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## Alan Goodman\* doesn't much care for the term "palliative care."

He's sitting in his recliner in his apartment in Toronto, with his two cats crawling affectionately over his lap and TV tray tables. He's just finished answering a slew of questions about himself (he's 92), his health (past heart failure and current lung cancer) and his personal life.

Then Dr. Sandy Buchman, a palliative care physician who will henceforth be caring for Goodman, asks him what he knows about palliative care. What does he think it is. Goodman pauses thoughtfully for a moment before answering. He knows it's a model with a particular focus on caring for the patient, he says without elaborating. But then his expression changes and sadness creeps into his voice. "I just wish they called it something else," he says.

For Goodman and many other Canadians, palliative care is weighed down by its associations with death. It's the kind of care you get when all other treatment options have been exhausted. It's the kind of care you get when cure or recovery is impossible. It is about preparing for the end and thus, a referral to these services—services most Canadians agree are both positive and good—begins to feel like a death sentence. For Goodman and others like him, despair, hopelessness, grief and all emotions that accompany death are forever yoked to palliative care.

But most palliative care doctors would probably say this is an unreasonably bleak view. As Dr. Buchman explains to Goodman, palliative care isn't *really* about death but about optimizing life with illness. There's an implicit belief that so much physical, emotional and psychological pain aren't an unavoidable part of dying, but rather by-products of the process. They can be managed, even if the outcome cannot.

Goodman still seems skeptical, but he's reassured by the explanation of the services.

"We put you in control, you're the boss," Dr. Buchman promises him. "We



## A better way to die

*Canada is only beginning to fully embrace the philosophies of palliative care. Here's why that matters*

BY TRISTAN BRONCA



Dr. Sandy Buchman

want to make sure everything goes according to your plan when it's time to go gently into that good night, as it were."

### A philosophical shift

Hospice care entered mainstream medicine in the 1960s under the guidance of Dr. Cicely Saunders. It was the forebear to modern palliative care, which

was actually named here in Canada by an Ottawa native

named Dr. Balfour Mount. He founded one of the nation's first palliative care units at the Royal Victoria Hospital in Montreal back in 1974. Two years later, "palliative medicine" was named a new specialty by the Royal College of London and Edinburgh.

But despite this, the uptake in the Canadian medical community hasn't been particularly swift or enthusiastic. Only last year was "palliative medicine" officially sanctioned as a subspecialty by the Royal College of Physicians and Surgeons and about one-in-five Canadian

GPs say they aren't particularly comfortable providing these services.

The biggest barriers are familiar ones: inadequate education and funding. According to a few different palliative care doctors interviewed for this article, a properly supplied region is supposed to have at least 10 hospice beds per 100,000 people in the population, but there are areas in Toronto where that many beds serve a population of over 1 million. The Canadian Hospice Palliative Care Association estimates that if access to pal-

**There's an implicit belief in palliative care that so much physical, emotional and psychological pain aren't an unavoidable part of dying, but rather by-products of the process.**

liative care had been expanded between 2003 and 2011, the savings in Ontario alone would have been between \$40 million and \$345.5 million. Yet, despite this, Canadian families personally pay for the majority of costs associated with palliative care at home (which is both the most cost effective and the most frequently requested form) and hospices are funded mostly through charitable donations.

That may soon change. Last May, a member of parliament introduced a bill that required the development of a framework to improve access to palliative care for all Canadians, and last year the federal government committed \$5 billion over 10 years for several health initiatives like home care, with some of that money earmarked for palliative care.

That funding is crucial but it also needs to accompany a broader philosophical shift. Patients do, after all, have the vast majority of their interactions of the health system in the final years of their life. Fully embracing palliative care means changing much of medicine.

### Palliative rehab: Start early, live longer

There is very good evidence that palliative care not only improves a patient's quality of life, but also extends it.

The morning Dr. Buchman met Goodman, we had visited another patient with a kidney cancer that had metastasized into his bones. In a field where most patients live a few months after their referral, this particular man had survived 12 years after his diagnosis. He has trouble sitting upright but

he still travels hours outside the city to vacation. He still—despite the incredible pain—walks, which should be impossible for someone with a cancer as advanced as his. Dr. Buchman said he's never seen anything like it.

One study published in the *New England Journal of Medicine* in 2010 found that among lung cancer patients who enrolled in palliative care at their point of diagnosis, the median survival rate was 11.6 months compared to 8.9 months for those who received the standard of care alone. Paradoxically, palliative patients lived longer despite receiving less aggressive intervention. Just this year, another study of 776 patients out of Sloan Kettering Cancer Centre in New York found that there was a five-month median survival benefit for those enrolled in a palliative care program. At the five-year mark, the survival rate for those patients was up 8%.

"The problem is that doctors don't always listen to patients," said Dr. Martin Chasen, a palliative care physician at William Osler Health Centre in Brampton, Ont. Physicians naturally fixate on disease-directed treatment at the expense of symptom management. But often it's the symptoms that cause the greatest suffering.

"A doctor sees an X-ray and starts going on about chemotherapy to shrink the tumour," he said. "The patient is saying 'but I can't breathe' and the doctor is saying 'but look, your lung cancer is small.'"

