

Part II End-of-Life Issues

1. Decisions about Using or Forgoing Life-Sustaining Treatments

Procedures

A *life-sustaining treatment* is “any medical intervention administered to a patient with the goal of prolonging life and delaying death.” (1) This category includes such treatments as:

- Cardiopulmonary resuscitation
- Chemotherapy
- Radiation treatment
- Kidney dialysis
- Ventilators
- Medically assisted nutrition and hydration (tube feeding)
- Antibiotics
- Blood transfusions and blood products
- Cardiovascular implantable electronic devices (e.g., pacemakers)
- Mechanical circulatory support (e.g., ventricular assist devices). (2)

In Church teaching, medically assisted nutrition and hydration (tube feeding) is placed in a special category and will be discussed in section II.2.

The Principle of Benefits and Burdens

Historically, Catholic moralists have drawn a distinction between *ordinary* and *extraordinary* treatments, and employed the principle that ordinary treatments must always be provided while extraordinary treatments are not obligatory and may be forgone. (3) Over time, multiple different meanings came to be attached to the terms “ordinary” and “extraordinary.” (4) The Vatican *Declaration on Euthanasia* (1980) began to move away from this terminology, speaking by way of clarification of *proportionate* and *disproportionate* means (5). The latter is now understood in terms of a consideration of *benefits and burdens* of a treatment. This evolution of terminology and concepts is explicit in the *Ethical and Religious Directives for Catholic Health Care Services*:

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. (no.56)

A person may 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. (no. 57) (6)

Benefits of a treatment may be understood in a broad sense. Obviously, a medical treatment is a benefit if it brings about the cure of a disease, or at least improves a patient’s condition or level

of functioning. It is beneficial if it relieves pain or other distressing symptoms the patient is experiencing. It is beneficial in a very basic sense if it prolongs the patient's life. Or again, a treatment is beneficial if it enables the patient to do things which are meaningful to him/her or which give satisfaction in life, for example, resume a job or hobby or participate in activities with grandchildren. A treatment is likewise beneficial if it enables the patient to fulfill specific life goals, for example, to finish a project, or to see a child graduate from college or get married. (7) These are examples of benefits, not an exhaustive list.

Similarly, *burdens* may be understood in a broad sense. Causing pain or substantial discomfort can be a burden of a treatment; one can think of the nausea, vomiting, and diarrhea some people experience as a result of chemotherapy. Some treatments can have debilitating side effects. For example, patients surviving CPR may suffer neurological and functional impairments. If a surgical procedure involves significant risks, that qualifies as a burdensome aspect of it. Burdens can also be psychological, for example, depression accompanying prolonged kidney dialysis. Difficulty in getting access to a treatment can also be a burdensome aspect of it, for example, the driving distance to get to a dialysis center. (8) Again, these are examples of burdens, not an exhaustive list.

The *Ethical and Religious Directives for Catholic Health Care Services* speaks of "excessive burden" and then adds, "or impose excessive expense on the family or the community." This may give the impression that the cost factor is something in addition to consideration of the burdens of a treatment. However, there are ethicists who place cost in the category of "treatment-related burden." (9)

The first principle for making decisions about using or forgoing life-sustaining treatments is that **we have a moral obligation to undertake medical treatments which offer a reasonable hope of benefit without being accompanied by any excessive burden.**

To illustrate this principle, consider the hypothetical case of Jeremy who is 78 and resides in an assisted living facility. Jeremy still participates in many activities. Recently he has developed pneumonia. Jeremy's doctor recommends hospitalization, with antibiotics and temporary supplemental oxygen. The doctor believes that this treatment will very likely succeed in curing Jeremy's pneumonia so that Jeremy can get back to the activities he enjoys. However, Jeremy has been a very independent person all his life. He tells the staff at the facility where he resides that he feels very comfortable in his apartment and "just doesn't feel like picking up and going to a sterile hospital." Jeremy is a widower but has two sons who don't agree with their father. They are trying to persuade their father to follow the doctor's advice and go to the hospital for treatment. From a moral point of view, would it be permissible for Jeremy to refuse the recommended treatment for his pneumonia?

