

Alberta Doctors' Digest

Death with and without Dignitas

Editor's note:

For the January-February 2019 issue of *Alberta Doctors' Digest*, we bring you this thought provoking *In a Different Vein* story from our archives (originally published in May-June 2014). *In a Different Vein* will return with a new story for the March-April 2019 issue.

Death with and without Dignitas

There's an old Yorkshire joke¹ illustrating, perhaps, the dourness of the Yorkshire soul.

The doctor visits the old man at home, confirms that he's dying and that there's nothing more to be done. But he suggests to the old fella's wife that he might like one last wish.

"Aye then, what would you like, Wilfred?" his wife asks.

"Ee' Ah'd luv a bit o' the ham that's in the larder."

"Well you can't have that, lad – that's the funeral ham."

Times have changed since that story had its heyday, although it's still trotted out from time-to-time, suggesting something universal here. The story is a reminder that death comes and goes but life goes on, including the banality of day-to-day existence.

These days the patient, if dying of cancer, might be considered for a phase 1 trial of a new drug. He or she will be reviewed by the palliative care team, the family doctor being absent from the process unless personally interested in the patient – though there are still some magnificent family doctors in Alberta who act as captain of the team. But not many.

Death, dying and the issue of euthanasia has risen again in Canada. Quebec's Bill 52, seeking to decriminalise euthanasia, died on the table with the election call but was only a few days away from becoming law. This issue is back and Canadian Medical Association (CMA) President, Dr. Louis Hugo Francescutti, has called for a discussion. I agree, and since I have had experience in the terminal cancer area – though not in the equally difficult area of chronic neurological disease – here are some thoughts.



"Dying these days can be a political as well as a medical process." - Alexander Paterson (Photo credit: Andreas Lischka, Pixabay.com)

In the last year I've been advising (from a distance) a friend whose 58-year-old sister, Trish, is facing progression of lung, mediastinal and neck nodes of a metastatic carcinoma (primary uncertain). This abscopal advising is something most doctors feel uneasy about. You don't know the fine details of the case and you don't know how the patient is perceived by the treating medical and nursing staff. You are an intrusive voice and not much good can come of it.

Trish resembles an older Jennifer Aniston. She was always a party girl, a regular to heavy drinker, a smoker – yet careful of her appearance. She's being managed by a private practice oncologist in Cambridge, United Kingdom, and has had radiotherapy to the neck and a course of palliative chemotherapy at reduced dose to avoid hair loss and minimize side effects. She's had a useful temporary disease stability but the disease has now progressed.

What to do? She's not keen on second-line chemo (which I had suggested) because it's not a "cure," and she's been entered into a phase 1 clinical trial by a fast-talking Australian clinical fellow – whom she took a shine to. He told her palliative chemotherapy wasn't going to cure her so why not try a new agent in phase 1 trials. You never know (he said) it might be a blockbuster. So she's signed up and is quite hopeful (for the moment).

From a distance I suggested that the Aussie was being too glib. The likelihood of a useful response in a phase 1 trial when its objectives are dose-related toxicity and side effects were about as high as the chances of the Not Your Grandfather's Party being re-elected to govern Alberta at the next provincial election. My friend did not understand this so I had to explain that the chances were quite low. This Antipodean resident also had a vested interest in getting her on study since his fellowship funds might be coming from the company whose drug was being studied.

I contacted an old friend in Cambridge – actually one of the investigators on Trish's phase 1 trial of this new Src/ABL inhibitor. He said, "We've reached a level where we see a biological effect, but no responses yet...."

What do I tell Trish who has entered the study in the forlorn hope of a complete response? I'll say nothing. And yet from society's perspective we need these phase 1 studies.

Trish has also made it clear that she will be the one deciding when enough is enough. She has contacted Dignitas, a Swiss company specializing in euthanasia.

Dignitas was founded in 1998 by a yodeller called Ludwig Minelli, a lawyer. The law in Switzerland allows non-criminal assisted suicide provided this is not motivated by self-interest. The Swiss definition of self-interest does not include some fairly hefty legal and medical fees. The group acts as a neutral party (which the Swiss are historically good at) and they are not quoted on the Swiss stock exchange.

There are two medical consultations by a psychiatrist, separated by a time gap to allow you to change your mind. There may be other consults (e.g., a neurologist or an oncologist) and you have to be assessed as of sound mind. You then sign a witnessed affidavit and you're in. Sometimes they take a video of you for legal purposes. I suspect you could purchase a copy for yourself.

After several opportunities to back out, you're given an antiemetic then an overdose of pentobarbital in juice (orange or grapefruit) and you die peacefully over the next 30 minutes. They've done around 1,500 assisted deaths, each costing up to \$10,000. Around one-fifth of those having an assisted suicide have (like Lycurgus in Plutarch's "Lives") "a weariness of life."

