

NCPD BOARD STATEMENT ON “FUTILE CARE”*

Introduction

Every principle tends “to expand itself to the limit of its logic.”¹ The principle that one may sometimes allow removal of treatment that sustains human life illustrates this point. Over the past three decades, the United States has witnessed a near stampede in the extension of patients’ legal right to refuse life-sustaining measures,² beginning with the removal of respirators³ to the more recent controversy over withdrawing food and hydration from those in a “persistent vegetative state.”⁴ The latest stage in this development concerns the issue of “futile care”—specifically, whether health care providers are ever justified in withholding or withdrawing care or treatment that they consider inappropriate against the wishes of patients or their surrogates.

The use of the term “futile care” generally refers to the claim that “Physicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefiting their patients.”⁵ Unfortunately, there is no agreement within the medical community as to when such interventions lack sufficient benefit to be judged futile. For example, “[s]ome physicians use ‘futile’ narrowly, considering treatments to be futile if they would be physiologically ineffective or would fail to postpone death. ... Many [other] physicians embrace a broader, more elastic understanding of the term. ... [A] treatment might be seen as futile if it

* Approved by the Board of Directors of the National Catholic Partnership on Disability, August 22, 2008. We understand that the U.S. Bishops will consider revisions to their *Ethical and Religious Directives for Catholic Health Care Services* this November. We will determine whether changes to this statement are needed in light of those revisions once they are issued.

¹ BENJAMIN N. CARDOZO, NATURE OF THE JUDICIAL PROCESS 51 (1949).

² See *Cruzan v. Director, Mo. Dept. of Health*, 497 U.S. 261, 277, 278 (1990) (“[T]he common-law doctrine of informed consent is viewed as generally encompassing the right of a competent individual to refuse medical treatment. ... The principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions.”).

³ See *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

⁴ See *Cruzan*, 497 U.S. 261; *Schiavo Family Marks Her Death Anniversary; Anti-Euthanasia Effort Announced*, WASH. TIMES, Mar. 31, 2006. See also 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) (“[The artificial administration of water and food] should be considered, in principle, ordinary and proportionate, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality ...”), available at http://www.vatican.va/.../john_paul_ii/speeches/2004/march/documents/hf_jp-ii_spe_20040320_congress-fiamc_en.html (last visited Nov. 5, 2007). We will use the term “persistent vegetative state” because it is accepted in the medical profession, putting it in quotations, however, since we agree with John Paul II that it “is certainly not the most felicitous when applied to human beings.” *Id.* at #3.

⁵ AMA Opinion E-2.035 “Futile Care,” available at <http://www.ama-assn.org/ama/pub/category/2830.html> (last visited Dec. 5, 2007). Though the term “futile care” generally refers to medical treatment, it has also been used to justify the withdrawal of food and hydration, whether or not artificially supplied, which official Catholic teaching considers, not a medical act, but rather ordinary and proportionate care. See *infra* note 46.

does not offer what [these] physicians consider an acceptable quality of life.”⁶

We have a vital interest in the outcome of this question, given its obvious importance for the lives of countless critically ill and disabled people. We offer the present statement to explore what light Catholic moral teaching sheds on whether health providers can ever withhold or withdraw life-sustaining care or treatment they consider futile.⁷ Though we will continue to use the label “futile care” because it is an accepted term of art, we reject any implication that the lives involved, rather than simply their care or treatment, are futile.⁸ We maintain at the outset that all human life, no matter how disabled or critically ill, is of quality and incomparable worth and no less entitled on that account to adequate health care.⁹

We begin our discussion of the question of “futile care” by reviewing recent developments in Texas.

Background

Under a 1999 amendment to Texas’ Health and Safety Code, attending physicians are permitted to withhold or withdraw life-sustaining treatment, contrary to patients’ or their surrogates’ wishes, when such physicians consider that treatment inappropriate.¹⁰ The authorization applies to “qualified patients”¹¹ with “terminal”¹² or “irreversible”¹³ conditions and includes the artificial

⁶ “Will Your Advance Directive Be Followed?”, Robert Powell Center for Medical Ethics of the National Right to Life Committee, 5 (May 20, 2007) (quoting the New York State Task Force on Life and the Law, “When Others Must Choose: Deciding for Patients Without Capacity” (New York: n.p., 1992, pp. 196-97), *available at* <http://www.nrlc.org/euthanasia/AdvanceDirectives/ReportRevised2007.pdf> (last visited Nov. 5, 2007).

⁷ We do not mean to imply that health providers are obliged to deliver services not readily available or outside their area of specialization. Our inquiry centers on whether a patient otherwise qualified to receive the type of services a health provider supplies can be deprived of these services because the provider considers them, in this patient's case, futile.

⁸ As with “persistent vegetative state,” we will refer to the term “futile care” in quotations.

