

## Submission to Special Joint Committee on Physician Assisted Dying

Author: Katherine Hammond

Please allow me to provide information to the Special Committee on Physician Assisted Dying. I am the adult daughter of Margot Bentley, a woman who continues to be kept alive, even though she has End Stage dementia (stage 7 of 7) and had clearly expressed a wish, when competent, to be allowed to die. My mother is now living out a tragic situation she feared and dreaded and tried to prevent. She can no longer speak for herself, so I ask you to give me the chance to speak on her behalf. I feel it is important for the committee members to hear from people whose lives have been directly affected by our current laws.

My mom started to talk about dying 30 years ago; her end of life was incredibly important to her. She did not fear death. What she did fear, however, was a slow lingering, a gradual decline, degradation and loss of her dignity. She spoke about this many times with her family. In 1991, when my mom was of sound mind and body, she wrote what she called her Living Will. The Advanced Directives which she detailed made her wishes very clear, in our opinion. She wrote: "If at such a time the situation should arise that there is no reasonable expectation of my recovery from extreme physical or mental disability, I direct that I be allowed to die and not be kept alive by artificial means or heroic measures". She also wrote that she be given **no nourishment or liquids**. She added a hand written note under E: OTHER in her Living Will; it reads "**In the event that mental deterioration is such that I am unable to recognize members of my family, I ask that I be euthanized**".

In 1999, 8 short years later, my mom was diagnosed with Alzheimers; she was horrified. We were all horrified. She was a Registered Nurse and knew well what her future would hold. She made her family promise that her Living Will would be honored.

My mom was looked after at home for about 5 years, until it became impossible. She has been in long term care now for over 12 years. She started to lose the ability to recognize us about 10 years ago; her words became garbled and incomprehensible and she then gradually lost the ability to speak. My mom stopped walking or moving, and then could no longer even stand to be transferred. Eventually she was unable to even sit up in a chair. For the past 5 years she has been vegetative; she lies silent and motionless in bed, contracted and spastic, unable to speak or to move, eyes closed most of the time, essentially unresponsive and diapered. She is being kept alive by being "force fed", in the words of her family physician. The care facility where my mom resides is ignoring his written order that stipulates that the staff feed his patient only if she indicates a desire to eat; she has been unable to indicate anything at all for many years. Her doctor respects the rights of his (mentally competent adult) patients to refuse care, treatment or intervention of any kind, even if this means they will die. He is supportive of my mom's previously expressed wishes to simply be left alone, to be allowed to die, while of course, being provided with sedation and pain relief and compassionate end of life care.

My mom has what we believe to be the very basic rooting reflex of a newborn infant or a severely brain damaged adult; when her mouth is prodded with a spoon, she will open it, reflexively, even if the spoon is empty. Several legal opinions have described the force feeding of my mom as a "battery" – she is being touched with a spoon without her consent and against her (previously expressed) wishes.

In 2011, my family approached the care facility where my mom resides and asked that her Living Will be honored. Initially it seemed that it would be, that force feeding would stop and that she would be kept comfortable with medication and sedation and be allowed to die. We all felt incredibly relieved. However, a couple of short days later, the local Health Authority intervened

and stated that they had a duty to provide care to my mom, a duty to continue to feed her. In the British Columbia Health Care Act, Medical care is differentiated from Basic Care, with legal representatives being allowed to make decisions about *medical* choices (ie: no antibiotics) but **not** allowed to make decisions about *basic care*, and it was argued later in court as to whether the provision of nourishment and liquids is health care or basic care. Our position was that food and water form the most basic and essential elements of health care because, without them, we will all die, no matter what other medical interventions might be initiated. I believe that this is a very badly written law that is much too open to interpretation and it should be rewritten or amended.

Margot Bentley's wishes are being denied and her family, as her representative, has been ignored.

In 2012 a Vancouver lawyer graciously offered to represent my mom, on a pro bono basis, and we went to the Supreme Court of British Columbia seeking an injunction to prevent anybody from feeding Margot Bentley. We received what I believe to be a very wrong finding of fact by the judge, who ruled that my mom, acknowledged to be in End Stage Dementia, stage 7 of 7 (severe cognitive impairment) was capable of making decisions, of making choices about what she ate. The issue of battery was not even addressed by the Court. We were utterly shocked, upset, angry and sad. An Appeal was launched and it too, was unsuccessful.

There is a Police Order on my mom's chart, written by the "Adult Abuse and Neglect" department of the local Health Authority that prevents my family from moving my mom. The local Police are to be called if we attempt to come and get her. This is appalling and we see it as a huge infringement both on our rights and the rights of Margot Bentley. My family has been told that if we formally arrange with the Health Authority to take her home, we have to continue to force feed her and we will not agree to do this, we will not go against her wishes.

My mother is being forced to exist in the very state that she tried so hard to avoid; she is caught in a legal limbo between life and death, her suffering prolonged by others. As noted above, my mother wrote that she wanted to be euthanized; **she requested Doctor Assisted Dying when she was a bright, active, mentally competent woman in 1991**, and she reiterated her wishes in 1999 following her diagnosis of Alzheimers Disease. These wishes, so clearly expressed, should be honored when Doctor Assisted Dying is legislated in Canada. This is an issue that will impact a growing number of aging Canadians with Dementia and I strongly urge the Committee to include legislation that will enable their voices to be heard, even when they are no longer able to speak.

Submitted by Katherine Hammond,  
Daughter of Margot Bentley, Proxy in her Living Will

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