

## Quebec tackles difficult end-of-life care issue

**Mark Pavilons**

One characteristic that's u



ique to the human condition is dignity.

It's really hard to put into words, but we all know exactly what it is and what it feels like.

If you've ever had to care for a sick, elderly or disabled family member, you will know full well what this means.

My sister Angela passed away in her mid-40s, after suffering kidney failure and having to endure years of dialysis and blindness.

My father had lymphoma and spent his last days at home with family at this side.

My mom had a debilitating stroke and spent her last days in a nursing home.

So I am well versed on the subject of end-of-life care, currently being debated and legislated in Quebec.

That province is dealing with Bill 52, an Act that is attempting to deal with the controversial issue of medical euthanasia, or doctor-assisted suicide.

The issue is not new at all.

European countries allow the practise of doctor-assisted suicides.

Jack Kevorkian, known as "Dr. Death," was arrested in 1999 and tried for his direct role in a case of voluntary euthanasia. He was convicted of second-degree murder and served eight years of a 10-to-25-year prison sentence. He was released on parole on June 1, 2007, on condition he would not offer suicide advice to any other person.

He was an American pathologist, euthanasia activist, painter, author, composer and instrumentalist. He is best known for publicly championing a terminal patient's right to die via physician-assisted suicide. He claimed to have assisted at least 130 patients to that end.

If you remember him, you likely remember, and perhaps engaged in some lively discussions on the topic.

For anyone who's had to take care of a terminally ill relative, it cuts deep.

The Quebec act is intended to ensure that end-of-life patients are provided care that is respectful of their dignity and their autonomy. The Act establishes the rights of such patients as well as the organization of and a framework for end-of-life care so that everyone may have access, throughout the continuum of care, to quality care that is appropriate to their needs, including prevention and relief of suffering.

In addition, the Act recognizes the primacy of freely and clearly expressed wishes with respect to care, in particular by establishing an advance medical directives regime.

The provision of end-of-life care is to be guided by the following principles:

??Respect for end-of-life patients and recognition of their rights and freedoms must inspire every act performed in their regard.

? End-of-life patients must be treated, at all times, with understanding, compassion, courtesy and fairness, and with respect for their dignity, autonomy, needs and safety.

? The healthcare team providing care to end-of-life patients must establish and maintain open and transparent communication with them.

The act requires that every institution has end-of-life care policies, a code of ethics, etc.

In the final stages of my mother's life, she was in tremendous pain, suffering from both lung and pancreatic cancer. She was

paralyzed on her left side from a stroke and was never really the same.

My youngest daughter calls the day she had the stroke the 'day oma died.'

She was right, in many ways.

It's hard enough dealing with an elderly family member. Add an illness to the mix, and it often becomes too much to bear.

No one wants to put their aging parent in a home. And very few want to end up in these places, as necessary as they are.

I visited her almost every day and that in itself became increasingly difficult. If you've ever been in this situation, you know full well what I'm talking about.

Some days she was as sharp as a tack, others, she barely remembered me or my last visit. She often complained about the surroundings, the care she received and the pain.

My wife and I spoke to the nurses several times about pain management. They were surprised that my mom was constantly complaining about the level of pain she was in.

Had they known about the stage of her cancer, it would have all been obvious.

Again, at that point in a person's life, what quality do they enjoy? They can't fend for themselves and likely can't even ask for a perch next to a window in the lounge.

I hated myself for having to put her in such a place and that her final days were filled with pain and sorrow.

If she had the chance, would she have opted for assisted suicide? Yes. There's no question in my mind. And I would have supported her decision.

How often have we said of deceased relatives that they are 'better off' without the pain and suffering here on earth?

There are many who oppose this practise and yet one of our largest provinces is poised to enact legislation.

Will Ontario follow suit?

It's difficult to say.

Perhaps a referendum on the matter would help shed some light regarding public opinion.

This is not an easy topic to debate.

It's also not easy to watch a loved one wither and pass away.