⁹ *See Ethical and Religious Directives for Catholic Health Care Services*, U.S. Conference of Catholic Bishops, Gen. Intro., ERD 3 (4th ed.) (June 15, 2001) (“[T]he person with mental or physical disabilities, regardless of the cause or severity, must be treated as a unique person of incomparable worth, with the same right to life and to adequate health care as all other persons.”), *available at* <http://www.usccb.org/bishops/directives.shtml#introduction> (last visited Jan. 9, 2008).

¹⁰ *See* V.T.C.A., Health & Safety Code § 166.046(e) (“If the patient or the person responsible for the health care decisions of the patient is requesting life-sustaining treatment that the attending physician has decided and the review process has affirmed is inappropriate treatment, the patient shall be given available life-sustaining treatment pending transfer The physician and the health care facility are not obligated to provide life-sustaining treatment after the 10th day after the written decision ... is provided to the patient or the person responsible for the health care decisions of the patient unless ordered to do so [by an appropriate state district or county court.]”).

¹¹ *See id.* § 166.031(1).

¹² “Terminal condition” means “an incurable condition caused by injury, disease, or illness that according to reasonable medical judgment will produce death within six months, even with available life-sustaining treatment[.]” *Id.* § 166.002(13).

provision of food and hydration.¹⁴ An ethics committee must review the decision, and life-support must continue pending review.¹⁵ If the decision is affirmed, patients will receive life support pending transfer but only for ten days after receipt of the committee's determination.¹⁶

A private survey of five years' operation under the Amendment found that 974 ethics committee reviews were held on medical futility cases, affirming treatment-cessation decisions in 65 instances and resulting in the ultimate removal of life-support for 27 patients.¹⁷ While the survey did not distinguish between patients with terminal and irreversible conditions, there is some evidence that those in a "persistent vegetative state" were among the subjects of such decisions.¹⁸

Texas' procedure attracted national attention when Children's Hospital in Austin proposed removing a respirator from a 17-month-old baby, Emilio Gonzalez, diagnosed with Leigh's disease, a fatally degenerative brain disorder.¹⁹ The hospital, operated by the Sisters of Charity, contended that the treatment was painful and merely prolonged the child's death. The hospital's position was supported by the Catholic Bishop of Austin who appealed to standards established by Catholic moral teaching.²⁰ The child's mother, however, insisted that the treatment continue and was joined in her efforts by the Texas Right to Life Committee, the ACLU of Texas, and various disability groups.²¹ After an unsuccessful search to find another facility willing to

¹³ "Irreversible condition" means "a condition, injury, or illness:

(A) that may be treated but is never cured or eliminated;

(B) that leaves a person unable to care for or make decisions for the person's own self; and

(C) that, without life-sustaining treatment provided in accordance with the prevailing standard of medical care, is fatal." *Id.* § 166.002(9).

¹⁴ *See id.* § 166.002(10) ("Life-sustaining treatment' includes both life-sustaining medications and artificial life support, such as mechanical breathing machines, kidney dialysis treatment, and artificial nutrition and hydration.").

¹⁵ *See id.* § 166.046(a) ("If an attending physician refuses to honor a patient's advance directive or a health care or treatment decision made by or on behalf of a patient, the physician's refusal shall be reviewed by an ethics or medical committee. ...The patient shall be given life-sustaining treatment during the review.").

¹⁶ *See supra* note 10.

¹⁷ *See The Scope of the End-of-Life Issue*, Dallas Morning News, Feb. 15, 2007 (reporting on findings by Dr. Robert L. Fine, director, Office of Clinical Ethics, Baylor Health Care System, for 11 Texas hospitals over a 5 year period and 5 additional hospitals over a 2 year period), available at www.dallasnews.com/sharedcontent/dws/dn/latestnews/stories/021507dntexendoflife.1798039.html (last visited Mar. 8, 2008); *Proposed Bills Give Families Final Say in Life-Sustaining Treatment for Patients*, TEX. LAW., Mar. 5, 2007(same), available at www.law.com/jsp/tx/PubArticleTX.jsp?id=1172829796788 (last visited Mar. 13, 2008).

¹⁸ *See id. Cf. Bills Challenge Limits for Terminal Patients: Some Say 10 Days to Transfer Isn't Enough Before Treatment Ends*, Dallas Morning News, Feb. 15, 2007 (reporting that patient's treatment removal was based on diagnosis of an irreversible "vegetative state" and possible suffering, but further asserting that patient was dying).

¹⁹ *See, e.g., Case Puts Texas Futile-Treatment Law Under a Microscope*, WASH. POST, Apr. 11, 2007.

²⁰ *See Letter of Bishop Gregory Aymond, Diocese of Austin, Texas* (Apr. 15, 2007), available at www.txcatholic.org/documents/bishop_aymond_end_of_life.pdf (last visited Nov. 5, 2007).

²¹ *See Is care ever futile? Texas MDs, Advocates Square Off*, MED. ETHICS ADVISOR, June 1, 2007.

continue treatment, a probate judge granted the child's mother a temporary restraining order. The trial was set for May 30th, 2007, but Emilio died of natural causes eleven days before trial.

