one in Ontario devoted solely to caring for terminally ill cancer patients and their families. The house, which opened on a 0.7-hectare ravine lot in suburban Oakville in December 1997, offers a view of landscaped gardens from each of its 6 private rooms, a user-friendly country kitchen, a sitting room warmed by a gas-powered fireplace and 24-hour nursing and health care. Patients are free to come and go, couples can pull out a bed and sleep together, and anyone can help themselves to tea or the stash of yogurt and melons in the refrigerator. It is a place where people come to live until they die.

It was a struggle to get Ian Anderson House established. For 7 years, Anderson and her volunteer Board of Directors fought bureaucracy and neighbourhood opposition. Her initial offer to fund a hospital-based palliative care ward was rejected because the hospital could not afford to staff a new ward. Then the Ontario Ministry of Health refused to give grants to build a freestanding facility. Finally, local opposition to a neighbourhood hospice — the not-in-my-backyard syndrome — forced Anderson to change locations. She has invested $1 million of her own money and works full time lobbying and organizing bingos and walk-a-thons to raise the $350 000 a year she needs in operating funds.

Setting up the hospice was also emotionally distressing for Anderson, but she persevered because she is convinced that freestanding hospices can fill an important void in palliative care in Canada. "I think the entire family should be cared for and nur-

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tured through and I do not think that happened," she says. "There are so many people out there without support."

Palliative care shortage

Canadian hospitals offer just 1200 palliative care beds, and one-third of them are in acute-care wards. As a result, most patients with terminal illnesses are sent home to die. Although the majority prefer to die at home, their families are often ill-equipped for the physical and emotional strain of dispensing complex care to someone they love. And even though most home-care programs provide nurses, equipment and treatments such as physiotherapy, services are usually limited and do not include family counselling or emergency support. "If it is 2 o'clock in the morning and the person is in pain, you are the one injecting the morphine," says Ottawa health policy researcher Mary Colbran-Smith.

She knows the subject as more than a policy issue. Last winter, Colbran-Smith and her sister nursed their dying mother, Elizabeth. Although a home-care nurse visited regularly, Colbran-Smith and her sister were left with most of the daily chores of caring for their mother, with backup from other family members. "We had to deal with blocked catheters," she says. "We were giving enemas. I was constantly wondering if I had made the right decision. Should I give her more to drink? Would she be better if I gave her more solids? The decisions we had to make just left us drained and second guessing ourselves."

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Margaret Anderson struggled for 7 years to establish Ian Anderson House

Canada's 25 freestanding hospices are meant to help patients endure their last days by finding some middle ground between the comfort of home and the medically secure but sterile surroundings of an acute-care ward. At Ian Anderson House, the focus is on the family. "If they are relieved of some of the burden, the benefit spreads to the patient, too," says Anderson. In addition to the services provided by home care, 2 full-time nurses and 7 health care aides staff the hospice around the clock. Everyone who is admitted must have a personal physician, who will visit once a week and be available in emergencies.

If a family chooses, the staff looks after daily hygiene and health needs, offers informal counselling and assists with important decisions. There are no intercoms or announcements, no rules about waking times or when meals are served, and none of the rush and fuss inherent in most hospital stays. Colbran-Smith, whose mother was admitted to Ian Anderson House in mid-January, says the program "allowed us time to be family members again."

Home away from home

Elizabeth Colbran brought her own pillow, flowered sheets and quilt, decorated her room with paintings she had done as a young woman, and hung a bird-feeder outside her window. Hospice staff took over bathing and health care duties, and helped make crucial decisions such as when to stop giving fluids by mouth. "Her last 3 hours were very peaceful," says Colbran-Smith. "We were right beside her. There were birds at her feeder. The sun was streaming in on her. It was as close to home as you're going to get without being at home."

Dr. Sol Stern, who has admitted 2 patients to Ian Anderson House, says the hospice also eases pressure on doctors and hospitals. "When someone is at home, families either panic and call too often, or they do not call enough," says Stern, the chair of palliative care at Oakville-Trafalgar Memorial Hospital. He says hospice staff have a better sense of when a doctor is required and can help avoid unnecessary house calls and hospital admissions.

The hospice's status as a stand-alone facility may also help doctors enhance palliative care, says Dr. Robert Sauls, head of palliative care at the Credit Valley Hospital in Mississauga. He says the best treatment program may include a range of traditional and alternative techniques designed to address physical and spiritual needs, but hospital bureaucracies often prohibit new approaches. "Hospitals are the bastions of a traditional medical model," says Sauls. "Having a site outside the hospital allows you to be more creative. It may help us to stop medicalizing death so that we can focus on other things, like how can we create a space for living rather than dying."

With that kind of medical support behind her, Anderson hopes that Ian Anderson House will be the first in a long series of new freestanding hospices. At least 3 others, including one for children, are planned for southern Ontario. However, like Anderson, their founders have been unable to secure government funding and are now in the midst of raising private funds. Whether they succeed will depend on the generosity of people who recognize that the last days of life are as important as the first. ?