

More on End-of-Life

In the fall issue of *Health Care Ethics USA*, Ethical Currents began with the observation that “care at the end of life has been receiving considerable attention of late, much of it in the popular press....” Much the same can be said three months later. End of life issues have been very prominent in a variety of media outlets. But whereas the previous attention dealt mostly with improving end-of-life care through better advance care planning and the like, more recent developments raise ethical concerns.

Of course, there were all the media reports about the self-inflicted death on November 1, 2014 of Brittany Maynard, a 29-year-old woman who had terminal brain cancer. At least two major themes emerged from this event. First, as ethicist Arthur Caplan observed, Maynard’s youth changed the optics of the debate over physician-assisted suicide. Two videos she created for Compassion and Choices, posted on You Tube, generated more than 15 million views as of mid-January 2015. Maynard was featured on the cover of *People* magazine, appeared on several network morning and evening news programs and posted a page on the Compassion and Choices website that attracted more than five million visits. Compassion and Choices chief program officer noted that “nothing has touched as many people as Brittany’s story and changed the dialogue around death with dignity the way this has.” (Paula Span, “A New Face on the End-of-Life Debate,”

New York Times, November 5, 2014). This may well be the case.

Second, Compassion and Choices President Barbara Combs Lee stated that there is no more fundamental right than the right of the terminally ill to control the manner and timing of their death. This belief was a constant refrain before and after Brittany Maynard’s death and it seems to be gaining popularity judging by the frequency with which it was appealed to by so many who commented on Maynard’s death. A survey of more than 21,000 physicians conducted by Medscape from September through November 2014 and published in December 2014 found that 54 percent of physicians supported the right of patients with an incurable illness to seek “a dignified death” (Medscape Ethics Report 2014 at http://www.medscape.com/features/slideshow/public/ethics2014-part1?src=ban_wnl_2). This was up from 46 percent when the same question was asked in a 2010 Medscape survey.

In a December 26, 2014 op-ed in the *LA Times*, a journalist and retired family medicine physician wrote: “Clearly, we can no longer hide behind the flimsy shield of the Hippocratic oath. The drumbeat for change has begun. To pretend otherwise shows a lack of compassion and a disregard for not just for medicine but for the dignity of life.” They go on to say: “But perhaps we should set aside the debate over the [Hippocratic] oath and what it means. Should we allow our dedication to an ideal ... to outweigh an individual’s stated

choice of forgoing pain and suffering? If we allow medicine to prolong life, should we also allow it to shorten life for the terminally ill?” So as not to burden physicians who oppose aid-in-dying, the authors suggest forming a new class of medical professional—licensed death doula—who would oversee the end of life for the terminally ill (Nora Zamichow and Ken Murray, “The Hippocratic Oath and the Terminally Ill”).

A Pew Research poll in 2013 found that 63 percent believed that a person has a “moral right” to suicide when “suffering great pain with no hope of improvement” (up from 55 percent in 1990), though 49 percent say they oppose doctor-assisted suicide for the terminally ill (<http://www.pewresearch.org/fact-tank/2014/10/22/americans-of-all-ages-divided-over-doctor-assisted-suicide-laws/>).

A seeming shift in public sentiment regarding the legitimacy and availability of physician aid in dying is evidenced in the growing number of state legislatures that are considering its legalization. Oregon, Vermont and Washington are currently the only three states with aid-in-dying legislation in place. New Mexico and Montana have court rulings that protect physicians who help patients to die.

Currently, there is aid-in-dying activity in at least six states. In California, Compassion and Choices has hired staff, held community meetings, and is lobbying local public officials. On January 22, 2015, two California state senators introduced a bill that would legalize

physician aid-in-dying. A recent poll there found that nearly two-thirds of those asked would vote in favor of such a bill. Two state legislators in Colorado are drafting legislation modeled after the Oregon law that they hope to introduce this year. This follows on the heels of a very public request to legislators last year by an ALS patient explicitly asking them in an open letter in the *Denver Post* to “show mercy on the terminally ill. Please.” Charles Selsberg, the 77-year-old who died because he stopped eating, has become the face of proposed legislation in Colorado.

In New Jersey, the State Assembly passed a bill in late 2014 and a senate committee voted toward the end of December 2014 to allow the New Jersey Death with Dignity Act to proceed to the full senate for a vote. A state senator from Manhattan is seeking support for a bill that is modeled after the Oregon law. While unlikely to pass in 2015, it has raised the issue among New Yorkers. In Pennsylvania, two legislators entered bills into the state house and senate last year, bills that are also modeled after the Oregon Death with Dignity Act. The bills did not come up for a vote before the session ended in December but are likely to be re-introduced in 2015. Finally, there is activity to legalize assisted suicide in Wyoming and Washington, D.C.

