

Brief for the Select Committee on Dying with Dignity

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I am a family physician with over 25 years' experience both in primary care and as a consultant in a specialized geriatric clinic. I work in the Division of Geriatric Medicine at the McGill University Health Centre and am an assistant professor in the Department of Family Medicine at McGill University.

I have both a professional and a personal interest in end of life issues. My day-to-day work is with older people who are losing autonomy, becoming frail and coming face to face with dependency and their eventual mortality. In the fall of 2009 I lost my father to end-stage chronic lung disease, and this experience of being a family member as well as a professional gave me new insights into the care of the dying.

In my clinic I see patients who are referred for all kinds of health issues related to aging, but most often for impaired cognition and dementia. I often follow patients from the early stages of their disease until their institutionalization or death. This work has taught me a great deal about how patients and their families cope with degenerative and terminal illness.

Patients who receive a diagnosis of dementia are understandably worried about the future. If they understand the natural course of the disease they are aware that, even with treatment, it will gradually get worse until it ends their life, unless another illness, such as heart disease or stroke, intervenes to end it sooner. They foresee that they will become more and more dependent on their family or on community home care services, and possibly need to move to an institution. Fear is a natural reaction on the part of both patients and families.

As time goes on, patients and their families go through a learning experience. Many come to understand that life is not over because they or their parent have dementia. They obtain the help they need and a new equilibrium is reached. Roles change and often reverse, with the child caring for the increasingly dependent parent. This is far from being a universally negative experience; it often strengthens bonds and creates closeness in the family that was not there before. A young man, whose mother and aunt have Alzheimer's disease and are my patients, describes how enriching the experience has been for his family: "you develop new ways of connecting and bonding... you say things you would not have said earlier in the relationship... a lot of beautiful things can happen." Of course, not everyone does so well. Caring for a patient with dementia can also cause anxiety, conflict and exhaustion. It can strain relationships to the breaking point.

Whether the dementing illness makes or breaks the patient, the family and their relationships depends on many factors. The obvious one is the characteristics of the dementia itself. Caring for someone with paranoia, agitation or behaviour problems is a challenge to anyone, and if the symptoms cannot be treated, will be a source of distress to

all concerned. Factors that are less obvious include the nature of the pre-existing family dynamics, the caregiver's ability to adapt to his or her new role, and the support provided by the health care system. Providing appropriate support to patients and families can sometimes turn an unbearable situation into one that is almost positive.

Dementia is often cited as an example of a fate worse than death. This is not my experience. Patients beyond the early stages are often oblivious to their condition, and are happy if they are loved and cared for. Family members suffer because of specific problems that can often be addressed. Some would advocate for advance directives allowing for euthanasia in the case of advanced dementia. I propose a more optimistic approach: do everything we can to treat difficult symptoms. Support the family. Maybe then we will hear caregivers saying, as the wife of a man with Alzheimer's disease once said: "I have lost a husband, but I have gained a child."

My father's case was completely different. He was an active retired businessman, involved in his family and his community and with many hobbies and interests, who became increasingly short of breath and was diagnosed with chronic lung disease about five years ago. In the space of a few months he went from playing tennis (more and more with the head than with the legs!) to needing home oxygen and turning blue if he tried to work in his garden. His family doctor instituted treatment and referred him to the local CLSC, who provided the oxygen and began visiting him regularly at home. He was an accountant by training and had always been very meticulous. He made great efforts to understand his disease and to learn to manage it so as to maintain as active a lifestyle as possible. With the help of his doctor and the home care services he returned to gardening and bird watching and continued many other activities he enjoyed, including family parties and symphony concerts.

About a year before he died, his lung disease began to cause serious heart problems as well. He developed severe leg swelling, his breathing got worse, and little by little he had to curtail his activities again. During this year we could see him coming to terms, little by little, with the fact that his disease was irreversible and that it would eventually end his life.

In the last few months he was in and out of the hospital several times with leg swelling and shortness of breath of increasing severity that could not be controlled even with very strong diuretics. One Sunday morning we got a call from my mother saying that he had pneumonia and was being transferred to the intensive care unit. My siblings and I converged on the small-town hospital where he was, about an hour's drive from Montreal. To my great relief, the internist on call was an excellent physician who had spent some time in my department during his training and who had cared for my father on previous occasions. My father was not doing well, and the doctor was already asking questions such as "do we put him on a ventilator if his breathing deteriorates?" He sat down with my mother, two of my siblings and myself, and explained that my father's lungs were much damaged, that his heart was failing badly, that if he was put on a ventilator he would probably never get off it, and that while on it he would be unable to communicate. He gave us the information clearly, kindly and in terms the non-physicians

