

Duncan Schellenberg, November 15, 2015

“An Act Respecting End of Life Care”

There is a new law in the land of the living that will change the rules about dying. At least in Québec, and at least a little bit. Bill C-52 entitled "An Act Respecting End of Life Care" was passed in Québec's National Assembly on June 10, 2014 with a significant majority in a free vote with support from all three parties. The act stipulates that the End of Life care must be delivered with the utmost respect for the dignity, autonomy of the patient's wishes and suffering. The law does add a new provision : that patients who are suffering from an incurable disease which will only deteriorate over time and is causing them tremendous suffering may now request a new tool; medical aid in dying to deal with their suffering. Physicians may now perform a new medical act which means administering to a patient sedation and paralytic agents which would immediately end the life of their patient. The act modifies the Quebec criminal code, the civil code and the medical act. It comes in effect on December 10, 2015.

The College des Physicians responded with an 88 page document outlining the precise protocols, down to which medications to use and how to document the discussions in the patients file. The College states that there are four aspects of discussing and treating the patient at the end of life that are already an important part of the physician's responsibility. These are the DNR, or do not resuscitate order; the non-initiation or withdrawal of life sustaining treatment. This means essentially the decision not to put a patient on a respirator or to withdraw the patient from a respirator; to discuss or offer palliative care instead of curative care; and finally, to offer terminal palliative sedation to a patient who is immanently dying. This is essentially when the physician gives sedation to a patient in the last hours or days of their life which might depress their level of consciousness and respiration but would reduce the suffering in the dying moment.

To that end the College believes that offering medical aid in dying is a small and natural extension of these provisions, and that it fits well into the physician's deontology, which is to offer relief of suffering when restoring health is no longer feasible. However, there are many parameters and rules to follow, the most important of which is that the request for medical aid in dying must come freely from the patient themselves, and it must be made by a person fully capable of understanding what they are requesting. In other words, a physician is supposed to discuss and explain the concepts of DNR, or palliative sedation, as part of their assessment of the patient's condition in addition to curative options that may be

available. However, they are specifically not supposed to discuss medical aid in dying. The patient has to think of it and ask themselves without being prompted.

My conversation today is not an attempt to convince you that this is the right thing to do. I recognize that many people hold strong well articulated opposition to this bill. The opposition to the bill is largely centered on the idea of protecting the vulnerable who cannot speak for themselves. This is a very valid and important concern that I share. However, I will let others lead you through this aspect of the bill.

My own practice is in a small intensive care unit in a small hospital and in a nursing home. Many of my patients are simply at the end of their lives. My own view of medicine is heavily weighted to patients who have already been through multiple life saving therapies and are in varying states of loss of function. They will not get better, and an important part of my job is to lead patients and their families through the issues regarding what kind of care they want to receive at the end of life. There is barely a week that goes by, and never a month, that I am not involved in a discussion, or making a decision, regarding one of the four aspects of end of life care. I have accompanied many, many, patients and families right through to death. At the same time, let's keep a little perspective. Over the last 19 years that I have been a licensed physician, I can only think of a handful of my patients that might have asked for medical aid in dying. In my own practice, while it is not impossible that I will receive a request to perform medical aid in dying, it will be very rare indeed. I thought I would share a little of what it is like to discuss end of life care with patients and families and share a little of my own personal reflections as a doctor who may be involved with patients who might request of me or my hospital medical assistance in dying.

At the heart of the matter is one of personal conviction and faith. In my view, nowhere do the worlds of medical science and faith interact on a more immediate, personal, and universal level than in the discussion of the end of life. Certainly there are the blood tests, the x-rays, the CT scans, the pathology reports which require careful interpretation and explanation. When medical science is able to restore health and functioning, that is of course a marvelous thing. A gift of the modern age.

But medical science eventually runs out of options and patients eventually decline in their functioning. Medical technology has advanced to the point where much can be done to stabilise and improve cardiac and pulmonary function, but cannot always improve mobility or cognitive functions. Medical treatments may actually

impose further restrictions on daily functioning : as they strive to stabilise one organ system, they may adversely affect another. Palliative medicine may help reduce some of the more egregious symptoms of pain, nausea et shortness of breath, but is very limited in its ability to improve mobility, energy, strength and cognition, which for many people are central to how they perceive their quality of life.

When this happens, does death need to be feared? Do all patients in fact fear death? How does one face the decline in functioning that inevitably leads to death? Can patients or their families choose how they want to face this final phase? If we can choose medical science to extend life beyond what it could 50 or 100 years ago, can we make choices about how we face death? At what point will the patient put the brakes on medical treatment and investigation, allow the disease to follow its natural evolution and ask the doctor to supply relief of the symptoms imposed by disease? What is worse, living in a state of complete dependence on others for basic needs of daily living, often in a state of total body weakness and cognitive decline, or dying?

There are two main responses. About half of my patients believe that death is not the worst outcome; that death can be faced in an attitude of calm and serenity; that when contemplating therapies and investigation that the therapeutic goal must not be only the preservation of life but a restoration of some form of function that allows them to live life with a degree of autonomy that the patient sees as consistent with a good quality of life. These patients feel that living a life of total dependence on others - as is the case in a nursing home - is not consistent with the way they want to live life and that that would be worse than death.

