



Forgoing life-supporting or death-prolonging therapy: a policy statement

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■ Avoiding death is not always the preeminent goal of health care, and decisions about the use of life-supporting treatment may either hasten or forestall death. What are the health care professional's responsibilities regarding the use of life-supporting therapy? This report offers general and specific guidelines for termination of life-supporting treatment.

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ONE OF THE FUNCTIONS of the Ethics Committee of The Cleveland Clinic Foundation is the development of ethical guidelines and policies. This report presents one in a series of ethical guidelines developed by the Ethics Committee. Other policy statements on brain death, care of the hopelessly ill, and do not resuscitate were published in the *Cleveland Clinic Journal of Medicine* in 1990.^{1,2} This policy on forgoing life-supporting or death-prolonging therapy was approved by the Board of Governors effective January 1, 1991, and is based largely on the Hastings Center report, "Guidelines on the termination of life-sustaining treatment and the care of the dying."³

GENERAL GUIDELINES

One of the guiding principles of medicine is that the health and well-being of the individual patient is of paramount consideration. In keeping with this

philosophy, there is a legitimate moral and legal presumption in favor of preserving life and providing beneficial medical care with the patient's informed consent. Clearly, however, avoiding death should not always be the preeminent goal. Not all technologically possible means of prolonging life need be or should be used in every case. For the gravely ill patient and for his or her family, friends, and health care providers, decisions about the use of life-sustaining treatment have profound consequences. These decisions will, to some extent, hasten or forestall the time of death. They will also shape the patient's experience of his or her remaining life—where it is lived, with whom, and with what degree of comfort or suffering.

This document deals with the moral and ethical aspects of withdrawing or withholding life-sustaining therapy when the patient does not desire the treatment or when continuing to treat is equivalent to prolonging the dying process rather than sustaining or preserving meaningful life.

Life-sustaining treatment

Life-sustaining treatment is any medical intervention, technology, procedure, or medication that forestalls the moment of death, whether or not the treat-

This paper is a statement of policy developed by the Withdrawal of Life-sustaining Therapy Subcommittee (J.P.O., chairman) of the Cleveland Clinic Foundation Ethics Committee and approved by the Cleveland Clinic Foundation Board of Governors.

ment affects the underlying life-threatening diseases or biological processes. Examples include ventilators, dialysis, cardiopulmonary resuscitation, antibiotics, transfusions, nutrition, and hydration. Discussions about forgoing life-sustaining treatment will often be raised when death is the predictable or unavoidable outcome of the patient's underlying medical condition. However, a patient need not be terminally ill or imminently dying for these discussions to be held.

Extraordinary vs ordinary

The terms "extraordinary" and "ordinary" are often used in an attempt to distinguish a class of treatments that may be ethically withheld or withdrawn from a class of treatments that may not. Unfortunately, these terms are a source of great confusion. People sometimes distinguish ordinary from extraordinary by appealing to the prevalence of a treatment or its level of technological complexity. This is misleading because it focuses attention on factors that are ethically irrelevant to the decision to forgo treatment. Certain procedures for providing artificial nutrition and hydration, for example, are technologically rather complex, while administering chemotherapy is not. It clearly does not follow that the latter is ethically required because it is ordinary or technically simple, while the former is optional because it is extraordinary or technically complex. No treatment is intrinsically ordinary or extraordinary.

Withholding vs withdrawing

A great deal of confusion and anxiety surrounds the differences between *withholding* life-sustaining treatment, which many consider morally permissible, and *withdrawing* treatment that has already been instituted, which some consider morally wrong. Ethically, there is no difference between withholding or withdrawing a treatment: treatment can be ethically withdrawn whenever it can ethically be withheld. However, there are psychological and sociological differences between withholding and withdrawing treatment. It is sometimes psychologically more difficult to withdraw treatment than to withhold it, for withdrawal may be perceived as violating a special commitment the health care professional has made to the patient. Likewise, society may find it less intrusive not to start a treatment than to withdraw it, especially when the withdrawal of the treatment has more obvious consequences than never having started the treatment. However, from a medical standpoint it is usually better to initiate a treatment provisionally, with a plan for stopping it if it

proves ineffective or unduly burdensome to the patient, rather than withhold a treatment altogether for fear that stopping it will be impossible. When it is unclear whether the burdens or benefits are overwhelming, it is appropriate to choose on the side of life and provide the treatment. If a treatment is clearly futile in the sense that it will not achieve its physiological objective and so offers no benefit to the patient, there is no obligation to provide the treatment. It is both ethically and morally preferable to try a treatment and to withdraw it if it fails than not to try it at all.