Emilio's case served to galvanize opposition to the existing procedure for termination of treatment in the Texas General Assembly. One bill that would have increased the period for treatment pending transfer from 10 to 21 days, and exempted food and hydration from the list of treatments eligible for termination under this procedure, received unanimous support from the Texas Conference of Catholic Bishops.²² A rival bill would have required the provision of life-support until a transfer actually occurred.²³ Ultimately, time ran out before any remedial legislation could be passed. The Texas legislature is likely to reconsider the issue when it reconvenes in 2009.²⁴

As indicated,²⁵ existing Texas law authorizes health providers to withhold or withdraw life support they judge inappropriate from patients with terminal conditions, or with conditions that render them permanently unable to care for or make decisions for themselves and would be fatal without such support. It would permit withholding or withdrawing food and hydration, for example, not only from patients in a "persistent vegetative state" or suffering advanced dementia, but arguably even from those with cerebral palsy or developmental impairments who may require food and hydration administered artificially because of the severity of their conditions.²⁶ With so broad an approach to what constitutes "futile care," current Texas law is an open invitation to withhold or withdraw life-support from patients with severe disabilities on "quality of life" grounds.

Texas, however, is not unique in that regard. Statutes in many other states give health care providers wide discretion to disregard advance medical directives requesting life-support.²⁷

²² See Testimony of Bishop Gregory Aymond, Diocese of Austin, Texas, representing the Texas Catholic Bishops, on HB 3474, Texas General Assembly, House Committee on Public Health (Apr. 24, 2007), available at www.tx catholic.org/testimony-on-hb-3474.html (last visited Nov. 5, 2007).

²³ See *Futile care law is getting 1st aid/Medical groups will compromise in order to save contested statute*, HOUS. CHRON., Apr. 25, 2007.

²⁴ There are presently two reported court cases under the Texas statute. See *Hudson v. Children's Hospital*, 177 S.W. 3d 232 (Tex. Ct. App. 2005) (involving the attempted withdrawal of a respirator, apparently because too painful, from an infant diagnosed with "thanatophoric dysplasia," a fatal tissue abnormality); *Nikolouzos v. St. Luke's Episcopal Hospital*, 162 S.W. 3d 678, 683 (Tex. Ct. App. 2005) (involving the termination of life-support from an adult male described as not meeting "the criteria for 'brain death' because cerebral blood flow was present.").

²⁵ See *supra* notes 12 & 13.

²⁶ These examples fall within the exact terms of § 166.002(9). See *supra* note 12. Whether proponents originally intended so broad a scope for that provision is irrelevant since, "[i]f the disputed statute is clear and unambiguous extrinsic aids and rules of statutory construction are inappropriate[.]" *Cail v. Service Motors, Inc.*, 660 S.W.2d 814, 815 (Tex. 1983).

²⁷ See "Will Your Advance Directive Be Followed?" (Appendix of State Statutes), *supra* note 6. Six states (Alaska, Connecticut, Delaware, Michigan, Texas, Virginia) permit health care providers to disregard an advance directive requesting life-support if they judge it medically inappropriate. *Id.* Four states (Colorado, Missouri, Massachusetts, New York) permit health care providers to disregard an advance directive if honoring it would violate religious beliefs central to their operating principles. *Id.* Statutes in two states (Nebraska, West Virginia) list both of the

Although patients can transfer if they can find another provider willing to honor their wishes, few states guarantee life-sustaining treatment pending transfer.²⁸ Given that care of patients on life support can prove costly,²⁹ health care providers have a strong incentive to resort to laws authorizing withholding or withdrawing care or treatment more frequently in the future.³⁰ Likewise, few providers have an incentive to accept such patients once their original provider refuses to continue treating them.

We offer the following analysis of issues surrounding “futile care” that we believe is consistent with our advocacy for critically ill and disabled people and with our Catholic faith.

aforementioned grounds, either of which would permit health care providers to disregard an advance directive requesting life support. *Id.* Two states (Hawaii, New Mexico) allow health care providers to disregard an advance directive requesting life support for reasons of conscience or if it is considered medically inappropriate. *Id.* In the majority of states (Alabama, Arizona, Arkansas, California, Florida, Georgia, Idaho, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Minnesota, Mississippi, Montana, Nevada, New Hampshire, New Jersey, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, South Dakota, Tennessee, Utah, Vermont, Washington, Wisconsin, Wyoming, and likewise District of Columbia, Guam, Virgin Islands), physicians or health care facilities may disregard an advance directive if they are “unwilling to comply” or “decline to comply,” sometimes for reasons of morality or conscience. *Id.* North Carolina has no statute concerning when health care providers are permitted to disregard an advance directive requesting life-support. *Id.* Our reservation about these statutes is not that they recognize a right of conscientious objection in cases where providers consider the proposed life-sustaining measures to be inherently immoral, so-called life saving abortions, for example, and the like. Our concern rather is that providers can argue that these statutes also grant them the right to object to providing treatment on quality of life grounds.

