



Wrap-around hospice care

COMPASSIONATE SERVICES HELP PATIENTS, FAMILIES FACE DEATH

By H el ene Beaulieu

EVERY MORNING for the last six years, Mearl Steckly has driven the five minutes from his home in Cambridge to tend the bird feeders on the Speedsville Road property of Lisaard House. For the 83-year-old, it's a labour borne by love and enlightenment that honours the passing of his wife, Helen, and those who cared for her with such compassion and respect that he feels he can never repay them.

Lisaard House is a six-bed residential hospice which cares each year for about 80 people in the final stage of cancer. Situated on a beautiful treed lot set back from the road in a small ravine that abounds with wildlife, it's the first residence of its kind in Waterloo Region.

Until Lisaard opened its doors in July 2000, there were few options for people needing assistance in their end-of-life journey. The more fortunate received support at home, thanks to family willing to take on the responsibility.

Yet often, despite the best of intentions, the burden of care leaves families emotionally fractured and physically exhausted. In the final days or weeks, they are forced to move their loved one to hospital, the last place they want to be.

"They get to the end of their rope at home and they can't manage any more and everyone's worn out," Connie Dwyer, executive director of Lisaard House, explains. "Then they come here and everybody relaxes. They settle down and people start



Photography • Philip Walker

Executive director Connie Dwyer pauses in the sunroom of Lisaard House in Cambridge.

to do well again. That's what we want."

"It's a tremendous stress on people to take care of people that are dying," says Sheila Ainsworth, president of the Lisaard board of directors. "When they're here, the family can come and go as they need to and get the rest that they need. Families can then take that journey with that person in a comfortable, caring manner rather than being so stressed out."

Home care was not an option for Helen Steckly. She spent a month in hospital, and then moved to Lisaard for her final three months. "When we found out there were only six beds and she could have one of them, we were so fortunate," Mearl says. "This was the best place she could have ever been. They are experts in pain management. She would have been in a lot



of pain otherwise."

Mearl has fond memories of his months with Helen at Lisaard. "We had so many nice picnics here. It was in the summertime, it was July." Helen was surrounded by family the night she died, and she died smiling "because she was comfortable, she was cared for. She was ready to go," he says.

People's perceptions of dying and death

are heavily influenced by images — often of pain, uncertainty, fear and loneliness — that they see in movies and on television. Hospice care challenges those expectations as it addresses physical, psychological, social, spiritual and practical needs of the dying, and their families.

Hospice is a relatively new model of palliative care. Over the last two decades, local hospitals responded to the trend by

creating dedicated palliative teams and increasing bed capacity. Still, it is widely recognized that the demands of institutional scheduling and the high volume of work often prevent nursing staff from giving dying patients the optimal level of care.

In a residential hospice, such care is the staff's primary responsibility. "We don't want people at the end of their life to be

A PLACE OF MEMORIES

Mearl Steckly's wife, Helen, spent her final three months at Lisaard House. In gratitude for her care, he has volunteered daily at the hospice for six years.

Photography • Philip Walker

miserable," says Lisaard's Ainsworth. "The idea is that they live to the very end. We want to make that possible and make it comfortable; they have to be comfortable. That means getting rid of their pain and making sure their personal care and all those things that make a life are taken care of."

Only a fraction of Lisaard's residents are elderly. The average age is 54-55, and ▶

► Dwyer says they see a growing number of people about 40. “As we’re getting younger people, the reality of life is someone still has to go out and work. There’s the loss of one income and a caregiver in the family, and it gets to be very difficult for families who provide care. It’s heavy work — not always, but it can be. It can be very difficult for families to keep people at home. Hospice is a wonderful answer.”

Lisaard is supported by four family physicians with a special interest in palliative care. Ruth Adler, Janet Zettel, Erin Owens and Michael Casey rotate duties over two-month periods. During his or her two months, the doctor visits Lisaard twice a week, meets with all the residents and their families, and is on call around the clock.

“They are all wonderful,” Dwyer says. “Each one of them has their own way — the way they talk with the residents and the families — and they do a full range of jobs. They’ve given us fantastic service,



Photography • Philip Walker

Lisaard House was built by Cambridge’s Sheila and Val O’Donovan, who also established an endowment for it.

absolutely fantastic.”

A 2002 Canadian Hospice Palliative Care Association report says modern hospice care had its start in the United Kingdom in the mid-1960s. When the concept came to Canada in 1975, the term “palliative care,” meaning comfort but not active treatment,

was coined.

The same report notes that while hospitals introduced palliative care, “hospice care developed within the community as free-standing, primarily volunteer programs.... Over time, these programs gradually evolved from individual, grass-

roots efforts to a cohesive movement that aims to relieve suffering and improve quality of life for those who are living with, or dying from, an illness.”

