

A family way of dying

The story of a residential palliative care facility

Story by Sarah de Leeuw

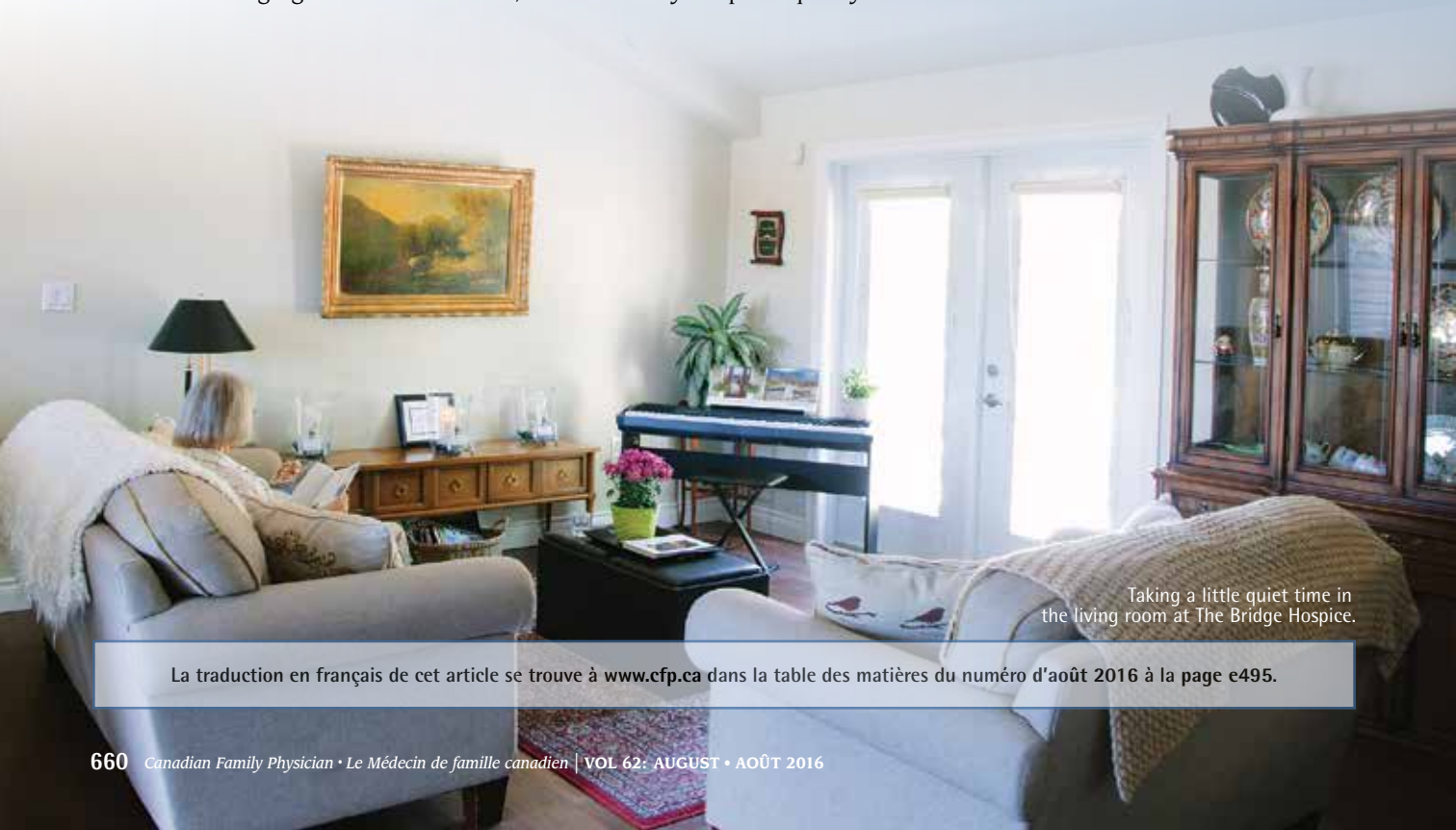
Like it was for many Canadians, although by no means all of us, March 25, 2016, was Good Friday on Dr Bob Henderson's calendar.

It's a day when people around the world are carefully reflecting upon the transformative power of death and dying.

On this particular Good Friday, at around noon, Dr Henderson's wife, Cathy, is phoning him from The Bridge Hospice, a residential palliative care facility in Warkworth, Ont, a rural community about an hour east of Toronto. Cathy is hungry, having not packed herself a lunch before she set off for a volunteer shift at The Bridge Hospice. The few restaurants in the mostly agricultural area are closed for the holiday.

Bob is responsive to his wife; he'll soon have to stop interviewing about the care facility in order to take care of someone he loves who is actually working in the house. After all, the house began with an idea bantered around by a group of nurses talking over tea, so Dr Henderson is not about to ignore the needs of his wife who is also a nurse.

"Actually, it was my wife who was the first of us to be involved in the idea of a residential palliative care facility. I have been a family doctor for 40 years. I work in a 35-bed community hospital and I have seen many people who died of terminal chronic illnesses. I was unhappy with the atmosphere in which they had to die. Sometimes it was in a 2-bed ward, so family would congregate to say their final goodbyes, but there was no privacy. Often you would see family members hanging around in the halls, with no ability to spend quality time with their loved ones."



Taking a little quiet time in the living room at The Bridge Hospice.

La traduction en français de cet article se trouve à www.cfp.ca dans la table des matières du numéro d'août 2016 à la page e495.