²⁸ See *id.* at A11-A14 (setting forth the statutory provisions of 11 States (Alabama, Florida, Kansas, Maryland, Massachusetts, Minnesota, New Hampshire, New York, Ohio, Oklahoma, Wyoming) requiring life-preserving treatment pending transfer, with no time limit); *id.* at A10 (setting forth the statutory provisions of 2 States (Texas, Virginia) requiring life-preserving treatment pending transfer, but only for 10 & 14 days respectively).

²⁹ See, e.g., *Boy At Center Of Ethics Case Dies: Dallas Mother’s Fight For Life Support Brought Attention To Law*, Dallas Morning News, May 31, 2007 (reporting that the cost for Emilio’s 142 days of ICU care reached \$1.68 million).

³⁰ “Managed care plans ... encourage physicians to make cost-conscious treatment decisions through the use of financial incentives. ... [Such] plans typically use incentives for physicians to limit their use of diagnostic tests, referrals to other physicians, hospital care, or other ancillary services. For example, managed care plans often pay bonuses to physicians, with the amount of the bonus increasing as the plans’ expenditures for patient care decrease. Or plans often withhold a fixed percentage of their physicians’ compensation until the end of the year to cover any shortfalls in the funds budgeted for expenditures on patient care. If there is no shortfall, or the shortfall can be covered by part of the withheld fees, the remaining withheld fees are returned to the physicians.” Council on Ethical and Judicial Affairs, AMA, “Ethical Issues in Managed Care” 2 (1995), available at www.ama-assn.org/ama1/pub/upload/mm/369/ceja_13a94.pdf (last visited Mar. 11, 2008). By 1995, “[m]ore than half the states ha[d] passed laws restricting money-saving methods of health maintenance organizations[.]” *States Take Aim at HMOs*, Balt. Sun, May 7, 1995. A particular focus of legislative activity was the twenty-four hour limit HMOs began to impose on reimbursement of hospital stays for routine vaginal deliveries. Critics argued that mothers often needed more time to rest and to master breastfeeding techniques, while some complications newborns encountered did not show up immediately. See *Mother and Newborn: How Long in the Hospital?*, N.Y. Times, Aug. 20, 1995; *Physicians Protest Maternity Insurance*, N.Y. Times, Mar. 5, 1995. In response, several states mandated longer minimum reimbursed hospital stays. See *Moms’ Wails Prevail; Nine States OK Laws Extending Maternity Stays*, West’s Legal News, Apr. 18, 1996 (listing enacted and pending legislation).

“Futile Care” and Catholic Moral Teaching

We begin by setting forth the general principles that have guided our consideration of this issue. The first is that “[w]e have a duty to preserve our life and to use it for the glory of God, but the duty to preserve life is not absolute, for we may reject life-prolonging procedures that are insufficiently beneficial or excessively burdensome.”³¹ The second is that “the value of a man’s life cannot be made subordinate to any judgment of its quality expressed by other men[.]”³² The last is that the first duty of health care providers is to promote the best interest of their patients, not their patients’ families or the community at large.³³

Whether health care providers can withhold or withdraw life-sustaining treatment they consider futile is largely unresolved in official Catholic teaching. In a 1957 Address to an International Congress of Anesthesiologists,³⁴ Pius XII did indicate that physicians could licitly withdraw mechanical respiration under circumstances where their patients, if competent, could ethically make that choice, but his comments provide limited guidance for the problem of “futile care.”³⁵ He addressed only whether physicians could cease resuscitation efforts that merely prolonged the death of unconscious patients, with no hope of regaining spontaneous respiration, at the insistence of their families and apparently where the patients’ own wishes were unknown.³⁶

In addition, the *Declaration on Euthanasia* of the Sacred Congregation for the Doctrine of the Faith does permit physicians to interrupt what is considered experimental treatment, but only “with the patient’s consent[.]”³⁷ All the same, the Declaration further provides that, “for such a

³¹ *Ethical and Religious Directives for Catholic Health Care Services*, Pt. Five, “Issues in Care for the Dying” (Introduction), available at www.usccb.org/bishops/directives.shtml#partfive (last visited Nov. 5, 2007).

³² Address of John Paul II to the participants in the International Congress “On Life-sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas,” #6, *supra* note 4.

³³ See “Ethical Issues in Managed Care,” at 4 (“While this responsibility to guard society’s resources is an important one, physicians must remain primarily dedicated to the health care needs of their individual patients.”), *supra* note 30.

³⁴ See Pius XII, Address to an International Congress of Anesthesiologists (Nov. 24, 1957), available at www.lifeissues.net/writers/doc/doc_31resuscitation.html (last visited May 7, 2007).

³⁵ Pius XII was addressing the following questions concerning whether physicians could terminate efforts at resuscitation: “[D]oes one have the right, or is one under obligation, to remove the artificial respiration apparatus when, after several days, the state of deep unconsciousness does not improve if, when it is removed, blood circulation will stop within a few minutes? What must be done in this case if the family of the patient, who has already received the last sacraments, urges the doctor to remove the apparatus? Is Extreme Unction still valid at this time?” *Id.*

³⁶ *Cf. id.* (“In general ... [the physician] can take action only if the patient explicitly or implicitly, directly or indirectly, gives him permission.”).