Locally, that grass-roots movement can be traced to the establishment of the non-residential Hospice of Waterloo Region in 1993. Almost 15 years later, it has about 160 well-trained volunteers who are matched with dying patients and go wherever they are needed — to private homes, long-term care facilities, hospitals or Lisaard House — to offer companionship, emotional support and practical assistance. Their help can range from simply holding a hand to washing dishes, minding children or driving patients to medical appointments. They may spend months, even years with a patient and family.

Hospice has a roster of 730 patients it helps in some way. The agency’s motto is “call sooner.”

“The more progressive way of looking at end-of-life care is to consider the path that

someone is on and the help they need throughout that process,” executive director Irena Borg explains. “We’ve found that the time to work with people is in the very many months before they actually die. That’s where you build relationships with people, you support their families, you help them to understand what’s coming up and how they’re going to deal with it.”

Lisaard House was built and financed by Sheila O’Donovan and her late husband, Val, the founder of Com Dev, who also set up an endowment to help with operating costs.

Lisaard has 22 full- and part-time professional staff, plus volunteers, and initially, fundraising was necessary to meet most of its expenses. Now it receives provincial funding of about \$450,000 toward its \$800,000 annual budget. Funds raised in the community go to operating costs, the endowment or as directed by the donor.

Residents do not pay to stay at Lisaard and any support services the government

would have covered in patients’ homes move with them to the hospice.

In 2005, Ontario launched a three-year plan to spend \$115.5 million on end-of-life care, plus \$10 million in capital funding for six residential hospices in Toronto, Caledon, Stoney Creek, Etobicoke, Niagara and Windsor Essex.

Kitchener MPP John Milloy says “we have to recognize that (palliative care) is part of the health care system ... the final stage, and that people need to be supported and supported in a way that preserves their dignity. That’s the whole philosophy.”

Conservative health critic and former health minister Elizabeth Witmer, MPP for Kitchener-Waterloo, remembers when the concept of hospice care first came to her attention during her early years in office. She supports the national thrust to develop an end-of-life care strategy and believes there should be one at the provincial level, too.

“Although money has been flowing, ►

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► it's been flowing in a way that is not integrated and is not co-ordinated," she says. "If you look at the Local Health Integration Networks within the province, we have 14 and I think only two of them have made palliative care a priority on their agenda."

Sharon Baxter, executive director of the Ottawa-based Canadian Hospice Palliative Care Association, describes hospice palliative care across Canada as a hodge-podge of services. "We have seen many problems ... when many provinces went to regional health authorities. One region covers something — a mile down the road in another authority they don't. Inflexibility of coverage between regions has been an ongoing problem — it will be interesting to see how the new developments in Ontario play out."

Until 2006, Hospice of Waterloo Region received just 18 per cent of its operating budget (which this year totals \$300,000) from the health ministry. Now grants cover

nearly 50 per cent but, like Lisaard, the agency has to raise the other half itself.

Hospice is also midway through a \$2-million capital campaign to build a free-standing Hospice Family Centre at Freeport Health Centre.

"We need to have a place where we can train volunteers and educate health care workers, one that will attract people who are interested in doing the work," Borg explains. "We want to grow our volunteer force. We want to build this group up so we have comprehensive service."

Hospice currently leases office space at Freeport, and "begs and borrows" people to help with the 33 hours of training each volunteer gets. Helpers include nursing students at Conestoga College where hands-on instruction in transferring patients and use of medical equipment is provided.

Hospice also runs programs for pre-schoolers, children and teenagers coping with loss and bereavement throughout the

region. The plan is that once the agency has its own building, all those services will be offered under one roof. Bereaved Families of Ontario will move in, and HopeSpring Cancer Support Centre has been invited to share the building, too.

"We need to take care of people today, where they are, where they live now," Borg says. "That's why we're building this community hospice."

Another initiative underway would create yet a different model of hospice care.

Marjorie Paleshi of Elmira has spent several years raising money to build All Our Relations Residential Hospice and Retreat Centre on land already purchased in Bloomingdale.

She knows only too well "when it comes to funding and fundraising, there is no government support until the building is there and you're up and running."

As designed, the building would house seven dying people. As at Lisaard, family members would be welcome to stay

overnight. Another part of the building would have conference and community rooms. Ideally, a separate guest house would provide accommodation for an entire family to visit.

Paleshi says they could build the centre with \$3.7 million, but \$5 million would cover two years' operating expenses as well.

Her goal is to combine life-enhancing services, promoting rest, reflection, meditation and healing, with palliative care.

While the concept is unusual, it reflects a growing movement toward a more considered or thoughtful kind of care throughout the life cycle.

