

*The President's Council on Bioethics  
Testimony of Stephen L. Mikochik  
September 12, 2008*

Thank you for the opportunity to testify about the concerns we disabled people have regarding futile care.

My name is Stephen Mikochik. I am a professor at Temple Law School in Philadelphia and the chair-elect of the National Catholic Partnership on Disability.

NCPD was established by the U.S. Catholic Bishops in 1982 to implement their *Pastoral Statement on People with Disabilities*. A central aim of our mission is "to increase the public's sensitivity toward the needs of ... [disabled] people ... and support their rightful demand for justice."<sup>1</sup>

On behalf of the 14 million American Catholics with disabilities, we ask you to consider our concerns about futile care. Specifically, we fear that the pressure to contain cost will increasingly influence physicians to withhold or withdraw life-support from disabled patients, not because they consider such measures futile in prolonging our lives but because they consider futile the lives such measures prolong.

We recognize that there comes a time when physicians should "shift the intent of care" away from "further intervention to prolong ... life" and "toward comfort and closure."<sup>2</sup> Yet, we must equally acknowledge, as did the New York State Task Force on Life and the Law, that "physicians' judgments about the value of continued life for the patient will be shaped by the physician's own attitudes about illness, physical dependence, pain, and disability."<sup>3</sup> Moreover, we cannot ignore the pressures physicians face today to contain costs. As the AMA observed, "[w]hen deciding whether to order a test or procedure for a patient under managed care, the physician must consider whether the slot should be saved for another patient or not used at all to conserve the plan's resources."<sup>4</sup> It would blink reality to deny that more physicians will rest such determinations on "quality of life" considerations in the future and that insurers will become less inclined to pay for treatment for patients with severe disabilities.

The legal structure that would allow this is largely in place. Texas, for example, permits physicians to withhold or withdraw life-support they judge inappropriate from patients with conditions that render them permanently unable to care for or make decisions for themselves and would be fatal without such support,<sup>5</sup> an open invitation to forgo life-support for patients with severe disabilities on "quality of life" grounds. And Texas is

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<sup>1</sup> *Pastoral Statement of the U.S. Catholic Bishops on People with Disabilities*, ¶ 11 (Nov. 16, 1978).

<sup>2</sup> AMA Opinion E-2.037 "Medical Futility in End-of-Life Care."

<sup>3</sup> N.Y. State Task Force on Life & the Law, "When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context," 123 (May, 1994).

<sup>4</sup> AMA Council on Ethical and Judicial Affairs, "Ethical Issues in Managed Care," 2-3 (1995).

<sup>5</sup> See V.T.C.A., Health & Safety Code § 166.002(9).

not unique in this regard. According to the Robert Powell Center for Medical Ethics, statutes in many other states give physicians wide discretion to disregard their patients' requests for life-support.<sup>6</sup>

Simply put, we fear that these factors will combine to make futile care for disabled patients a mere euphemism for euthanasia by omission. We urge you to avoid these ends by avoiding these beginnings and recommend policies on futile care that strongly presume in favor of continued life-support. We have detailed our approach in a statement our Governance Board adopted this August that we have submitted for your review. Though we rely on official Catholic teaching, the principles we use are distinctly rational. I will briefly set forth our conclusions.

Clearly, if it were immoral for the patient to forgo care or treatment, it would be equally wrong for the physician. We believe it is immoral for patients, and thus for physicians, to forgo ordinary means of preserving life. We agree with recent Catholic teaching that such means include artificially supplied nutrition and hydration, unless altogether useless in sustaining life, substantially and intractably painful for the patient, or productive of serious ancillary complications.<sup>7</sup>

On the other hand, it is morally permissible for patients to forgo extraordinary means of preserving life. Extraordinary means are those that "in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community."<sup>8</sup>

In striking this balance, however, we believe that a physician's standing is not the same as the patient's. For example, given that the physician has already assumed responsibility for the patient's care and thus owes him a high professional duty, the physician does not have the latitude a patient has in deciding whether the hope of benefit, weighed against the anticipated burdens, is sufficiently reasonable to warrant commencing or continuing treatment.

Accordingly, we believe first that physicians can withhold or withdraw life-support, not otherwise burdensome, only when they can demonstrate that such measures provide no real benefit to the patient because death is inevitable and imminent-- inevitable, to avoid "quality of life" rather than quality of treatment decisions, imminent, to ensure that the terminal condition, not the withdrawal of treatment, is the cause of death.

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<sup>6</sup> See "Will Your Advance Directive Be Followed?", Robert Powell Center for Medical Ethics of the National Right to Life Committee (Appendix of State Statutes) (May 20, 2007).

<sup>7</sup> See Address of John Paul II to the participants in the International Congress on "Life-sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas," #4 (Mar. 20, 2004); *Responses to Certain Questions Concerning Artificial Nutrition and Hydration with Accompanying Commentary*, Sacred Congregation for the Doctrine of the Faith (Aug. 1, 2007).

<sup>8</sup> *Ethical and Religious Directives for Catholic Health Care Services*, U.S. Conference of Catholic Bishops (4th ed.) (June 15, 2001), Pt. Five, ERD 57, "Issues in Care for the Dying" (footnote omitted).

By contrast, since their duty is ultimately to the patient and not the patient's family, physicians can withdraw life-sustaining measures, even over family objections, when such measures cause substantial, intractable pain. Physicians can legitimately presume that incompetent patients would not desire such treatment, provided there are no reasonable grounds to believe a patient would wish otherwise.

Physicians, however, are obviously in no position to second-guess the impact of patient care on family finances, particularly when their judgment goes against the family's wishes.

Further, we note that the overall cost of providing ordinary care to patients on life support often far exceeds the expense of life-sustaining measures themselves. However, to withhold or withdraw such measures because a patient's earlier death may obviate the need for such ordinary care and hence ease financial burdens on health care providers or the community at large would effectively constitute euthanasia.

Alternatively, where life support itself proves exceptionally costly, patients, in their free and informed discretion, can selflessly forgo it to save the community expense; but no one can make this choice for another. Thus, without clear evidence of their patients' intent, we believe that physicians can withhold or withdraw life-support because of expense only when the cost is so disproportionate to its hoped-for prolongation of life that it would be plainly unreasonable for patients to have chosen otherwise.

Finally, we note that procedural safeguards are often as important as substantive requirements. Consistent with a strong presumption in favor of continued life-support, the procedures outlined in our statement place a heavy burden of proof on those seeking to withhold or withdraw such measures.

Undoubtedly, identifying when physicians can ethically withhold or withdraw life-support they consider futile is an urgent task. It is not too much to say that the lives of countless disabled people hang in the balance.