From a moral point of view, Jeremy should undertake the recommended treatment. It is clearly expected to be of benefit to him in curing his pneumonia. The burdens associated with the treatment are minor: the disruption of leaving his "home" in his assisted living apartment for a temporary stay in a less enjoyable hospital environment. These cannot be considered "excessive" burdens. They do not compare with the benefit of curing his pneumonia, which could potentially develop into a life-threatening condition.

On the other hand, **it is morally permissible to forgo (that is, withhold or withdraw) a life-sustaining treatment that does not offer a reasonable hope of benefit for the patient.**

By way of illustration, consider the hypothetical case of Marta, 85. She still lives at home but for some years has suffered from a heart condition which is getting progressively worse. She knows that some day her heart will just “give out.” Marta tells her daughter that she is “ready to go home to God.” Marta’s daughter, who is a nurse, suggests that her mother get a “Do Not Resuscitate” (DNR) order. When Marta and her daughter raise the issue of a DNR order with Marta’s physician, the physician comments that resuscitation “probably would not even work for her” because of her underlying physical problems. From a moral point of view, is it permissible for Marta to have a DNR order written?

The answer is yes, it is morally permissible in this case to withhold cardiopulmonary resuscitation because the resuscitation procedure is not likely to work to revive Marta. Resuscitation does not hold a reasonable hope of benefitting Marta.

Further, **it is morally permissible to forgo (that is, withhold or withdraw) a life-sustaining treatment when it is excessively burdensome for the patient.** “Excessively burdensome” has been interpreted by some ethicists as the burdens of a treatment outweighing its benefits. (10)

Consider the actual case of Shirley Waring, who developed blood cancer after being traumatized by the suicide of her son. Shirley underwent 13 months of chemotherapy on an outpatient basis, but then the treatment stopped working. She was admitted to the hospital to try something more toxic. After her latest chemotherapy treatment, Shirley felt really sick and suffered a bleeding ulcer and esophagitis. She was told that the next chemotherapy treatment would cause heart damage and lung damage. At this point, Shirley decided to stop the chemotherapy treatments. (11) The organ damage caused by the chemotherapy can indeed be considered an excessively burdensome aspect of the treatment.

We want to emphasize that these examples are offered for illustrative, educational purposes only and do not describe all types of cases in which treatments ought to be used or may be forgone.

According to the benefits and burdens principle, there is no medical treatment whose use is always mandatory nor is there any medical treatment which can automatically be forgone. The benefits and burdens of a medical treatment must always be assessed on a case by case basis, for each patient in view of his/her particular health condition, in consultation with the patient’s health care providers. The question to be asked is: What will this treatment do for this particular patient who is in this particular condition? Thus some medical treatments, such as antibiotics, may be commonly available and commonly used yet burdensome in some respects or to some patients, or even futile in some cases. When excessively burdensome or offering no reasonable hope of benefit, even common treatments may be forgone.

It is important to note that, “when assessing burdens and benefits, the Catholic tradition considers one’s total well-being as a person and not just the benefits of treatment to a particular organ.” (12) Thus, for example, a medical intervention may replace a patient’s kidney function (e.g., dialysis) but, given the patient’s overall medical condition, may not really be a benefit to the person. (13)

If a life-sustaining treatment is initiated, there should be ongoing assessment of its use. This is because the benefits and burdens of the treatment may change as the condition of the patient changes over time.

If the benefits and burdens of a treatment are difficult to assess in advance for a particular patient, a time-limited trial may be used, if medically feasible. In a time-limited trial, a medical treatment is started “with the prior understanding that after a defined period, the desirability of continuing the treatment will be reassessed.” (14) It is “preferable to offer a time-limited trial of a treatment that has potential for benefit and to withdraw it if it fails, rather than to rule it out without offering a trial.” (15) Further, a time-limited trial may “reduce a patient’s fears of losing the ability to stop treatment after making a decision to start it or help a patient or loved ones to be at peace with a subsequent decision to withdraw treatment.” (16)

Even when a decision is made to forgo life-sustaining treatments, measures which provide comfort to the patient should still be provided.

Patient Autonomy

Today there is much emphasis placed on patient *autonomy*. Autonomy refers to self-determination. (17) Autonomy “establishes the right of the patient to determine the nature of his or her own medical care.” (18)

The *Ethical and Religious Directives for Catholic Health Care Services* affirms that “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.” (19) Thus Catholic teaching respects patient choice; however, a patient’s decision making about using or forgoing life-sustaining treatments should not be arbitrary but should be guided by the principle of benefits and burdens that we have been discussing.