could understand. He asked for direction without pushing, although it was clear he thought that treatment with a ventilator would be futile. As my father was still fully lucid, we said the decision was his, and the situation was explained to him. He initially still felt that he wanted to fight, but after a few hours of reflection and soul-searching called us in and said "I don't want the tube". He was prepared to face the inevitable. He was kept in the ICU, on BIPAP, a machine that facilitates breathing without intubation and without taking over the body's work of breathing, and all other medical treatments were continued. The medical and nursing care were excellent, and the staff kept us informed of his condition. During the next two days out-of-town family members arrived and we took turns staying with him at the hospital, taking care of my mother, and going to work when we could. I arrived early Tuesday morning and found my father's family physician at his bedside. He said that he was now in respiratory failure and recommended withdrawing the BIPAP. Nothing would be done to accelerate his death: the fact that he had a fatal disease was recognized and treatments that would not help him would be withdrawn. My father understood and agreed. He had said all he wanted to say to the family, and just wanted to spend his last moments with us. I have a cherished memory of spending that morning in my father's room with my sister, each holding one of his hands, saying nothing or talking quietly about family members and events. The others were sleeping at my mother's house, having spent the night at the hospital. Little by little the BIPAP was removed and replaced with oxygen and morphine to make his breathing as comfortable as possible. The monitors were removed and in the afternoon he was transferred to a private room outside the ICU. We were all there as he gradually lost consciousness and finally stopped breathing at about 5:00 p.m.

My father had a good death. He was at peace, and left us at peace, despite our sorrow at losing him. This was the result of many factors, including his own personality, support from his family, the physicians and other health professionals who cared for him, and his medical condition that did not drag on endlessly or cause extreme pain. The system worked well for him. I'm not sure it would have worked as well in the university teaching hospital where I work, where everything is bigger and more complicated. . I have seen many ways in which terminal illness and death can go wrong. I am grateful that my father's went right.

The Select Committee on Dying with Dignity presumably has the goal of improving the well-being of dying Quebecers. I applaud this goal, but it is far from being reached. Our health system, with its many merits, still fails often in providing good care to the dying.

My father had a family physician he had known for years and with whom he had an excellent relationship. Many Quebecers lack access to a family physician. He had expert home care, adapted to his medical diagnosis and his needs. He did not need very much: he remained autonomous for the most part and was well surrounded by his family. Not everyone is so fortunate. I have many patients living at home in high risk situations, isolated, undernourished, not taking their medications appropriately, because the home care service has a limited budget, and family members are far away or non-existent.

My father's hospital care, prior to his final illness, was far from perfect. He spent many days in emergency rooms waiting for a bed in the hospital. Emergency rooms are not staffed to care for people waiting for beds: they are busy with those who keep coming in. My mother observed to me once that, of course, he could never brush his teeth in the emergency room: there were not enough personnel to help patients with basic hygiene. He did not need the diagnostic services the ER provides, or to see a doctor he had never seen before and who had to start from scratch to understand his condition. If there had been a way for his own doctor to admit him directly to the hospital and start treatment, it would have saved him grief and unburdened the emergency room. But the only door to the hospital now is through emergency, except for elective surgery. No matter how well you are known and how clear your needs are. So emergency rooms continue to warehouse patients to whom they cannot provide adequate care.

My father was not confused, and was able to ask for what he needed. Others are not so lucky, and the environment in the ER makes them acutely confused. Just the other day a patient of mine who has dementia became agitated in the short stay unit. The reason? She was awoken in the ER and transferred to this unit at 11:00 p.m., had no idea where she was or why, and was expected to immediately calm down and go to sleep. Because of the agitation she was given a strong sedative (which made her confusion worse for several days) and tied to her bed.

My father's last days in the ICU went well because he had the care he needed: neither more nor less. They might have been awful had he, or we, not understood his condition and fought the inevitable. They would have been even worse had those caring for him been ill at ease with dying patients and not discussed the decisions with us honestly and clearly. This often happens, especially with young doctors or nurses who are inexperienced with death but are left on their own to deal with it. Or with physicians who are being pulled in too many directions and lack the time, skills or inclination to sit down with the patient and family and guide them through the decision-making. It would have been terrible had the staff been impatient for things to be over, and tried to rush us through those last moments. This happens all the time, for emotional reasons or because of a shortage of resources.

I was astonished, on reading the material provided by the Committee and the online questionnaire, to see that the sole focus of the discussion is euthanasia and assisted suicide. There are so many issues that need to be discussed and improved before even remotely considering killing patients to relieve their suffering. I have mentioned some, and could raise others, such as the availability of palliative care to all those who need it, educating students and health professionals on the care of the dying, and the necessary humanization of the whole health care system. People are not dogs that we put down when they are in pain. Our patients deserve all our skill, expertise and resources to help them face this last great challenge of their life.