

# Alberta Doctors' Digest

## MAID in Alberta

The ancient philosophy of Stoicism was prevalent in Greece in the third century BC and later in Rome. Still followed with many variations today, it held that the taking of one's own life was not wrong provided it was taken rationally. When things became unendurable as a result of disease, lost honor, or defeat, you always had as a last resort the "open door" – suicide.

Lycurgus, the great Lawgiver of Sparta, much admired by the Stoics, committed suicide by starving himself after completing a seemingly successful life. As Plutarch put it in his "Lives," "[Lycurgus] was now about that age in which life was still tolerable, and yet might be quitted without regret." Stoicism was about appreciation of life and control of the emotions ... self-control, and it is of continued interest now as an aspect of the thinking of those who argue for easing of current limits to qualify for medical assistance in dying (MAID).

In the 1970s, were I to have suggested to a consultant staff physician or surgeon that a patient with advanced cancer suffering and clearly wishing to end their misery might be assisted in dying, I would have received a startled look and a footnote in my file to the effect that I might have to be watched.



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Dr. Jackson Wu, Calgary

Dr. Jackson Wu (l), Dr. Alexander Paterson (r)

There was however an effective approach – a round-the-clock dispensing of "Brompton's cocktail," a mixture of heroin, cocaine, chlorpromazine and a splash of whisky to one's taste. This was recognized as an effective remedy for pain and distress and even promoted a dash of sociability – and if it shortened life a bit, then so be it.

I also know that some patients (including some well-known names) received high doses of intravenous opiates at their request from colleagues or partners in the setting of advanced malignancy. The line between good symptom palliation and the hastening of death was often blurred in the interests of good symptom management – and I do not recall much introspective discussion as to whether this was ethical or not. It was a medical response to obvious human suffering.

It's my strong impression that the complexity of pain syndromes (in oncology at least) is greater, and the duration of suffering is longer, than it used to be, say, 40 years ago. This may be partly due to the evolution of effective anti-cancer drugs and better radiation scheduling whereby metastatic disease is halted in its progress for a time but which then shows up at sites hitherto uncommon such as the central nervous system – sites that lead to more difficult-to-manage symptoms.

So the transition to medical assistance in dying, while being of great consequence to the public and our legislators, has been less of a leap to those of us used to caring for patients with terrible symptoms where symptom management will sometimes cross over to knowing that a dose increase (e.g., of midazolam) to manage a symptom may hasten the demise of the patient. For patients in extremis, there is a name for it: “continuous palliative sedation.”

Four years ago, I wrote an article in *Alberta Doctors' Digest* (re-published in November-December 2018) on the national discussion ongoing at that time on MAID using as an example the impending death of a dear friend, party-loving Trish, who had consulted Dignitas in Switzerland. At the time of the article's publication, she was alive and not in extremis. She had participated in a phase 1 trial of a new agent in Oxford which was put to her rather slyly as an opportunity to use a promising new agent rather than some tired old palliative chemo which would not cure her. To bring this sad case to a close, she became very unwell on the agent, unfortunately receiving the highest dose level in this dose-finding phase 1 study. She lost her hair, had wicked diarrhea and skin rash, and as I predicted, regretted doing this. I still feel annoyed at the obvious conflict of interest of the clinical fellow whose job depended on accrual to the study. The professor in charge (whom I know) should have been the one to put it to Trish. Anyway, she was referred on to an excellent palliative care team and was managed professionally and with great symptom management skill to the extent that the issue of MAID did not come up, and she died peacefully.

In June 2016, when our parliament passed legislation allowing Canadian adults (18 years or over, with consent following voluntary application and with a “grievous and irremediable medical condition”) to request MAID, Canada joined five other countries: Belgium, Germany, Luxembourg, Netherlands and Switzerland; and several American jurisdictions: California, Colorado, District of Columbia, Hawaii, Oregon, Vermont and Washington.

