

Barbara Kay: We are ignoring a key part of 'dying with dignity'

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Ing Wong-Ward is disabled, dependent on a wheelchair and afflicted with colon cancer, accompanied, for the past year, by a stubbornly persistent abdominal abscess. This seems a depressing scenario, but Wong-Ward presents as anything but depressed in her promotional article for palliative care in Saturday's *Globe and Mail*, "Living — and dying — with dignity." Wong-Ward writes she was surprised to discover that palliative care — which, like many Canadians, she identifies as meaning "you are about to die" — is more about guidance and protection for patients "who are coping with the most difficult time of their lives," which may or may not include the prospect of imminent death. In fact, Wong-Ward was told she may have years to live in spite of her cancer. But through consultation with a palliative-care expert, her fears of a gruesome death (for although she wants no heroic measures at the end, she also does not wish to be euthanized) were assuaged, and she was given "the window I need to live my life, as compromised as it now is." Palliative care is more about guidance and protection for patients (--image--)

(--image--)

Wong-Ward resists the freighted term "dying with dignity." She is well aware that many euthanasia proponents would not consider the constrained circumstances she grapples with "dignified," but that troubles her, as well it should. She is "trying to live with dignity as I always have, despite the very real medical indignities" she endures. Wong-Ward's final pitch echoes my own point of view on this subject. It "dismays" her that the state makes it easy for people without terminal conditions to end their lives, and that lobby groups such as Dying with Dignity are not "actively lobbying for increased access to palliative and hospice care." They aren't, because according to my reading of the literature, activists for euthanasia regard activists for palliative care as rivals for the same "customers," rather than purveyors of an equally worthy but different "product." Furthermore, in assessing what happens in countries or other jurisdictions where euthanasia becomes legal, it is clear to me that citizens with poor quality of life who demand greater resources for "assisted living" rather than opting for "dying with dignity" are looked at with a certain impatience and disrespect. Activists for euthanasia regard activists for palliative care as rivals for the same 'customers' (--image--)

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Take, for example, the Ontario case of 42-year-old Roger Foley. Foley's mind is perfectly functional, but his body is ravaged by a progressive neurodegenerative disease, cerebellar ataxia, which renders him dependent on intensive caregiving. Foley is exactly the kind of individual Dying with Dignity was formed to assist with euthanasia, for his condition is both irremediable and, to most euthanasia proponents, what they would consider intolerable. Alas for them, Foley wants to play out the cards he was dealt. He wants to live at home with assistance but, having arrived at suicidal ideation due to alleged injuries, food poisoning and other incompetency-induced indignities at the hands of government-funded care, he has been hospitalized in a London hospital for two years. According to Foley, he now has two options: "forced discharge" from hospital and return to "contracted agencies that have failed him," or euthanasia. Foley seeks a third option, "assisted life with self-directed funding," and he is suing the hospital, several health agencies and the attorneys general of Ontario and Canada to get it. His demand seems reasonable to me. It will be less costly than hospitalization, and it will give him a measure of control he cannot feel as the infantilized ward of an impersonal state. Barbara Kay: If ideologues are teaching our judges, the public has a need to know Barbara Kay: Getting to the heart of what M-103 was always all about Barbara Kay: There's no safe space on campus to debate bathroom politics What comes across in Foley's story is institutional insensitivity to his individual needs, and — in my interpretation — resentment that he is complaining about substandard care, and worse, demanding to live optimally, rather than die to validate the theory that death is, or should be, preferable to radically diminished physical independence. I have just read, and recommend, a beautiful new book about palliative care, *With the End in Mind*, by Kathryn Mannix, a British physician specializing in Cognitive Behaviour Therapy with palliative-care patients. The book is a series of stories (somewhat edited to conceal identities) about deaths that Mannix has overseen, both easy and difficult, experienced by a broad spectrum of humanity: toddlers, teens, mid-lifers, the elderly. Mannix is a loving presence, exactly the kind of "deathwife," as she calls palliative-care practitioners, one would want for oneself at the end. Committed as she is to palliative care as the best way to die, Mannix is not the least bit ideological (although one story, of a Dutch patient who moved to England because his Dutch doctors kept pressing him toward euthanasia, was disturbing). I recommend it to all those facing the end who have fears of the process itself (in most cases not nearly as awful as we imagine) and anxiety about discussing it with loved ones. This book will comfort and ease passage for the dying and for their circle of support alike. • Email: kaybarb@gmail.com |

Twitter: BarbaraRKay This column has been updated to correct the name of Roger Foley.