

**Brief submitted to the Quebec Commission on Dying with Dignity
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“Lessons from the Bedside”**

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Languages: First language: English

Second language: French—verbally fluent

Reason for Submitting a brief:

Between my past experience as a registered nurse and more recently in my role as a family caregiver, I have been at the bedside of many dying people. I would like to share some of what I have learned from those experiences--some recent, some in the distant past--with the Commission. I would also like to share several conclusions that I have reached about the question of dying with dignity and some specific recommendations based on my experiences.

Summary of the brief:

During my days as a registered nurse and more recently as a family caregiver, I learned that debilitating illnesses and the process of dying are not something to be shunned or feared. Instead, they are an integral part of life from which we have much to learn. I have observed that the fear of suffering and dying is greater in the anticipation than in the actual experience. I have witnessed and experienced the deepening of affection and understanding that can come about between family members during an illness and death. I have also learned that people almost never come to regret caring for a loved one but almost always suffer enormous regret for not having done so. These lessons have led me to the conclusion that dying with dignity is about being treated as a valuable human being right to the very end of life and not being discarded as a broken machine that serves no purpose. True compassion entails caring for, not discarding, the incapacitated and dying, and respecting their humanity no matter what condition they are in.

Content of the brief:

- A. A description of specific incidents that illustrate the main lessons I have learned from being with the sick and dying.
- B. The conclusions I have drawn about dying with dignity.
- C. 10 recommendations that I would like to submit to the Commission for its consideration.

Total Number of pages (printed): 5

Brief from S. Jones cont'd

Section A: Lessons Learned from Caregiving: Some Illustrations

My first encounters with death and dying were as a young nursing student at the Royal Victoria Hospital in Montreal. I vividly recall a young Father in his 30s who was dying of bone cancer. Despite being in pain, he was determined to spend as much time as he possibly could with his family and he was always optimistic and pleasant. He showed me how to face adversity in life, and how to remain serene by being focused more on the needs of others than on oneself. His courage in the face of pain and imminent death was remarkable and now, over forty years later, he remains a model of dying with dignity for me.

A second vivid memory relates to a young boy who had leukemia. It was 1973 and he was a patient at the Montreal Children's Hospital where I then worked. The rate of remission for acute leukemia was not high. He was receiving experimental drugs which had some very harsh side-effects. One day I arrived at his bedside with an intravenous bag, prepared to administer the next round of chemotherapy. He shook his head and asked me to take it away. I did. I contacted his doctor and, after reviewing his bloodwork, it was agreed that his condition was deteriorating and more medication would serve only to make his last days more uncomfortable. We switched our approach and provided palliative care though it wasn't called that in those days. We never considered that ending active treatment under such circumstances was a form of euthanasia—we knew it was not; we were not terminating his life, we were terminating futile treatment. It was the right action to take when further treatment would do harm rather than good.. Nine-year old Guy died peacefully in his hospital bed surrounded by loving family and caring nurses.

The hospital ward that I worked on at the Montreal Children's Hospital was for adolescents. The movie, *Love Story*, was a box office hit and some of our young patients with leukemia watched it together. Afterwards they were filled with romantic notions about slipping into a coma and dying prettily rather than continuing treatment with all of its unpleasant side-effects. Some of these patients, whose bloodwork showed they were going into remission, asked to have their treatment stopped. Again, the answer was obvious but in this case it was no. Several years later, I enrolled in the same university course as a young fellow who had been one of the patients that was ready to give up on treatment. I was and remain grateful that no one had proclaimed a blanket right for patients to refuse treatment.

These are but a few of the many lessons about death and dying that I recall from my nursing days. My experience as a family caregiver also taught me a lot about this stage in life.

My Father was diagnosed with throat cancer in 1986. We cared for him at home until his needs became more than we could manage. He was admitted to a four-bed ward in a palliative care facility in Toronto. I requested a single room but the palliative care nurse told me that patients who are dying take comfort in each other's presence and communicate with each other in ways that are mysterious to observers. I had only seen patients dying alone in a room and had no experience of this communication. My Father died within days of admission to the palliative care hospice. The patient across the room died at precisely the same moment. The patient in the bed beside his, a very ill man who seemed far from lucid, told me he'd seen my Father slip out with the other fellow. The experience proved to me once again that death is a mysterious and complex process and not simply the cessation of mechanical processes.

In 2001, my Mother, a widow in her 80s living independently in Montreal, was diagnosed with colon cancer. She had often said she would refuse treatment at that stage in life, preferring to die rather than to be kept going "past her time". But faced with the decision, she opted for the surgery. The cancer was successfully removed but she came out of the surgery in a state of confusion. In her doctor's words, we could send her to a near-by nursing home far from family where she would spend the rest of her days staring at the ceiling wondering who she was or we could bring her home and help her to recover much, though not all, of her mental function. That was the beginning of a five-year journey with Alzheimer's that taught all of our family about the hardship, heartache and intense rewards of being with someone suffering from that most dreaded of illnesses. Her mental state and memory did improve considerably about three

months after the surgery and we spent many enjoyable moments together walking the dogs, feeding ducks along the river and just sitting and talking. During those years I came to know my Mother in a way that had never been possible before.