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Between July 1 and December 31, 2017, there were 1,525 medically assisted deaths in Canada (evenly split between men and women), representing a 29% increase over the previous six-month reporting period. This accounted for 1.1% of deaths in Canada

during this period, consistent with other countries that allow assisted dying regimes. Of these assisted deaths, cancer was the most frequent underlying medical condition (65% of medically assisted deaths, with neuro-degenerative deaths comprising 10%).

MAID is administered mainly by physicians, with Alberta, British Columbia and Ontario also having nurse practitioners providing service in 5% of cases during this period. Of 1,066 requests in Alberta, British Columbia and Ontario, the most frequent reasons for refusal of MAID were loss of competency and death being “not reasonably foreseeable.”

In the Netherlands, with the longest MAID experience, 85% of MAID deaths are performed by family doctors, obviously specially trained. Each death is reviewed by a “euthanasia board.”

What is the status of MAID in Canada and Alberta now, nearly three years later? I talked to Dr. Jim Silvius, chair of the Ministerial Regulatory Review Committee, a policy-based group that deals with oversight of MAID issues and policies. There has been a sharp increase in MAID deaths in Alberta, rising from 63 deaths in the six months from June 2016 to December 2016, to 205 from January 2017 to December 2017, and to 305 from January 2018 to December 2018. Jim said several court challenges are also upcoming, such as Julia Lamb’s. She is a 26-year-old with spinal muscular atrophy whose death is not imminent but who wants to choose her own time of death. This case may have relevance to the awful problem of Alzheimer’s disease where death may be years away but consent can only be given while the patient has “capacity.”

I also discussed MAID with my dear friend Dr. Jackson Wu, radiation oncologist at the Tom Baker Cancer Centre. Jackson collaborates with the Calgary Zone MAID Care Coordination Service and a finer, more caring and educated doctor would be hard to find.

“Why did you get involved in this?” I asked Jackson.

He replied: “My father-in-law was in end-stage IPF on 10 L O<sub>2</sub> at home. He begged us to take him to Switzerland in his last months of life in early 2015. You appreciate illness suffering differently when it happens to someone close. Then my sister in Vancouver came down with unresectable cholangiocarcinoma, suffering pain and exhaustion that was hard to relieve. She asked for MAID when she was admitted for pain crisis, but she was clearly too close to the end to go through with the process and for my family to come to terms with it,” said Jackson. Even though her final days in hospice gave the family a chance to share the anguish and grief, he thought MAID was much superior to the kinds of facility deaths we physicians have experienced with relatives contacted last minute and flying in, the patient in various stages of exhaustion, and a lonely death occurring in the middle of the night with a tired resident clapping a stethoscope on the chest.

“The patient’s death needs to be ‘reasonably foreseeable’ – there are no specific requirements for prognosis or proximity to death – a rather muddy issue especially for non-cancer conditions. And their suffering has not been relieved or deemed tolerable under conditions acceptable to the patient. Bill C-14 also requires that a patient maintains mental capacity to make his or her own decision, essentially to be able to say ‘yes’ or ‘no’ with an understanding of what the procedure means.”

“How is that assessed?” I asked.

“If in doubt,” said Jackson, “psychiatry consult for capacity assessment is requested. The patient can have an associated mental illness, say depression, provided it does not interfere with his or her decisional capacity. Keep in mind we’re still talking here about incurable, progressing cancer as the irremediable condition.”

“You saw a long-suffering patient of mine last year,” I added. “I was surprised how committed she was to MAID. What’s the process?”

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Jackson explained: “If I do the first assessment, it’s likely I would be the one giving the drugs. Prior to seeing the patient, I do my usual review of the cancer history, looking at pathology, radiology and clinical notes to check for disease progression, treatments received – those elements that indicate irreversible decline. During a patient interview, I inquire about the patient’s suffering, the personal values and the purpose – is it the agony of intractable symptoms or the anguish of exhaustion, loss of meaning, emptiness of waiting to die? Are there obvious external pressures or vulnerability issues to check? Sometimes patients want to know more about what it’s like to die – in order, for example, to make an exit plan in case of future suffering, to know what symptoms can be managed with what kind of support, especially where palliative care services are available, with or without MAID. We usually keep the ‘10 clear days’ requirement between written request and MAID procedure, to allow opportunity for reflection, all part of the ‘contemplation phase.’ There is a second assessment by a different physician – again to ensure the requirements of MAID are being followed. This assessment may be more or less involved than the first review, depending on whether there are additional logistical issues to be addressed.”