"Our doors will be open to anyone coming to end of life," Paleshi vows. In a home-like environment on the hospice side, nurses, personal support workers and volunteers would provide any assistance needed. The retreat side would offer public seminars and education, plus research in pain relief through alternative therapies such as gentle massage, reflexology, thera-

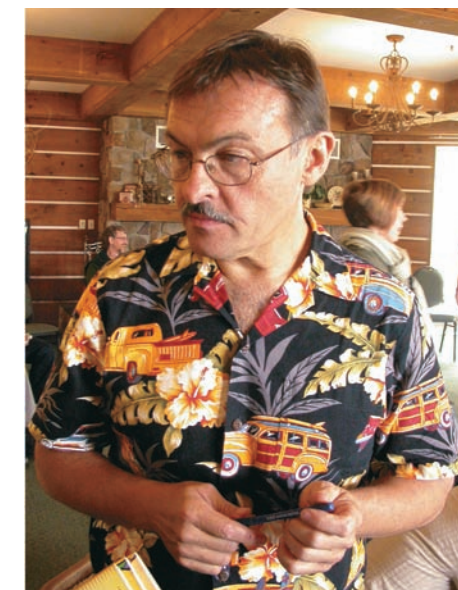
peutic touch and reiki.

"I think a lot of people don't want to talk about death, but once they've had an experience themselves, things change," Paleshi says. "Dying should be something we care about."

True to that philosophy, Paleshi, a holistic health practitioner herself, brought motivational speaker/writer Bernie Siegel and spiritual mind-body author Deepak Chopra to the region to speak in 2004 and 2005.

This year, All Our Relations partnered with Holly Oak Books in Waterloo to offer a three-day workshop on native spirituality called Coyote Wisdom: The Healing Power of Story and Dialogue, with Dr. Lewis Mehl-Madrona.

Mehl-Madrona, a psychiatrist, associate professor of family medicine at the University of Saskatchewan College of Medicine and director of the Centre of Aboriginal Health and Healing, pointed out that in many populations, knowledge is stored and communicated as narrative.



Photography • Hélène Beaulieu

Dr. Lewis Mehl-Madrona spoke recently at a workshop organized by All Our Relations hospice and retreat.

By putting information in story form, people are more likely to understand and remember it.

"Everyone has a different story," he said. ►

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► “We need to work with those stories rather than just the diagnosis.”

When professionals “bullet point” a medical condition into symptoms and treatments, they lose the bigger picture — the interaction and the richness that respects individuality and limitless possibilities, he told the workshop.

“Our goal ... is that people will learn to listen better and get more stories out of the people they work with ... that they’ll be more creative, more helpful and more tolerant of stories that are not their own. We’re building the capacity to listen and be more tolerant.”



Photography • Peter Lee

Seeing her sister, Pat Miller, through a fatal illness helped Debra Ropp of Waterloo see that dying can be peaceful.

Death can be beautiful

DEBRA ROPP has sat by the bedsides of two dying relatives; first, her elderly father, then her younger sister. As difficult as it was to watch them suffer, she’s immensely grateful for the system of care that allowed them peaceful passage.

Ropp’s sister, Pat Miller, was 41 when she was diagnosed with an aggressive form of breast cancer. After two years of debilitating therapies and serious reactions to them, a

progressive worsening of her condition led her to decide to stop all treatment.

“I’ve always been the sister who comes along and solves everything and I felt so helpless through this illness,” Ropp says.

“There was nothing I could do to help her, absolutely nothing except hold her and cry with her and talk to her. So they sent her home with a hospital bed and oxygen and they set her up at home to die.”

Nurses arrived daily to check her condition and made painkilling medication available for the family to administer. Miller’s husband, Brian, and her oldest daughter, Rachel, were responsible for most of her round-the-clock care.

“Thank goodness for medication,” says Ropp. “You need that help, your body needs it. Your body is dying and things are happening that your brain is not used to.”

In her last lucid hours, Miller decided she didn’t want to leave her three children with the memory of their mother dying at home. She went to hospital and died there, with her family at her side.

“It was so peaceful and Pat just had this angelic face when she passed away,” Ropp says. “To see loved ones go so beautifully, I don’t fear death myself.

“It’s just a journey into the next stage ... that journey doesn’t have to be horrific or filled with fear, or anxiety and pain and suffering. Even though Pat had a terrible disease, you’d never know it from her death. She took a horrible disease and made it into something so beautiful with her death.”

USEFUL WEBSITES

- Lisaard House
www.lisaard.com
- Hospice of Waterloo Region
www.hospicewaterloo.ca
- All Our Relations Hospice & Retreat
www.allourrelations.org
- Bereaved Families of Ontario
www.bfowaterloo.on.ca
- Community Care Access Centre
www.ccac-ont.ca
- HopeSpring Cancer Support Centre
www.hopespring.ca

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