

PALLIATIVE CARE NEEDS A CULTURE TO SUSTAIN IT

In an article titled “Letting Go” in the Aug. 2, 2010, issue of *The New Yorker*, Atul Gawande, a writer and surgeon, recounts the ordeal of a 34-year-old woman with incurable, metastatic lung cancer. Over the period of seven months, Sara Monopoli underwent four rounds of chemotherapy, none of which worked or even had much promise of working. She suffered a pulmonary embolism and received radiation treatments for metastases in both hemispheres of her brain. All the while, the original tumors continued to grow and the cancer spread from her left chest to the right and to her liver, the lining of her abdomen and her spine.



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Despite the odds, and her inevitable physical decline, Sara, her family and her medical team battled the cancer. It was only when Sara was admitted to the hospital with pneumonia that her primary care physician spoke with Sara and her family about the realities of her condition and, with their agreement, contacted the palliative care team. Two days later, Sara died.

Reflecting on this case, Gawande observes:

This is a modern tragedy, replayed millions of times over. When there is no way of knowing exactly how long our skeins will run — and when we imagine ourselves to have much more time than we do — our every impulse is to fight, to die with chemo in our veins or a tube in our throats or fresh sutures in our flesh. The fact that we may be shortening or worsening the time we have left hardly seems to register. We imagine that we can wait until the doctors tell us that there is *nothing* more they can do. But rarely is there nothing more that doctors can do. They can give toxic drugs of unknown efficacy, operate to try to remove part of a tumor, put in a feeding tube if a person can't eat; there's always something. We want these choices. We don't want anyone — certainly not bureaucrats or the marketplace — to limit them. But that does not mean we are eager to make the choices

ourselves. Instead, most often, we make no choice at all. We fall back on the default, and the default is: Do something. Is there any way out of this?

Is there any way out of this? Gawande seems to suggest the need for physicians to have tough, realistic conversations with their patients about end-of-life preferences. Yet not only Sara's oncologist, but also Gawande himself, had avoided those conversations with Sara. “When you have a patient like Sara Monopoli, the last thing you want to do is grapple with the truth,” he wrote. “I know, because [the oncologist] wasn't the only one avoiding that conversation with her. I was, too.”

Yet experience and many studies demonstrate that people who have substantive discussions with their doctor about their end-of-life preferences are “far more likely to die at peace and in control of their situation, and to spare their family anguish,” Gawande noted.

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Having the tough conversations is one piece of the equation. But there must be something else to offer in place of, or alongside the armamentarium of medical technologies. That alternative is what is highlighted in this issue of *Health Progress* — palliative care (which ought not to be reduced to end-of-life care). Great strides have been made over the past 15 or so years in developing

and implementing palliative care programs. “Do something” no longer need mean opting for the next form of aggressive treatment. But are tough conversations and palliative care, or hospice when treatment is no longer wanted, sufficient to improve how we die in this country? Perhaps not.

At the beginning of his marvelous book, *The Troubled Dream of Life: In Search of a Peaceful Death*, bioethicist Daniel Callahan describes the difference between a “tame death” and a “wild death” (a distinction first proposed by French historian Philippe Aries), the latter characterizing the current situation; the former occurring before the onslaught of high-tech medicine. In proposing a return to a tame or peaceful death, Callahan refers in passing to “the kind of culture necessary to sustain it.”¹ Do we presently have a culture that would sustain tough conversations and palliative care, or are such efforts an uphill climb because of the nature of the prevailing “culture” in medicine? Perhaps not.

The ordeal of Sara Monopoli suggests at least two cultural challenges. Gawande alludes to one when he writes: “An opportunity to prepare for the inevitable was forgone. And it all happened because of an assuredly normal circumstance: a patient and family unready to confront the reality of her disease.”

This is unsurprising. As a society, we do not do well dealing with our mortality even in the abstract, let alone when confronted with a relatively imminent threat of our demise. We deny and fight against death with every fiber of our being and enlist medicine in the effort. As Callahan observes, “we are all co-conspirators with medicine against death.”²

A second challenge to a culture that would sustain palliative care efforts are attitudes toward medicine and medical technology. On the part of patients, there appears to be an inability to deal realistically with medical limits. We seem to harbor naive hopes or expectations that, no matter what, modern medical technology will eventually win out over death. As Callahan puts it: “The power of modern medicine resides in its almost magical possibility of offering us a relief from biological necessity, granting us new powers to manage our fate and our destiny, presenting an image of unlimited hope, genuine knowledge and great progress. ... This is a powerful and compelling

image to a self all too conscious of its fragility.”³

A culture that will help sustain conversations about end-of-life preferences, palliative care services or hospice will be one, in part, in which human finitude is an accepted reality. “Our first task at present,” suggests Callahan, “is to recapture our mortality, to give it once again a meaningful relation to our lives. Death must be brought back to the surface, given its rightful place, brought back inside of life. ... Mortality must ... be built into the very definition of the self”⁴

Callahan describes a similar belief ingrained in the world of medicine. “[M]edicine,” he writes, “has come, in its working research, and often

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clinical agenda, to look upon death as a correctable biological deficiency. ... [W]e have been left fundamentally uncertain whether death is to be accepted as part of life or rejected as a repairable accident.”⁵

Furthermore, he writes, “in its sanctioned role as the enemy of disease and death, medicine in addition admits of no limits to its aspirations: every disease that can be cured should be cured, and there are none that in principle cannot be cured. Every death that can be averted should be averted, and there are none that in principle cannot be averted.”⁶

These beliefs undermine any sense of limits in the use of our vast technological armamentarium and result, he says, in “a stretching to the limit and beyond the power of technology to extend the life of organ systems independent of the welfare of the persons to whom they belong.”⁷ If this is even a somewhat accurate description of the culture of medicine, it can hardly be said to contribute to sustaining efforts to achieve a peaceful death.

Though some may say it is overstated, Callahan’s is a strong indictment of modern medicine and the faith that moderns have placed in it. It would seem that if palliative care is to exist and indeed thrive in a culture that supports it, patients and medical professionals will need to transform the culture, to bring to life-threatening illness a sense of limits. This does not mean passivity

or premature resignation or defeatism before illness. It simply means acknowledging there comes a point when human life and medicine have reached an end, when medicine “has put aside fantasies of medical miracles, has settled down to the enduringly important business of helping us live out, and die with, incurable illness.”

Of course, there are other threats to a sustaining culture. On the one hand, there are those who claim that hospice and even palliative care are simply disguises for euthanasia, and on the other hand, there are those who want to dispense with dying and opt instead for a quick death at one’s own hand with the assistance of a physician, or at the hand of another.

For those of us in Catholic health care, the *Ethical and Religious Directives for Catholic Health Care Services* offer a critical insight: “The use of life-sustaining technology is judged in light of the Christian meaning of life, suffering, and death. Only in this way are two extremes avoided: on the one hand, an insistence on useless or burdensome technology even when a patient may legitimately wish to forgo it and, on the other hand, the withdrawal of technology with the intention of causing death.”⁸

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NOTES

1. Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death* (Georgetown University Press, 2000), 53.
2. Callahan, 51.
3. Callahan, 126.
4. Callahan, 123-24.
5. Callahan, 58.
6. Callahan, 87.
7. Callahan, 41.
8. United Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 4th edition, Introduction to Part Five (Washington, D.C.: USCCB, 2009). Available online at www.usccb.org.

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