According to the *Ethical and Religious Directives for Catholic Health Care Services*, the assessment of the benefits and burdens of a treatment is done according to “the patient’s judgment,” not that of caregivers or others “from the outside.” (20) Different patients with the same disease may make different judgments about the burdensomeness of a particular treatment because of differences in such factors as physical stamina, age, and financial circumstances.

Historically, intense fear of or repugnance for a particular medical treatment on the part of a patient was allowed to qualify the treatment as “excessively burdensome.” (21) However, a word of caution is in order. Suppose that a person diagnosed with diabetes who needs daily injections of insulin has a pathological fear of needles. Common sense tells us that, given the clearly beneficial nature of the injections, counseling should be provided to the patient to assist him in overcoming his fear of this treatment before agreeing that he may forgo it. (22)

Proxy/Surrogate Decision Making

A proxy or surrogate decision maker is an individual who makes health care decisions for another person who lacks decision making capacity. A person, while competent, can legally appoint someone to serve in this capacity through a Durable Power of Attorney for Health Care document (see section II.4)

Iowa's Life-Sustaining Procedures Act has established the following prioritized list of proxy decision makers:

- the attorney-in-fact (i.e., the individual designated as the proxy decision maker in a Durable Power of Attorney for Health Care document);
- the patient's guardian;
- the patient's spouse;
- an adult child of the patient or, if the patient has more than one adult child, a majority of the adult children who are reasonably available for consultation;
- a parent of the patient, or parents if both are reasonably available;
- an adult sibling. (23)

The preferred standard for proxy decision making is the *principle of substituted judgment*. The proxy becomes the voice of the patient and tries to articulate the decision that patient would make. Relying on written advance directives, oral statements made by the patient, and knowledge of the patient's beliefs, values, preferences and life-long behavior patterns, the proxy predicts what the patient would want. In accord with the benefits and burdens principle, the proxy should consider how the patient would judge the benefits and burdens of the treatment.

The *best interests standard* is used for proxy decision making when the patient never expressed any treatment preferences while competent and when the patient's preferences cannot be inferred by the proxy from his/her knowledge of and experience with the patient. This standard is also used in the case of patients who never had decision making capability and whose values and preferences cannot reliably be inferred by the proxy. (24) Borrowing a concept from law, the proxy considers "what a 'reasonable person' would choose if in the patient's circumstances." (25) In other words, the proxy considers how a "reasonable person" would judge the benefits and burdens of treatment in this case. (26)

Addressing Some Misconceptions

Some individuals who are "pro-life" may be inclined towards vitalism, "the belief that human life is absolute and must be preserved at all cost." (27) According to vitalism, "any cessation of efforts to prolong life is medically and morally unconscionable." (28) This is not the position of the Catholic Church. Catholic teaching charts a course between two extremes. Taking measures to intentionally cause a patient's death (euthanasia and assisted suicide) is never acceptable, but the other extreme is "an insistence on useless or burdensome technology." (29)

We have been using the terminology "forgoing a life-sustaining treatment" to include both *withholding* a treatment (not starting it) and *withdrawing* a treatment (stopping it). Some patients or family members may feel guilty about withdrawing a life-sustaining treatment.

Emotionally and psychologically, it may be more difficult to stop a treatment than never to start it. However, withholding a treatment or withdrawing a treatment are equally permissible ethically if the treatment offers no reasonable hope of benefit or is excessively burdensome. Legally, both withholding and withdrawing treatments are permissible.

Some may fear that, in withdrawing a life-sustaining treatment, they are doing something that "kills the patient" and engaging in an act of euthanasia. It is important to keep in mind that, in the case of forgoing a life-sustaining treatment, there is an underlying disease process that made

the use of the life-sustaining treatment necessary in the first place and which will be the direct cause of the patient's death when treatment is stopped. Further, the intent in withdrawing a life-sustaining treatment is not to kill the patient but to stop a treatment that is no longer warranted medically or morally.

If a decision is made to withdraw a life-sustaining treatment, this does not mean that the treatment must be stopped immediately. Time can be given for family members and friends to say final good-byes and for religious rituals to take place before the treatment is stopped and the patient is allowed to die.