The other half of my patients feel that death is the worst outcome. Or at least, that it is not up to us to make decisions about death. Evangelical Christians are a good example of this approach. They recognize that death will be the final outcome, but they feel death should not be a chosen strategy. They feel that the decision and timing of death must be left to a higher power. They feel that enduring suffering on earth is a sign of faith in God and leads to the promise of everlasting life in paradise. They look to the miracles of Jesus for inspiration, and believe that remaining faithful to the possibility of the miracle is what gives them courage to face the suffering from disease. If death comes anyway, they do not feel abandoned by God. Rather, they feel God has a plan which is unknowable but ultimately wise. They need to feel that they did not choose death; that they relinquished that responsibility to God and they feel serene in that choice. They typically ask me to continue life saving therapy.

If I look at my own parents, grandparents, and members of my faith community from Manitoba, I see people who profess the same faith in God, but draw a different message from the gospels. They see that death is a natural end to life and that the Gospel message is one of doing good while on earth, but there is to be no fear in death. They see medical science as a gift from God, but a human tool nonetheless, with human limitations. They see persistent loss of autonomy as a sign from God that life is now drawing to a close. These signs need to be acknowledged and respected. They feel they are committing acts of faith and courage when they put the brakes on the excesses of medical science and direct the officers of medical science to focus on measures which relieve suffering. They see the miracles of Jesus as proof of God's existence, but not as a directive to petition God for one.

This is the attitude that most closely reflects my own personal views, and I share this with my patients and their families. But I go on to tell them that the next doctor coming on has a different view. His priority is to continue medical treatment and investigations and his convictions come from his personal and cultural background. They would get another opinion. This approach has allowed me to be open with my views. It allows patients and families to examine their own values and convictions and proceed according to those values rather than worrying about whether they are making the appropriate treatment decisions. It normalises the discussion and it reassures them that if they express that prolongation of life is the priority that I as a physician will listen, respect and aid them in this choice. If relief of suffering is the primary consideration I help them with this too, even when an imminent death is the outcome.

But what about the cases where the disease imposes serious limitations on functioning which medical science simply cannot restore, but that cardiac and pulmonary functioning may keep the patient alive for many years? The new law states that these people may now ask me to end their suffering by administering medications which will put an immediate end to their cardiac and pulmonary function. The difference with the new law is that it must be the patient who initiates the discussion. I cannot recommend medical assistance in dying as part of my treatment options.

From a professional point of view medical aid in dying is not a difficult move. I am already familiar with the medications that would be used for medical aid in dying. I already use them to put people on ventilators and to treat them while they are on life support. I know the doses, the time of action, their effects and side effects. I

would use the same medications but not the life support that comes with them. If a patient were to ask me for medical aid in dying, I know exactly what to do and how to do it. This law allows to me to do just that.

So what is the problem?

Well there is a difference. I tend to like the new law. But not as a health care provider, but rather as an eventual health care consumer. Personally I feel reassured that when the time comes that I may be facing months or years in a nursing home, that I could choose medical aid in dying rather than spend time in a nursing home. However, I still don't know whether I could actually administer the medications to someone else.

I will have to examine my own conscience carefully. As I do, I look to two sources of guidance from the ancient texts. I look in particular to the Gospel of Luke. If it is true that Luke was a physician, then he will have been trained in a Greek medical school. The teaching of Hippocrates was already in place 500 years before and widely disseminated during the time of Luke the physician. He will have already been well versed in the guiding principles that inform our current medical ethics. Do no harm. Do not offer false hope. Relief of suffering is more important than prolonging life.

Luke's enduring legacy to the world was not in medical science. It was in a Gospel of Good News and Hope to all the world. A gospel that proclaimed love to all. To treat others as you want to be treated; that disease and death are not a state of sin requiring judgement; that people who are suffering and vulnerable need compassion and to be treated with dignity; that there is forgiveness of sins and the promise of life after death.

Neither Luke nor Hippocrates knew about life support, nor about neuromuscular blockages nor about propofol perfusions. They did not give specific mention about medical aid in dying. I know it is possible to find in medical literature and the gospels any justification you choose once you have made a decision. If I choose to administer medical aid in dying, no doubt I could find a verse that will justify my decision, at least in my own mind. If I choose not to, I could find others. I do know that I want to act in compassion and kindness to people who are profoundly suffering, and I want to act to protect those who cannot protect themselves.

The way through appears to be to delve deeply into the wishes of the patient themselves and find ways to respect their core values and principles. To establish

with them their goals in each and every circumstance as they arise. To provide comfort and dignity to those who are being robbed of dignity by disease. Honestly, I hope I never receive a request to perform medical aid in dying. However, I do already have a sense based on suffering I have seen, that when it is my time I will feel comfort knowing I could ask a doctor for assistance in dying rather than subject myself to living in a nursing home.

One of the greatest and most universal commandments transmitted by Luke was to do unto others as you would have them do to you. Will this become my guiding principle?

I have a few more weeks to reflect on this.