Dr Henderson and his wife, Cathy, outside The Bridge Hospice in Warkworth, Ont.

Bob Henderson wasn't opposed to palliative hospital care back then—he just had a feeling something *else* could exist: “I thought there had to be a better way. Yes. The best thing is to die in the home. But often that's not possible. Nowadays, family is dispersed. Many people can't call on deep family resources that were once available. It's not that family wants to send loved ones to the emergency ward, but sometimes there's no option. Can you imagine spending your final days laying on a stretcher in an emergency ward? There had to be a better way.”

Getting involved in that “better way” became a way of life for Bob Henderson, a way of life centred on better ways of dying.

“The community was at this stage in the development of an idea. There was a non-profit set up, but they needed to take ideas to the next step, the bricks-and-mortar stage. I'd had a career where I'd gained experience serving on boards, with university and community administration. So I had some background in development. We wanted to move forward. Then a local supporter of the hospice concept offered to sell us a piece of land. We started fundraising in 2010. Hospice care wasn't even really on the radar of our health authority. They suggested adding beds to nursing homes. But our mantra was ‘a home-like environment in which to die,’ so we knew we couldn't be associated with an institution. In 2 or 3 years we'd raised over \$450 000.”



Dr Henderson and Cathy meeting in The Bridge Hospice office.



Enjoying a little conversation on the front deck at The Bridge Hospice.

COVER STORY

Dr Henderson argues that even 6 years ago, residential hospice care for palliative patients wasn't really being talked about: "It's been bubbling away on the back burner for the last 20 years, but it does take government a long time to prioritize other kinds of care. Five years ago we'd just had a new government in Ontario. We had no idea how things would go."

A history that often forgot, or at least overlooked, rural palliative care was another challenge for Bob and the dedicated people in Warkworth: "When palliative hospice care had been thought about, it was thought about in connection with urban centres. In Toronto, discussions and policies about palliative care really grew out of the AIDS and HIV epidemic in the '90s, when the government was investing in wards with 10 beds or more. Governments weren't really interested in thinking differently. But that model was *not* a response that could ever work in rural areas."

When it came to thinking about a residential palliative care facility, rurality and a family-centred way of dying were hand in hand for Bob Henderson: "In places like Warkworth, we really need 2 or 3 beds so our local people can go there in their final days. A huge amount of the work that hospices do is care for the families of the palliative person. We need volunteers who will give hugs, have a cup of tea, and talk about death. Of course there also needs to be day-to-day care, cleaning and feeding, which takes the weight off family members, allowing them to concentrate on loose ends, to grieve, to focus on their loved one."

The Bridge Hospice still doesn't have government funding, making long-term dreams of such intimate care difficult. Thankfully, as Bob will tell you, a little over a year ago the hospice entered into an agreement with the St Elizabeth Community Enterprise: for 5 years this agreement will ensure enough funds for round-the-clock professional care at The Bridge Hospice.

And, also as Bob will tell you, the times they are a-changin' in the upper echelons of government and health policy: the country's population is aging, we are becoming ever more geographically dispersed from family and loved ones, and more and more evidence is mounting about the cost-effectiveness of residential as opposed to emergency or institutional palliative care.

Bob Henderson is hopeful about provincial funding that's been earmarked for residential hospice care in Ontario. He has faith it's the future, sharing a few last stories about The Bridge Hospice before he knows he has to bring his wife lunch: "Over Christmas one year, a palliative resident's son came and cooked everyone dinner. The son was a gourmet chef from Toronto. A dying person doesn't eat much, but it's the aromas, the family, the feeling around meals. You can't get that in an emergency ward. We had a resident whose



PHOTOS ABOVE (top to bottom)

Dr Henderson in his rural office practice.

Dr Henderson and Cathy at the hospice.

Cathy, hospice Resident Care Coordinator, tending to some paperwork.

PHOTOS RIGHT (top, left to right)


Dr Henderson bringing his wife lunch.

Cathy in the kitchen of the hospice.

A short afternoon's walk through the woods near home.

Calgary-living son drove him up from Mississippi last year—even with an expired passport, the border guard let the dying father back into Canada. We made the son breakfast when they arrived at The Bridge Hospice early in the morning and the father died 24 hours later. That's the power of wanting to die with family in a homelike environment. We've had residents bring their dogs with them for that final journey."

Bob Henderson pauses on these final stories, knowing they will resonate. After all, it is Good Friday ... and his wife, Cathy, volunteering at the residential hospice facility they both helped build, needs lunch.

Which Bob is about to bring her, bringing home the point that in all things to do with death and dying, it really is family that is most important. 

Dr Henderson has practised rural family medicine for 40 years in Campbellford, Ont. He is Assistant Professor with the Department of Family and Community Medicine at the University of Toronto, Co-Chief of Staff at Campbellford Memorial Hospital, and Medical Director of The Bridge Hospice. **Cathy Henderson** is currently Resident Care Coordinator at The Bridge Hospice.

The Cover Project The Faces of Family Medicine project has evolved from individual faces of family medicine in Canada to portraits of physicians and communities across the country grappling with some of the inequities and challenges pervading society. It is our hope that over time this collection of covers and stories will help us to enhance our relationships with our patients in our own communities.



PHOTO

Dr Henderson and Cathy leaving The Bridge Hospice together at the end of a long day.

PHOTOGRAPHER Laura Bombier, Toronto, Ont