³⁷ See *Declaration on Euthanasia*, Sacred Congregation for the Doctrine of the Faith, Pt. IV (1980) (“It is also permitted, with the patient’s consent, to interrupt [experimental medical techniques] ... where the results fall short of expectations.”), available at www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19800505_euthanasia_en.html (last visited Nov. 5, 2007).

decision to be made, account will have to be taken of the reasonable wishes of the patient and the patient's family, as also of the advice of the doctors who are specially competent in the matter."³⁸

In their *Ethical and Religious Directives for Catholic Health Care Services*, however, the U.S. Bishops do provide a framework for addressing the issue. The Directives state that Catholic health care providers should normally comply with the informed judgments of competent adult patients concerning the use or withdrawal of life-sustaining procedures, unless aimed at suicide or otherwise contrary to Catholic moral teaching.³⁹ With the same qualifications, they should likewise honor the advance directives of incompetent patients or the judgments of their designated surrogates⁴⁰ who must decide on life-support consistent with the patients' wishes.⁴¹ Where no such authorization exists, those family and friends most familiar with the incompetent patient's wishes should participate in the treatment decision.⁴² In what follows, we discuss whether providers are ever justified under these Directives in withholding or withdrawing life support they consider inappropriate, contrary to their patients' known wishes or in cases where, for reasons of infancy, incompetence, patients' oversight, or the like, such wishes are unknown.

Clearly, if it were immoral for the patient to forgo care or treatment, it would be equally wrong for the provider to withhold or withdraw such measures.⁴³ Under Catholic moral teaching, it is immoral for patients, and thus for health care providers, to forgo ordinary or proportionate⁴⁴

³⁸ *Id.* (“[Such doctors] who are specially competent in the matter ... may in particular judge that the investment in instruments and personnel is disproportionate to the results foreseen ... [or] that the [experimental] techniques applied impose on the patient strain or suffering out of proportion with the benefits he or she may gain from such techniques.” *Id.*).

³⁹ See *Ethical and Religious Directives for Catholic Health Care Services*, Pt. Five, ERD 59, “Issues in Care for the Dying” (“The free and informed judgment made by a competent adult patient concerning the use or withdrawal of life-sustaining procedures should always be respected and normally complied with, unless it is contrary to Catholic moral teaching.”), *supra* note 31.

⁴⁰ See *Ethical and Religious Directives for Catholic Health Care Services*, Pt. Three, ERD 28, “The Professional-Patient Relationship” (“The free and informed health care decision of the person or the person's surrogate is to be followed so long as it does not contradict Catholic principles.”), available at www.usccb.org/bishops/directives.shtml#partthre (last visited Nov. 5, 2007). We are mindful that the wishes of an incompetent patient to authorize refusal or withdrawal of life-support may have changed from the time an advance directive was executed. Given the consequences, we think health care providers should follow such free and informed decisions, if not otherwise contrary to Catholic moral teaching, only where there are no reasonable grounds to believe that the patient would now wish otherwise.

⁴¹ See *id.* ERD 25 (“Decisions by the designated surrogate should be faithful to Catholic moral principles and to the person's intentions and values, or if the person's intentions are unknown, to the person's best interests.”).

⁴² See *id.* (“In the event that an advance directive is not executed, those who are in a position to know best the patient's wishes—usually family members and loved ones—should participate in the treatment decisions for the person who has lost the capacity to make health care decisions.”).

⁴³ See Pius XII, Address to an International Congress of Anesthesiologists (“The rights and duties of the doctor are correlative to those of the patient. The doctor, in fact, has no separate or independent right where the patient is concerned.”), *supra* note 34.

means of preserving life.⁴⁵ Such means include artificially supplied nutrition and hydration, which official Catholic teaching considers ordinary and proportionate⁴⁶ unless altogether useless in sustaining life,⁴⁷ or substantially and intractably painful for the patient,⁴⁸ or productive of serious ancillary complications.⁴⁹

⁴⁴ The term “proportionate means” is more consistent with current usage. See *Declaration on Euthanasia*, Pt. IV (“[S]ome people [today] prefer to speak of ‘proportionate’ and ‘disproportionate’ means.”), *supra* note 37.