There have been problems including allegations (none proven) that the director of Dignitas, Ludwig Minelli, has received large donations from rich clients (audit of the clinic's books has not been allowed) and that suicides have been assisted in private apartments, automobiles and in a building next door to a busy brothel. What is established is that a large number of cremation urns have been found in Lake Zurich.

In the British papers in April this year, an 89-year-old woman was reported as having killed herself at Dignitas because she had become "totally fed up with the idiotic modern world of emails, computers, smartphones, tablets, the Internet, flat-screen televisions and supermarket ready meals" – indicating to me that she was of exceedingly sound mind.

Changing your mind

Some cancer patients talk about suicide when they are in the early phases of a recurrence but back off when the reality of dying hits them and they will go the way of palliative care – which includes the judicious withholding of treatment that may prolong life. Nevertheless, knowing Trish's personality, the Dignitas path may be the way she will take. However, many patients enroll with Dignitas as a kind of insurance that this is something they could do if circumstances get intolerable.

The politics of dying

Dying these days can be a political as well as a medical process. Say that the patient is no longer able to make rational decisions. The family appears: the daughter from California who has been notably absent for most of the time, wants everything possible done to prolong life; the daughter from Red Deer (who has been appointed surrogate decision maker) wants no additional measures to prolong life; and the son from Vancouver doesn't know what he wants. There are then family consultations with everyone but the family dog having a role advising the right course. The physician becomes an arbitrator. I doubt this is what Trish will want.

Coercion

This can be overt or more likely covert and is particularly relevant in the chronically incapacitating neuro-degenerative diseases. Sensitive patients may feel completely worthless when they require total nursing care and feel they can best serve society by ending their lives.

Good palliative care

The face of dying has changed in the last 50 years with the evolution of palliative treatments, which can sometimes, not always, prolong life usefully but do not eradicate the disease.

In Alberta, we have excellent palliative care with devoted, expert, intelligent physicians and nursing staff. Good palliative care includes withholding any treatment that will unnecessarily prolong life as well as the appropriate use of “terminal sedation” where sedatives such as Midazolam are given to a dose level which entirely suppresses symptoms of pain and anxiety. Death generally will follow shortly after.

Hope, treatments and spiritual approaches

In the dead of night, the angst of timor mortis is terrifying. And the constant fear of dying or losing one’s mind or having chronic pain is draining. Maintaining hope in managing advanced cancer is important. But hope comes in many guises and may not be what the patient and family recognise (i.e., hope for a “cure”). It might be trying a new or different treatment approach but more importantly it could be achieving in the patient a degree of acceptance together with excellent management of symptoms. Good, experienced spiritual advisors and psychologists help achieve this state of mind, which at some point all of us will have to endeavor to achieve.

Yet despite available good palliative care ...

Some expertise in delivering good palliative care is a goal for all physicians, but the reality is that not all patients receive this and even in those who do receive palliative care, there can come exhaustion and a desire to end it all. There is little support or advice available in Canada for patients wanting to end their lives of suffering in their own time. Some resort to subterfuges: taking an overdose of narcotics. This happens from time-to-time.

And as a corollary to assisted suicide, the recent Rasouli case, where the Supreme Court of Canada’s split decision favoring the extension of what seems a futile continuation of preserving bodily functions at great expense to society, is highly contentious. They did suggest that decisions to end life-support should be made by an arm’s length council – the Consent and Capacity Board in Ontario. We do not have this in Alberta. Most people with whom I have discussed this case think that decisions involving expensive life-prolonging care should not be left to the family. We should consider establishing a board in Alberta to examine and advise on such cases.

This board should not be an “ethics committee” type of council nor a council full of lawyers. I have found hospital ethics committees to be well meaning but often unhelpful and time-consuming in individual cases, which usually are contingent on competing medical considerations of possible life-prolonging treatment versus the treatment’s futility. However, ethics committees are useful in elaborating principles.

So Trish has contacted Dignitas.

The idea of a patient saying goodbye to friends and relatives, getting on an aircraft to Switzerland and returning in a box or an urn doesn't sit easily with me, and yet it's the only path a determined patient in Canada can take.

I think patients "in sound mind" who have chronic debilitating symptoms unable to be alleviated adequately should have the right to choose their death process and timing – and request assistance from a properly trained physician. The idea that this is currently a criminal offence does not sit easily with me. The principle I am following here is the right of the individual to the disposal of his or her own body. Dr. Donald Low's recent appeal for decriminalizing assisted suicide is particularly compelling.

Few of us enjoy discussing death, but the joke at the beginning of this article shows that death is part of life and is a process that can be discussed with equipoise and pragmatism – at least in Yorkshire. And it's a reminder that we're all going to be visited by the skeleton with the scythe.

The CMA has asked for a discussion. What do you think?

Reference

1. I'm pretty sure this one originated in the English north country, either Yorkshire or Lancashire, but I've seen versions from Scotland especially featuring dying highlanders. Either way the prevailing societal approach is to face death with fortitude and humor.

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