Before coming to William Osler, Dr. Chasen worked at McGill in Montreal, and then in Ottawa. In both cities, and now in Toronto, he founded what he calls a palliative rehab program. It focuses on the most basic aspects of patient wellbeing, which are too often neglected during treatment: better nutritional advice, exercise, psychological and social support.

"Do you know what the biggest determinant of quality of life is in patients with advanced-stage cancer?" he asked. "Appetite." Years back, Dr. Chasen had a patient, this 230-pound man, who ate steaks regularly and smoked. Then he got tongue cancer. He couldn't eat. He dropped to 130 pounds. "Could you imagine what that's like?" Dr. Chasen asked. An illness like that is not only an assault on the body, but also the sense of self. The rehab program is about protecting what remains.

"If you have a pair of diamond earrings and you lose



**Dr. Martin Chasen**

one of them, what do you do with the other one?" Dr. Chasen often asks his patients when explaining the rehab program. "Do you just chuck it away, or do you look after it, polish it?"

#### How the homeless die

The prevailing view among Canadians is that, if given the choice, they would prefer to die at home. A lot of patients

don't get that choice, for many reasons. Sometimes their condition requires closer clinical oversight. Sometimes the familial support structures aren't there. Whatever the reasons, nearly 70% of Canadians die in hospital.

What's also clear is that there is a correlation between one's degree of choice and their socioeconomic standing. It's not exactly a secret that homeless and vulnerably housed Canadians face great difficulties accessing care, generally, and those difficulties

are amplified when they approach their end-of-life.

To address this, programs have opened in Ottawa, Calgary and Toronto. The Inner City Health Associates is a group of over 80 physicians working in over 50 street and shelter-based settings in Toronto, providing health care to the homeless and vulnerably housed. The palliative care component of that is PEACH, or Palliative Education And Care for the Homeless, which was founded by Dr. Naheed Dosani in 2014. At any given

time, there are between 50-75 patients in the program—patients who would have otherwise fallen through the proverbial cracks.

PEACH was born out of a sort of epiphany Dr. Dosani experienced when he met Terry. Terry was a man in his 30s suffering from a neck cancer, and doctors simply wouldn't prescribe him appropriate pain relief because of his history of addiction. So, he would bounce between ERs and walk-ins, suffering concurrently from mental health

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**References:** 1. IMS Brogan, Compuscript, January 2017. 2. ELIQUIS Product Monograph. Pfizer Canada Inc. and Bristol-Myers Squibb Canada. June 16, 2016.

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**Homeless and vulnerably housed men have just a 32% chance of living to their 75th birthday and women have just a 60% chance. The life expectancy of a homeless 25-year-old man is about the same as it was for someone living in 1921.**

issues in a system inadequately equipped to help him. One day he was found dead in the street, overdosed on alcohol and street drugs, desperately trying to find some relief. Dr. Dosani was so shaken by the

episode he took time off residency to reflect on how to help. There is little comfort in the general statistics. According to research out of Toronto's St. Michael's Hospital and published in the *British Medical*

*Journal* in 2009, homeless and vulnerably housed men have just a 32% chance of living to their 75th birthday and women have just a 60% chance. The life expectancy of a homeless 25-year-old man is about the

same as it was for someone living in 1921, before many of the advances of modern medicine. All this, simply by removing a roof over one's head.

These patients want the same things as other patients. They still want to die at home, Dr. Dosani said, it's just that the way they define home is different. PEACH does its best to equip willing shelters and boarding



**Dr. Naheed Dosani**

houses so they can accommodate those patients.

Perhaps the most revealing offering from PEACH is something it calls the Good Wishes Project, where patients are granted a final request. Those requests are almost always

remarkably modest. They range from a trip to see an estranged relative, to a new shower head, to payment on a phone bill. "They're things many of us wouldn't necessarily consider a 'wish,'" Dr. Dosani said. They're practical. They're things they need to survive.

**Things worse than death**

Towards the end of the consultation, Goodman tells Dr. Buchman that he doesn't want to be kept alive by artificial means; that when "his time comes" he'll be ready.

But Dr. Buchman presses him on these points. What exactly does he mean by "artificial means"? Medication, oxygen? He uses both now. Doctors, of course, don't know when his condition has deteriorated beyond repair and any episode if left untreated might mean it's "his time." Does he want to forgo the default interventions or a trip to the hospital if it means he'll be guaranteed to die at home? After all, the intervention may be successful. He might live comfortably for several weeks, months, years.

It's clear that Goodman hadn't considered the minutiae which, of course, is why Dr. Buchman is there, reassuring him, reminding him that he doesn't have to decide right away, that he can discuss it with his loved ones. He's there to remind him that he's still in control.

"Palliative care is not us saying there's nothing more we can do," Dr. Chasen said. Far from it. He referenced an unpublished 1992 study from his native South Africa that looked at the quality of life in breast cancer patients. Almost impossibly, there were two groups of women who said their lives improved as their cancer progressed: widowers and the poor. The widowers formed new social groups after their diagnosis and the poor were entitled to sorely needed disability grants. While the disease took so much from them, in a way, it also replaced something important in their lives.

"For many people a cancer diagnosis is the worst thing in their life, let's not kid ourselves," Dr. Chasen said. But for others, there are worse things than dying. MP

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