⁴⁵ See, e.g., *id.* at #4 (indicating that “ordinary and proportionate” means of preserving life are morally obligatory); *Responses To Certain Questions Concerning Artificial Nutrition And Hydration*, Sacred Congregation for the Doctrine of the Faith (Commentary) (Aug. 1, 2007) (referring to The Address of Pope Pius XII to an International Congress on Anesthesiology, *supra* note 34 (“On the one hand, natural reason and Christian morality teach that, in the case of a grave illness, the patient and those caring for him or her have the right and the duty to provide the care necessary to preserve health and life. On the other hand, this duty in general includes only the use of those means which, considering all the circumstances, are ordinary, that is to say, which do not impose an extraordinary burden on the patient or on others.”), available at www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20070629_commento-responsa_en.html (last visited Nov. 5, 2007); *Ethical and Religious Directives for Catholic Health Care Services*, Pt. Three, ERD 32, “The Professional-Patient Relationship” (footnote omitted) (“[E]very person is obliged to use ordinary means to preserve his or her health ...”), *supra* note 40; *Id.* at Pt. Five, ERD 56, “Issues in Care for the Dying” (footnote omitted) (“A person has a moral obligation to use ordinary or proportionate means of preserving his or her life.”), *supra* note 31.

⁴⁶ 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 (“[T]he administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act. Its use, furthermore, should be considered, in principle, ordinary and proportionate, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering.”), *supra* note 4; *Responses To Certain Questions Concerning Artificial Nutrition And Hydration* (Response to First Question) (“The administration of food and water even by artificial means is, in principle, an ordinary and proportionate means of preserving life. It is therefore obligatory to the extent to which, and for as long as, it is shown to accomplish its proper finality, which is the hydration and nourishment of the patient.”), available at www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20070801_risposte-usa_en.html (last visited Nov. 5, 2007). Both of the above statements are couched in general terms and, though responding to the specific condition of “persistent vegetative state,” do not appear limited to that immediate context. Nor does it occur to us why such general principles concerning “a natural means of preserving life” should be so limited. Cf. *Ethical and Religious Directives for Catholic Health Care Services*, Pt. Five, ERD 58, “Issues in Care for the Dying” (“There should be a presumption in favor of providing nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration, as long as this is of sufficient benefit to outweigh the burdens involved to the patient.”), *supra* note 31. We understand that at their June 2008 general meeting, the U.S. bishops voted to begin the process for amending this Directive to bring it into more explicit conformity with the recent statements by John Paul II and the Congregation for the Doctrine of the Faith.

⁴⁷ See *Responses To Certain Questions Concerning Artificial Nutrition And Hydration* (Commentary) (recognizing the permissibility of withdrawing food and hydration when, “due to emerging complications, a patient ... [is] unable to assimilate food and liquids, so that their provision becomes altogether useless.”), *supra* note 45; Q & A Regarding *The Holy See’s Responses on Nutrition and Hydration for Patients in a “Vegetative State,”* U.S. Conference of Catholic Bishops, Committee on Doctrine and Committee on Pro-Life Activities (Q & A #5) (recognizing the permissibility of withdrawing food and hydration “if the available means for administering ... [them] were not effective in providing the patient with nourishment (for example, because the patient can no longer assimilate these.)”), available at www.usccb.org/comm/hydrationq&a.doc (last visited Nov. 5, 2007). See also 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, *supra* note 4. We would also consider the provision of food and

On the other hand, it is morally permissible for patients to “forgo extraordinary or disproportionate means of preserving life. Disproportionate 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.”⁵⁰

In striking this balance, however, a health care provider’s standing is not the same as its patient’s. For example, given that the health care provider has already assumed responsibility for the patient’s care and thus owes him a high professional duty,⁵¹ it 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. Furthermore, “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.”⁵²

Accordingly, we believe first that a health care provider can withhold or withdraw life-support, not otherwise burdensome, only when it can demonstrate that such measures provide no real

hydration “altogether useless in sustaining life” if patients would die from some underlying pathology before death would result from dehydration or starvation should such care be withheld or withdrawn.

⁴⁸ See *Responses To Certain Questions Concerning Artificial Nutrition And Hydration* (Commentary) (recognizing the permissibility of withdrawing food and hydration when, “in some rare cases, artificial nourishment and hydration ... [is] excessively burdensome for the patient or ... cause[s] significant physical discomfort, for example resulting from complications in the use of the means employed.”), *supra* note 45; *Q & A Regarding The Holy See’s Responses on Nutrition and Hydration for Patients in a “Vegetative State”* (Q & A #4) (“[A] dying patient, or others who can speak for the patient, may [permissibly] decide to refuse further feeding because it causes pain and gives little benefit.”), *supra* note 47.

⁴⁹ See *id.* (Q & A #5) (recognizing that the withdrawal of food and hydration is permissible “if the means itself constituted a burden (for example, because the feeding tube is for some reason causing persistent infections).”).

⁵⁰ *Ethical and Religious Directives for Catholic Health Care Services*, Pt. Five, ERD 57, “Issues in Care for the Dying” (footnote omitted), *supra* note 31. See *Declaration on Euthanasia*, Pt. IV (“[Refusal of] a technique which is already in use but which carries a risk or is burdensome ... is not the equivalent of suicide; on the contrary, it should be considered as an acceptance of the human condition, or a wish to avoid the application of a medical procedure disproportionate to the results that can be expected, or a desire not to impose excessive expense on the family or the community.”), *supra* note 37; *Ethical and Religious Directives for Catholic Health Care Services*, Pt. Three, ERD 32, “The Professional-Patient Relationship” (footnote omitted) (“While every person is obliged to use ordinary means to preserve his or her health, no person should be obliged to submit to a health care procedure that the person has judged, with a free and informed conscience, not to provide a reasonable hope of benefit without imposing excessive risks and burdens on the patient or excessive expense to family or community.”), *supra* note 40.