Aid-in-dying is taken a step further in a letter to the editor in the November 15, 2014 issue of the *New York Times* (the Sunday Dialogue). The author writes: “Perhaps the moment is right for broaching the idea of what we might call

prophylactic suicide: the decision of an elderly person to pre-empt the grim reaper and avoid the disabilities of extended life. ... [A] recognized right to assisted suicide for those over 80 would ensure a painless death and allow an elderly person's loved ones to be there at the end. As someone who is 85, I know I would appreciate having that choice." (Joyce Appleby, "Prophylactic Suicide," at http://www.nytimes.com/2014/11/16/opinion/sunday/prophylactic-suicide.html?_r=0).

The legalization of aid-in-dying is not the only end-of-life option being discussed in the popular and professional literature of late. In the January 20, 2015 issue of the *New York Times*, there appeared an article titled "Complexities of Choosing an End Game for Dementia" (<http://www.nytimes.com/2015/01/20/health/complexities-of-choosing-an-end-game-for-dementia.html>). The author, Paula Span, tells the story of an elderly gentleman who in his advance directive specifies that if he develops Alzheimer's disease or another form of dementia, he does not want ordinary means of nutrition and hydration, generally referred to as voluntarily stopping eating and drinking (VSED).

In November 2014, the *Daily Beast* published an article titled, "The Nurse Coaching People Through Death by Starvation" (by Nick Tabor, at <http://www.thedailybeast.com/articles/2014/11/17/the-nurse-coaching-people-through-suicide-by-starvation.html>). Judith Schwarz, a 70-year-old nurse who until recently worked for Compassion and

Choices, estimates that she has "guided" more than 100 patients through a life-ending fast or VSED. It doesn't require physician assistance, medications, or legal approbation. "According to Schwarz's reasoning, during the late stages of a terminal illness, food can be akin to a life-prolonging drug—especially when the patient has no appetite. Death by pills or lethal injection might be unnatural, but she believes that declining nourishment and medications is not. ... She just wants to make it easier for them to act on their choices—particularly if they choose a speedier death."

The Hastings Center Report published two articles in the May-June 2014 issue (Vol. 44, no.3) on withholding food and water by mouth for persons with dementia when they request this in an advance directive. In their article ("Advance Directives, Dementia, and Withholding Food and Water by Mouth," pp. 23-37), Paul Menzel and M. Colette Chandler Cramer argue for a qualified acceptance of this position, while Rebecca Dresser ("Toward a Humane Death with Dementia," pp. 38-40) raises significant concerns about such a practice. A recent article in *The Linacre Quarterly* (vol. 81, no. 3, pp. 279-285) brings the issue home for Catholic health care. Maureen Cavanagh in her piece, "How Should a Catholic Hospice Respond to Patients Who Choose to Voluntarily Stop Eating and Drinking in Order to Hasten Death," examines the ethical issues involved from the perspective of the Catholic tradition and suggests strategies for the Catholic hospice to respond to such requests.

What are some learnings and implications of these “ethical currents” for Catholic health care and the Church? At least two things seem to stand out. First, the tide clearly seems to be changing with regard to societal attitudes toward favoring physician-assisted suicide. It will be extremely difficult if not ultimately impossible to stem this changing tide. In fact, it is probably only a matter of time before we reach a tipping point. The appeal to personal choice and control has great persuasive power in American society and it is very difficult to mount convincing counter-arguments, especially when that choice and control are aimed at ending suffering and a prolonged dying.

Second, the personification of the desire and/or “need” for the right to such choice is powerful and additionally persuasive. Putting a face on situations of actual or probable suffering and prolonged dying seeking relief is also a very effective “argument” and strategy for legalizing physician aid-in-dying. Personal stories, whether in the media or before legislatures, are difficult to counter.

Catholic (and other religious) efforts to prevent or slow the legalization of physician aid-in-dying will need to take account of the personification factor, the appeal to personal choice and control, and will need to offer persuasive reasons why someone’s dying should not be hastened when death is inevitable. The challenge here is considerable, especially since much of the recent success in shifting societal attitudes toward physician aid-in-dying is due to an appeal to emotions and not to reason.

Catholic health care in general as well as Catholic health care organizations (systems and facilities) will need to decide whether, to what degree, and how to get involved in opposing legislative efforts. But equally, if not more important, they need to intensify efforts to provide good end of life care both because it is the right thing to do for patients and also so as not to contribute to the problem of unnecessarily prolonged dying processes marked by unrelieved pain and suffering. The Catholic moral tradition provides excellent guidance for providing optimal end of life care. It simply needs to be implemented on a consistent basis in all Catholic health care facilities. And, finally, Catholic health care organizations will need to be clear on their policies and procedures for addressing requests for physician-aid-in dying where it is legal and, now, requests for VSED. Neither of these issues is likely to go away.

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