

## PUBLIC POLICY

# REDEFINING PALLIATIVE CARE

Patients and doctors often think it's only for the dying. New studies show it may extend life.

On March 24, Maclean's hosts the second in a series of town hall meetings, "End-of-Life Care: A National Dialogue." Held at the Fairmont Waterfront in Vancouver, in conjunction with the Canadian Medical Association, it will also be live-streamed at Macleans.ca. The conversation will continue in the coming months in the magazine, and at town hall meetings in Whitehorse, Regina and Mississauga, Ont.

BY KATE LUNAU · Spurred by aging Boomers, Canadians are increasingly thinking about how they wish to die—and whether they should have the right to say when, through euthanasia or assisted suicide. But that debate can't happen, argues Mary Shariff, law professor at the University of Manitoba, until palliative care is available to all. This type of care aims to relieve patients' suffering and improve quality of life, supporting them and their families through serious illness. Still, fewer than 30 per cent of Canadians can actually access it, says Dr. Louis Hugo Francescutti, president of the Canadian Medical Association. There's also huge variability in how palliative care is delivered across the country, notes Shariff. Canadian doctors have long been calling for a national palliative care strategy, which hasn't yet materialized. Until it's widely available, "there is a risk that a patient's request for assisted death will lack consent," Shariff wrote in the *Canadian Medical Association Journal*, because that request stems from untreated symptoms, pain, or the fear they'll become a burden to their loved ones. Perhaps, in some cases, palliative care could make life more livable.

One major hurdle appears to be a misconception: doctors and patients alike only associate palliative care with the end of life. As a result, not only do patients balk at the mention of it, "physicians are slow to refer them," Francescutti says. "The mindset is, there's always one more thing we can do,"



'Huge sigh of relief': Therese Barrett is grateful her mother's last days weren't spent in an ICU

one more treatment to pursue. What's not always understood is that the patient's well-being is at stake. Mounting evidence confirms that lack of access to palliative care can lead to physical suffering, greater emotional distress, pointless or painful interventions, and even a shortened lifespan.

"Palliative care suffers from an identity problem," reads a commentary published in the *New England Journal of Medicine* in December. Seventy per cent of people surveyed say they're "not at all knowledgeable" about palliative care; surprisingly, many believe it hastens death.

Doctors also view palliative care as synonymous with end-of-life care, "primarily because that's true," says Ravi Parikh of Harvard Medical School, co-author of the *NEJM* piece: it's still most often accessed only after life-prolonging treatments have failed, when they could be delivered side-by-side. "The use of palliative care in outpatient settings, where they're a bit more stable and have a longer prognosis, is tremendously low," says Parikh. That's unfortunate for the many patients who stand to benefit. Those with advanced cancer who receive palliative care consultations early in their disease report better symptom control, the paper argues, and are more likely

to understand their prognosis.

Cost is another frequently cited obstacle to establishing widespread palliative care, but in some cases, it saves the system money. In the U.S., hospitals with palliative care services have decreased lengths of stay, fewer admissions to the intensive care unit (in Canada, a patient's stay in an ICU bed costs an estimated \$1 million per year), and lower laboratory and pharmacy expenses, according to the *NEJM* article. Outpatient palliative care can reduce overall treatment costs for the seriously ill by 33 per cent per patient.

The Edmonton Zone Palliative Care Program, which is cited as one of the most successful models in Canada because of its wide reach and cost-effectiveness, started in the mid-nineties, "a time when there were cutbacks," says medical director Dr. Robin Fainsinger. The program extends to patients in "all the locations you can think of—at home, in hospitals, cancer clinics and in continuing-care centres." There's no free-standing hospice, although a tertiary palliative care unit, at Grey Nuns Community Hospital, exists "for the five per cent with the most challenging symptoms," Fainsinger says. Members of the palliative care team include occupational therapists, social workers, pharmacists, dietitians, a chaplain and physiotherapists,



in addition to family doctors and nurses. The model's been so successful that similar systems have been established in Winnipeg, Ottawa, Calgary, Vancouver and elsewhere.