⁵¹ See, e.g., *AMA Code of Ethics*, “Principles of Medical Ethics” (Preamble) (“[A] physician must recognize responsibility to patients first and foremost ...”) & (Principle VIII) (“A physician shall, while caring for a patient, regard responsibility to the patient as paramount.”), available at www.ama-assn.org/ama/pub/category/2512.html (last visited Aug. 26, 2008).

⁵² N.Y. State Task Force on Life & the Law, “When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context,” 123 (May, 1994).

benefit to the patient because death is inevitable and imminent.⁵³ Death should be inevitable, to avoid “quality of life” rather than quality of treatment decisions. It should be imminent, to ensure that the terminal condition, not the withholding or withdrawal of treatment, is the cause of death.⁵⁴

By contrast, since its duty is ultimately to the patient and not the patient’s family, a health care provider can withhold or withdraw life-sustaining measures, even over family objections, when such measures cause substantial, intractable pain.⁵⁵ Providers can legitimately presume that incompetent patients would not desire such treatment,⁵⁶ provided there are no reasonable grounds to believe a patient would wish otherwise.⁵⁷ If there are such grounds, however, providers should respect their patients’ wishes since a choice to continue life support even at the cost of considerable pain is not itself unreasonable, given the family or religious motives patients may have for enduring such treatment.⁵⁸

A health care provider, however, is obviously in no position to second-guess the impact of patient care on family finances, particularly when its judgment goes against the family’s wishes.

Finally, we note that the overall cost of providing ordinary or proportionate care to patients on

⁵³ Cf. *Declaration on Euthanasia*, Pt. IV (“[In those circumstances w]hen inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted.”), *supra* note 37.

⁵⁴ Since there is no medical reason for commencing or continuing such treatment, providers can withhold or withdraw life support under these circumstances in the absence of or even contrary to patients’ known wishes. This would be a case where care is “futile” in the strict sense of the term.

⁵⁵ Cf. *Ethical and Religious Directives for Catholic Health Care Services*, Pt. Three, ERD 33, “The Professional-Patient Relationship” (“The well-being of the whole person must be taken into account in deciding about any therapeutic intervention or use of technology. Therapeutic procedures that are likely to cause harm or undesirable side-effects can be justified only by a proportionate benefit to the patient.”), *supra* note 40. In contrast, withholding or withdrawing life-sustaining measures because patients consider their lives, and not such measures, unbearably painful would constitute euthanasia. Such a standard, though seemingly humane, is so open-ended and subjective that it could authorize death on demand.

⁵⁶ As for those [patients] who are not in a state to express themselves, one can [in addition] reasonably presume that they wish to take ... painkillers, and have them administered according to the doctor’s advice. *Declaration on Euthanasia*, Pt. III, *supra* note 37.

⁵⁷ Whether a treatment is psychologically repugnant involves deeply subjective judgments that carry a high risk of reliance on “quality of life” considerations. We, therefore, do not believe it should constitute grounds for health care providers to withhold or withdraw life support, unless there is clear evidence such treatment is repugnant to a particular patient.

⁵⁸ See John Paul II, *Evangelium Vitae*, no. 65 (Mar. 25, 1995) (“While praise may be due to the person who voluntarily accepts suffering by forgoing treatment with pain-killers in order to remain fully lucid and, if a believer, to share consciously in the Lord’s Passion, such ‘heroic’ behavior cannot be considered the duty of everyone.”), available at www.newadvent.org/library/docs_jp02ev.htm (last visited June 13, 2008); *Declaration on Euthanasia*, Pt. III (“[P]ainkillers that cause unconsciousness need special consideration. For a person not only has to be able to satisfy his or her moral duties and family obligations; he or she also has to prepare himself or herself with full consciousness for meeting Christ.”), *supra* note 37.

life support often far exceeds the expense of life-sustaining measures themselves.⁵⁹ 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.⁶⁰ Alternatively, where life support itself proves exceptionally costly, patients, in their free and informed discretion, can selflessly forgo it to save the community expense,⁶¹ but no one can make this choice for another. Thus, without clear evidence of their patients' intent, health care providers 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.