Autonomy and obligation to treat

Patients have a right to control what happens to their bodies, so the decision about whether to use life-sustaining treatment should, in the final analysis, be theirs. This is often referred to as the principle of self-determination or autonomy. When a patient's request for specific therapy conflicts with the physician's judgment, there is no obligation to render useless care or to violate an established community standard of practice. Rather, physicians should decide how much to do according to what they perceive is medically best for that patient. A doctor is entitled to decline to provide any treatment that he or she believes is not beneficial, but there is a distinction between treatment a doctor believes is detrimental to a patient's best interest, and treatment to which a physician has a conscientious objection. A doctor must not allow the decision as to what is in the best interest of the patient to be influenced by his or her own personal beliefs. When the patient opts for a course of action that violates the health care professional's personal, ethical, or religious convictions, the professional should discuss the problem with the patient, and it may be necessary to transfer the patient to another professional's care with the patient's consent.

Capacity and surrogacy

Proper determination of capacity is crucial to an ethical decision-making process. Caregivers have a duty to respect the wishes of a patient with decision-making capacity. Decision-making capacity differs from competence. Competence and incompetence are legal terms and frequently refer to situations in which a formal judicial determination of mental illness has been made. Decision-making capacity, on the other hand, refers to a patient's functional ability to make informed health care decisions in accordance with the patient's personal values. The key elements of decision-making capacity are the ability to com-

prehend information relevant to the decision, the ability to deliberate about the choices in accordance with personal values and goals, and the ability to communicate either verbally or nonverbally with the caregivers.

When a patient lacks decision-making capacity, and attempts to restore that capacity (rectifying reversible causes such as overmedication, pain, or dehydration) fail or are not possible, then a surrogate must be identified who will be the ultimate source of consent or refusal to the health care team's plan of action. In identifying a surrogate, the physician should first honor any surrogate the patient has chosen in advance. In the absence of the above, the goal is to find the person who is most involved with the patient and most knowledgeable about the patient's present and past feelings and preferences. This person may be the spouse, parent, adult son or daughter, adult brother or sister, or a close friend. A family member is generally the best choice. In the absence of an available or willing surrogate, a surrogate can be selected and his or her decisions reviewed by the ethics committee. The primary function of the surrogate is to express those choices that the patient would if he or she were able.

Legal guardians of a patient, whether natural parents or appointed by a court, have the legal right to make decisions on behalf of the patient. In the situation where a patient does not have decision-making capacity and a legal guardian or surrogate does not exist, the physician should provide the course of treatment which the physician believes in his or her best medical judgment would be the course chosen by the patient.

By law and custom, parents usually act as the surrogate decision-makers for their minor child, but in the rare case when the treatment choice the parents are making is considered contrary to the child's best interest, the physician should not honor the parent's choice. The ethics committee may also be consulted. Referral to a court of law should be used only as the last resort.

Advance directives can be useful in documenting a patient's desires in regards to terminal treatment. We firmly endorse the right of a patient with decision-making capacity to decide to forgo any life-sustaining medical treatment. We also endorse giving a strong consideration to the advice of an appropriate surrogate for a patient who lacks capacity. Health care professionals must in many ways be advocates for life, even though they are willing to honor decisions to forgo life-sustaining therapy or to administer necessary treatment to alleviate pain that may at the same time

hasten death. Physicians, however, should not participate in active euthanasia or assist in suicide.

SPECIFIC TREATMENT TERMINATION GUIDELINES

Cardiopulmonary resuscitation

Cardiopulmonary resuscitation (CPR) refers to measures used to restore ventilation and circulation in individuals in whom these functions have been interrupted. Resuscitation techniques have no value in the management of irreversible or terminal disease states. They are intended to revive otherwise healthy individuals who experience some reversible catastrophe that interrupts breathing and circulation. Ideally, because of the emergency character of CPR, a patient or surrogate should be consulted in advance about whether to begin resuscitation in the event of a cardiac or respiratory arrest. Patients who are at increased risk for cardiopulmonary arrest should be given the opportunity to make a decision about CPR while they are still capable of making the decision. In the absence of a "do not resuscitate" order, resuscitation should be attempted, and if any doubt exists as to whether a decision to forgo treatment has been properly made, treatment to preserve life should be given. Deceptive resuscitation efforts known as "show codes" or "slow codes" should be avoided.