Other initiatives aim to integrate palliative care more directly into hospitals, and to help patients access it early on in their treatment. A study published in *The Lancet* in February describes one such effort, at the Princess Margaret Cancer Centre in Toronto: 461 patients with advanced cancer were either automatically referred early on to palliative care, or were given standard treatment (including a palliative care referral, if requested). Four months in, the palliative care group reported better symptom control and quality of life, and higher satisfaction with their care.

"The criticism is that we can't possibly have enough palliative care physicians for everybody to see one right at the beginning," acknowledges lead author Dr. Camilla Zimmermann. "I do think we need to train more palliative care physicians, and that's happening." (Only last year, the Royal College of Physicians and Surgeons of Canada approved the development of palliative care as a subspecialty of its own.)

Mount Sinai Hospital in New York has run a pilot project similar to Princess Margaret's. In that initiative, any patient with late-stage, metastatic solid tumours and uncontrolled symptoms was automatically offered a palliative care consultation. The number of consultations quickly doubled, and patients showed improvement. Readmission to the hospital within 30 days of discharge dropped from 36 to 17 per cent; the oncology inpatient service mortality rate saw a significant reduction. The pilot was so successful that the hospital has funded an "entire extra palliative care team," says oncologist and lead author Kerin Adelson, of Mount Sinai's Tisch Cancer Institute. "This is now our standard of care for every patient who meets criteria. It's changed the culture of our service."

Study after study confirms how palliative care can relieve suffering and benefit patients: in one, a group of lung cancer patients who received such care alongside chemotherapy had a nearly three-month longer median survival. They also opted for less aggressive chemotherapy toward the end of their lives.

Advocates are fighting hard to unlink palliative care from end-of-life care in doctors' and patients' minds, with good reason—but the truth is, patients can find comfort in such

care. About 45 per cent of cancer patients die in acute-care hospitals, according to a 2013 study from the Canadian Institute for Health Information—although most people say they don't want to live out their last days in hospital. Therese Barrett is grateful that her mother's last days were not spent in an intensive care unit. Shortly after Thanksgiving in 2010, Mary Carroll, in the final stages of amyotrophic lateral sclerosis, was admitted to the West Island Palliative Care Residence (WIPCR), a hospice in Kirkland, Que. Arriving there was a "huge sigh of relief," Barrett says. "When you walk through the doors, it's like going into a house—not a hospital. There's a welcoming feeling." Barrett, who'd been in hospital for the last 72 hours with her mom, was taken upstairs, offered a shower, and given a clean shirt and pair of slippers, then breakfast. As for her mother, "her pain was finally managed," Barrett says.

Carroll, 78, died three days after arriving at the WIPCR. "On Saturday night, we stayed in the room, and nobody slept,"

Barrett says. "We were singing, and laughing, reminiscing." On Sunday, nurses insisted they eat dinner as a family, so they went to the dining room. "When we came back, it was almost like she needed us to be together as a family one

last time," says Barrett. Half an hour later, Mary Carroll died. "It was peaceful," says Barrett, who today is one of more than 250 volunteers at the WIPCR. "She wasn't in pain."

Given Canada's aging population, and the chronic diseases that plague us—from cancer to Alzheimer's disease—palliative care will become more critical. "No Canadian should die alone, no Canadian should die afraid, and absolutely no Canadian should die in pain," Francescutti says. The debate around assisted suicide and euthanasia is one we need to have; but until palliative care is more widely available, it might just be premature. ♦

The Vancouver town hall will be moderated by Ken MacQueen, *Maclean's* Vancouver bureau chief, with opening remarks by Dr. Louis Hugo Francescutti, CMA president. The panel features Dr. Doris Barwich, president, Canadian Society of Palliative Care Physicians and program medical director, End of Life Care, Fraser Health; Louise Donald, family caregiver and palliative care volunteer, Vancouver Coastal Health; and Dr. Jeff Blackmer, executive director of medical ethics, CMA.

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