Ethics Consults

Health care facilities commonly have an ethics committee in place which offers consulting services to patients and families struggling with difficult medical treatment decisions. Pastoral counselors should keep this resource in mind for referral. If the consult will take place at an other-than-Catholic facility, a parish staff member may wish to be present at the consult to ensure that the Catholic moral perspective will be included in the discussion.

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Notes

1. Nancy Berlinger, Bruce Jennings, and Susan M. Wolf, *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life*, 2nd ed. (New York: Oxford University Press, 2013), p. 204.
2. *Ibid.*, pp. 161-84.
3. Daniel J. Cronin, *Conserving Human Life* in Russell E. Smith (ed.), *Conserving Human Life* (Braintree, MA: Pope John XXIII Medical-Moral Research and Education Center, 1989).
4. *Ibid.*, pp. 86-7.
5. Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, sect. IV (1980). http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19800505_euthanasia_en.html. Accessed July 2019.
6. United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 6th ed. (2018). <http://www.usccb.org/about/doctrine/ethical-and-religious-directives>. Accessed July 2019.
7. Berlinger, Jennings, and Wolf, *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life*, p. 54.
8. John Connery, SJ, "Prolonging Life: The Duty and its Limits" in Donald G. McCarthy and Albert S. Moraczewski (eds.), *Moral Responsibility in Prolonging Life Decisions* (St. Louis: Pope John Center, 1981), p. 127; Missouri Catholic Conference, *A Catholic Guide to End-of-Life Decisions for Individuals and Families*, p. 6, available at <https://mocatolic.org/sites/missouricc/files/endoflifeguideenglish-revised-18.pdf>, accessed July 2019; Msgr. Orville N. Griese, *Catholic Identity in Health Care: Principles and Practice* (Braintree, MA: Pope John Center, 1987), pp. 160-1.
9. Berlinger, Jennings, and Wolf, *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life*, pp. 28-29, 54. Or again Kevin O'Rourke gives the example that "drug therapy for patients with AIDS may offer hope of benefit" but that "some patients might deem it an excessive burden because of the expense involved." "The Catholic Tradition on Forgoing Life-Support," *National Catholic Bioethics Quarterly* 5/3 (2005): 537-53 at 537, 547.
10. See, for example, William E. May, *Catholic Bioethics and the Gift of Human Life*, 3rd ed. (Huntington, IN: Our Sunday Visitor, 2013), p. 272; David F. Kelly, *Medical Care at the End of Life A Catholic Perspective* (Washington, DC: Georgetown University Press, 2006), p. 11.
11. This example is taken from the video *Living Fully Until Death* (Dartmouth-Hitchcock Medical Center).
12. Catholic Health Association of the United States, *End-of-Life Guides: Advance Directives Expressing Your Health Care Wishes* (St. Louis: Catholic Health Association of the United

- States, 2015), p. 22. Cf. United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 6th ed., no. 33.
13. Catholic Health Association of the United States, *End-of-Life Guides: Advance Directives Expressing Your Health Care Wishes*, pp. 22-23.
14. Berlinger, Jennings, and Wolf, *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life*, p. 62.
15. *Ibid.*
16. *Ibid.*
17. The Hastings Center, *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* (Briarcliff Manor, NY: Hastings Center, 1987), p. 7.
18. *Ibid.*
19. United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 6th ed., no. 59.
20. *Ibid.*, nos. 56-57, quoted above in the text.
21. Catholic Health Association of the United States, *End-of-Life Guides: Caring for People at the End of Life* (St. Louis: Catholic Health Association of the United States, 2015), p. 12.
22. Nicanor Pier Giorgio Austriaco, O.P., *Biomedicine & Beatitude An Introduction to Catholic Bioethics* (Washington, DC: Catholic University of America Press, 2011), p. 44.
23. Code of Iowa 144A.7.
24. Berlinger, Jennings, and Wolf, *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life*, p. 203.
25. *Ibid.*
26. Cf. United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 6th ed., no. 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.”
27. Gerald D. Coleman, “Subjectivism, Vitalism? Catholic Teaching Avoids Extremes,” *Health Progress* 95/1 (Jan.-Feb. 2014): 32-38 at 32.
28. *Ibid.*, p. 34.
29. Cf. United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 6th ed., Part Five, Introduction.