“Advanced directives are, at present, not considered an appropriate approach to access MAID. There must be a request in writing with two independent witnesses and the inevitable AHS forms must be completed,” Jackson said. “We want to maintain respect of the medical and lay community, recognizing that patients are often under good care by other specialists, home care and/or family. We try to assess that no one closely involved in the care of that individual has serious objection, at least not without an opportunity to come to a resolution and find peace, although that is not something we can guarantee.”

Rather nervously I asked about the pharmaceutical protocol used – possibly because of the silly association in my mind with botched criminal executions in the US, which have no relationship to MAID.

“The nurse with me (who may also be the MAID care team coordinator) starts the IV,” said Jackson. “The IV protocol calls for midazolam for sedation, lidocaine to prep the vein because propofol is irritating, then propofol for anesthesia induction, and finally rocuronium for paralysis, with normal saline flushes in between agents. Breathing invariably stops within about five minutes, the heart within about 10. No one in Alberta has gone through with the alternative oral protocol, yet.”

So far there have been no mishaps, though occasionally the wait time for patients has been longer than ideal, for example if there is a difficulty getting a provider or the prescription filled promptly. It's critical to rule out poor symptom management, especially pain control. A patient of mine with chronic metastatic bone disease had a recurrence of severe pain three years ago. The pain did not respond to simple oral morphine, and she requested MAID. I arranged a review with the palliative care team who got on top of her pain quickly and efficiently and she is still alive, mobile and (I think) fairly happy today.

"How do you dress," I asked (probably stupidly). But I wanted to get a picture in my mind's eye.

"Well, certainly no white coat," he said, smiling. "I also gave up on wearing a blazer or sports jacket when I do consults. Patients are smart and will try to tell you what they think you want to hear if you look like a generic consultant. Shirt and cardigan combo is the routine. Also I try to lose the pager, or have it on silent mode. Any distraction is disturbing for all. If the patient has religious affiliations, their minister might attend," Jackson added. "On those occasions, their presence brings a palpable sense of wholeness and peace to the event."

Jackson offered additional thoughts on consent: "We're likely not ready for advanced directives from patients currently lacking capacity since consent must be current and is always requested again at the time of the procedure. The non-durability of the consent is, if nothing else, a logistical constraint. From a practical point of view, without invoking complicated issues around advance directives, it would certainly ease a lot of patient and family anxiety if consent can be durable for say 48 or 72 hours. That way patients won't have to worry about taking adequate opioids or sedatives for symptom control that might inadvertently compromise alertness on provision day."

"How do you relax, Jackson? How do you avoid getting overwhelmed by this?" I asked, recalling my Edmonton dentist who asked me the same kind of question: "Don't you find working at the Cross depressing?" His question came as my mouth was gagged with a rubber dam. Later I cruelly told him I'd be a hell of a lot more depressed doing nothing but filling teeth day after day.

Jackson listens to music, usually classical (think requiem), through stereophile-grade equipment, to help him clear out the cache of entangled clinical and emotional experience, without the need to block out difficult sad scenes. "I could live in a concert hall, I think. But my wife brings home many happy stories from her obstetrical practice ... Our experience at the two extremes of life kind of balances out," he explains.

In Alberta, MAID occurs roughly equally among hospital, hospice and home. Usually members of the family are present, but if there are no living relatives, the family doctor or the health care service coordinator may be the closest, and their presence is as good as that of a family.

MAID is still a work-in-progress. Outstanding issues include a role for advanced directives, MAID in under 18 age group, and the definition of "foreseeable death." Allowing mental illness as a qualifier is going to be particularly difficult. The Stoics also would have had difficulty with that.

**Editor's note**

Commentaries provided reflect personal communications. Readers should refer to CPSA and AHS MAID websites for standardized information and materials.

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