Required Procedures

Clearly, procedural safeguards are often as important as substantive requirements. Accordingly, we believe that attending physicians who wish to withhold or withdraw life-support against their patients' expressed or implied wishes⁶² should first use their best efforts to find a provider willing to fulfill such wishes.⁶³ If this is unsuccessful, all necessary life support should continue pending institutional review, where a patient advocate is available to represent objecting parties who have not secured counsel. If the attending physician's decision is affirmed, such life support should continue for a time sufficient for patients, their representatives, or the institution to pursue

⁵⁹ See, e.g., *Responses To Certain Questions Concerning Artificial Nutrition And Hydration* (Commentary) (indicating that the artificial provision of food and hydration to patients in a "vegetative state" "does not involve excessive expense... [and] is within the capacity of an average health-care system," while "[w]hat may become a notable burden is when the 'vegetative state' of a family member is prolonged over time."), *supra* note 45; *Q & A Regarding The Holy See's Responses on Nutrition and Hydration for Patients in a "Vegetative State"* (Q & A #6) ("[T]he costs directly attributable to the administration of nutrition and hydration are generally not excessive. To be sure, the costs and other burdens placed on families by the patient's need for prolonged care may become very significant."), *supra* note 47.

⁶⁰ According to the Sacred Congregation for the Doctrine of the Faith, "euthanasia" includes "an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated." *Declaration on Euthanasia*, Pt. II (emphasis added), *supra* note 37. Even if the explicit or stated intent is not to kill the patient, withholding or withdrawing life support succeeds in avoiding the cost of ordinary and proportionate care only if it succeeds in hastening the patient's death – a patient who does not survive will not need any such care. Thus, hastening death is intended, as the means for avoiding expense, and thereby constitutes euthanasia. See *Q & A Regarding The Holy Sees Responses on Nutrition and Hydration for Patients in a "Vegetative State"* (Q & A #6) ("to end life because life itself is seen as a burden, or imposes an obligation of care on others, would be euthanasia."), *supra* note 47.

⁶¹ See *supra* note 50 & accompanying text. See also *Ethical and Religious Directives for Catholic Health Care Services*, Pt. Five, ERD 56, "Issues in Care for the Dying" (footnote omitted) ("A person has a moral obligation to use ordinary or proportionate means of preserving his or her life. Proportionate means are those that in the judgment of the patient offer a reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or the community."), *supra* note 31.

⁶² The same procedures are called for when physicians seek to withhold or withdraw life support in the best interest of children, incompetent adults, or other patients whose wishes are unknown.

⁶³ We do not mean to imply that physicians who withhold or withdraw life support on conscientious or religious grounds, because they consider the proposed means to be inherently immoral, are also obliged to refer to a willing provider.

alternative placements or judicial review in which the institution should have the burden of proving that, to a reasonable medical certainty, continued life support would constitute “futile care” in accordance with the standards set out above.

Conclusion

Undoubtedly, there comes a time when health care providers should “shift the intent of care” away from “further intervention to prolong ... life” and “toward comfort and closure.”⁶⁴ We believe that the vast majority of providers make this decision with competence and compassion. Yet we must equally acknowledge the pressures that providers face today to contain costs.⁶⁵ For example, according to some policies, “[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.”⁶⁶ It simply acknowledges reality to expect 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, in effect bureaucratizing euthanasia by omission.⁶⁷ Thus, identifying when health care providers can ethically withhold or withdraw life-support they consider inappropriate is truly an urgent task. It is not too much to say that the lives of countless critically ill and disabled people hang in the balance.⁶⁸

⁶⁴ AMA Opinion E-2.037 “Medical Futility in End-of-Life Care,” *supra* note 5.

⁶⁵ Furthermore, providers may share the negative attitudes pervasive in society about the quality of disabled people’s lives that in turn can influence their decisions whether to withdraw life support. *See generally*, Werth, James L., Jr., “Concerns About Decisions Related to Withholding/Withdrawing Life-sustaining Treatment and Futility for Persons with Disabilities,” *Journal of Disability Policy Studies* (16:1, June 22, 2005). *Cf.* Stith, Marah, “The Semblance of Autonomy: Treatment of Persons with Disabilities under the Uniform Health-Decisions Act,” 22 *Issues L. & Med.* 39, 60-61 (Summer, 2006); *supra* note 52 & accompanying text.

⁶⁶ “Ethical Issues in Managed Care,” at 2-3 (“[Under managed care,] physicians are expected to balance the interests of their patients with the interests of other patients.” *Id.* at 2), *supra* note 30.

⁶⁷ *Cf.* Cessario, Romanus, O.P., “Catholic Considerations on Palliative Care,” *The National Catholic Bioethics Quarterly* (6:4, Winter 2006), p. 649 (footnote omitted) (“The danger exists, as Mary Ann Glendon reports from a recent meeting of the Pontifical Council of Social Sciences, that euthanasia will be imposed. This unhappy circumstance may emerge not because of the successes of the Compassion in Dying Federation but because of the implosion of the social welfare services. According to Alan Greenspan, the country ‘will almost surely be unable to meet the demands on resources that the retirement of the baby boom generation will make.’”).

⁶⁸ *See* “Concerns About Decisions Related to Withholding/Withdrawing Life-sustaining Treatment and Futility for Persons with Disabilities” (literature review concluding that “futile care” may prove a greater threat to disabled people than the legalization of assisted suicide), *supra* note 65.