There were many good days but in moments of frustration my Mother would say she was going to do away with herself by stepping out in traffic. It was a signal that she was feeling lost or useless, not truly suicidal. Providing something useful for her to do usually put an end to such talk. But when she went to stay at a local respite centre, they took her talk of suicide seriously and referred her to a geriatric psychiatrist. We went to the appointment. With great solemnity he said, "Mme Trudeau, I understand you've been talking about ending your life. "Yes", she replied and then she looked him in the eye and said "But I'm here aren't I".

I came to realize that too often we stop letting people with advanced illness make a contribution and instead take over for them. Its an easy trap to fall into. They need a long time to do awkwardly what a well person can do effortlessly in a fraction of the time. We often think we are helping them but in fact we are just brushing them aside for our own convenience. We make them feel unwanted and push them to thoughts of suicide. There's no room for the slow or deficient in our fast-paced, highly efficient society. And so not surprisingly, people who are failing come to feel like failures whose only option, only service to society is to end their lives.

The time came when we had to request placement for my Mother but more than a year went by and still no opening was available.. Finally, while in respite care, she became combative and was sent to the Gatineau Hospital emergency. From there she was placed in Le Foyer de Bonheur, a long-term care facility in Hull, in the special Alzheimer's unit where patients roam around in a state of half-dress; some talking to themselves, some yelling. It is painful and frightening to see. Had I been asked at the outset if this was living, I might have said no. But in the three months that my Mother remained in the unit, my husband and I came to see things very differently. We got to know and care about the patients on the unit and their families. We came to see that they responded to attention, that they had likes and dislikes, and that they were very aware of the way they were being treated by the people around them.

Unfortunately, the care that these people deserved at this delicate stage of life was sadly lacking. Inadequately trained aids, too few in number, are the only staff that regularly attend to these people. Most of the aids don't know even the fundamentals of care and let secondary complications set in that should never occur. In my Mother's case, inadequate fluid intake led to a bladder infection that went undiagnosed despite my requests for a urinalysis to determine why she was suddenly failing. I was told I was over-reacting; I was told all patients go downhill when they come into a facility. My Mother's complaints of pain were dismissed by the aid. "She didn't fall", the aid told me, "and we don't call the doctor for anything but falls" By the time the infection was confirmed, it had spread to the kidneys That same afternoon my Mother turned to me and said, very matter of factly, "I'm dying". A little later, she took some ice cream from a spoon. "Thank you, that is so good" she said smiling. Those were her last words. Later that day she slipped into a coma.

One might expect that the nursing aids in a long term care facility, where almost every patient will die, would know how to care for and position a dying person. It is a very important part of alleviating suffering. But I had to show the aids how it should be done. To their credit, they wanted to learn whatever I could teach them. Morphine was readily administered by the registered nurses and the simple and equally important physical comforts such as mouth care and skin care were carried out by my sister and I. It was a final act of love on our part and one that brought us closer together. My Mother's suffering was controlled, she was surrounded with love and compassion and died with dignity.

In summary, as a nurse and family caregiver, I have learned the following lessons:

- a) Death is a deeply meaningful part of life that should neither be feared nor trivialized but met with courage and handled with the utmost respect;
- b) Contrary to popular belief, the dying have much to teach us about life and how to live it, if we're prepared to learn from them. For that to happen, we have to overcome our fears of illness and suffering and allow ourselves to be close to the sick and dying.
- c) The loss of dignity at the time of death does not come from declining faculties, nor from the loss of bodily control, but from being treated as a non-person, as a failing machine that is in the way.
- d) The choices people make about the end of life while they are healthy can change radically when they are ill.
- e) Viewed from a distance, it is hard to see the human dignity in the infirm and elderly; up close it is very easy to see, even in the most incapacitated of persons.

B. Main Conclusions:

Expediting death does not make it dignified; treating the dying with care and compassion is what allows a person to die in dignity and in as little discomfort as possible.

It is one thing not to prolong a patient's life but quite another to shorten it, even unintentionally. Neglect, let alone deliberate lethal measures, should never be an acceptable part of end of life care.

The pressure for euthanasia and assisted-suicide stems from a long list of fears: fear of suffering, of being a burden, of futile treatment, of lack of sufficient palliative care and of sky-rocketing costs. Perhaps the biggest fear of all is that of losing control not only over one's own life but over the lives of others. But a society that capitulates to fear rather than overcoming it with love and patience is not a compassionate society. It is simply a fear-based society. True compassion requires love and respect for each individual's life, no matter how compromised.

C. Recommendations

The recommendations I would like to make to the Commission based on my experience are:

1. Improve home care services for patients suffering from dementia;
2. Increase support for family care givers;
3. Expand palliative care facilities;
4. Better training for aids in long-term care and respite facilities;
5. Facilitate medical conferences on the topic of terminating treatment to help doctors determine what is futile and when it is worth continuing;
6. Promote public understanding of the difference between terminating treatment and terminating life to overcome the confusion between withdrawing futile treatment and letting a person die from their disease or injury on the one hand and deliberately terminating the person's life on the other;
7. Promote public understanding of the circumstances in which a person can refuse treatment for themselves or for someone in their care;
8. Do promote public understanding of the difference between administering pain medication and sedatives to relieve suffering and administering medication to deliberately terminate a life.
9. **Do not** redefine the ordering or giving of a lethal dose of medication to terminate life as an acceptable medical act, nor as an act of compassion;
10. **Do not** redefine the withdrawal of food and water as an acceptable termination of futile treatment.