Any code should be a full code unless a partial code or limited resuscitation effort has been explicitly requested by an informed patient or surrogate. At the time of cardiac or respiratory arrest, if the health care professional summoned to direct resuscitation realizes that CPR cannot restore cardiac and respiratory function, the professional may call off the effort. Likewise, when a patient in an intensive care unit (ICU) is receiving full but ineffective treatment for failure of other organ systems, and irreversible hemodynamic or respiratory failure develops, it is appropriate not to institute CPR.

ICU admission

The following patients are candidates for admission to ICUs when it is consistent with their treatment preference and goals: critically ill patients who require life support for organ system failure that may be reversible or remediable; patients with irreversible organ system failure who cannot be treated appropriately in another setting; patients at risk of life-threatening complications who require monitoring or treatment; and patients receiving a trial period of monitoring or treatment when there is doubt about the prognosis or

the effectiveness of therapy. A decision to forgo some forms of life-sustaining treatment, such as CPR, should not automatically preclude other forms of treatment and admission to the ICU. Admission should be subject to the constraints imposed by the availability of space, equipment, and personnel, the needs of the patients already in the unit, and the needs of others who are also candidates for admission. Patients who generally should not be admitted to the ICU include the following: patients with documented irreversible cessation of all functions of the entire brain; patients who have been firmly diagnosed as irreversibly unconscious; patients with irreversible illness who are near death; and patients who, while capable of making decisions, have requested that they not receive intensive care or its equivalent. Patients are entitled to refuse admission to an ICU even when doing so puts them at risk of death. However, patients should not be able to demand admission to an ICU. A request by a patient or a surrogate for admission to an ICU may be denied if admission would be medically inappropriate for the patient, detrimental to patients already in the unit, or contrary to admission criteria. Patients should be transferred from the ICU to another setting within the hospital or to another institution when intensive care will no longer be of benefit—either because they have improved to a point where intensive care is no longer necessary, or because they have deteriorated to a point where it no longer offers reasonable promise of benefit. Such triage is ethically appropriate.

Mechanical ventilation

It is important to emphasize again that treatment can ethically be withdrawn whenever it can be ethically withheld. However, it is not appropriate to remove a ventilator-dependent patient from a ventilator without the permission of the patient or surrogate, or to pretend to use the ventilator properly while intentionally using it inadequately. The responsible health care professional should not request other health care personnel to carry out a decision that he or she would not personally carry out. In the situation of a decision by a patient or a surrogate to forgo ventilation, it is ethically acceptable to sedate the patient if necessary to ensure comfort. Supplemental oxygen can be used to relieve dyspnea from hypoxemia. If relieving the patient's dyspnea or other discomfort requires sedation to the point of unconsciousness, it is ethically acceptable to do so with the consent of the patient or surrogate. A patient may also decline to be weaned from a ventilator and may wish to be simply disconnected from mechanical ven-

tilation as part of a fundamental decision to forgo life-sustaining treatment. In such a case, it is permissible to disconnect the ventilator without weaning.

Dialysis

A vital part of the discussion of whether to forgo dialysis concerns the patient's transplantation options. In order to make an informed decision about whether to forgo dialysis, the patient or surrogate must receive an evaluation of whether the patient could receive a transplant and, if so, what the transplant possibilities are and what transplantation involves. Because dialysis is frequently supervised most directly by personnel other than the primary health care providers, it is important that all such personnel participate in the evaluation process. It is important to explore with patients already on dialysis why they wish to stop the treatment. It may be that their discomfort can be ameliorated without stopping the treatment entirely. Another important aspect of the discussion should be the question of where death will occur when the decision has been made to forgo dialysis. Often a patient will wish to die in the hospital where supportive and palliative care are readily available. If the patient wishes to die at home, the health care professional should inform the patient and caregivers of the risks and burdens. The patient's preference concerning the place of death should ordinarily prevail as long as adequate care can be arranged. When dialysis treatment is clearly futile and of no benefit to the patient, there is no obligation to continue the therapy.

Transfusion

Among the treatments a patient may choose to forgo is the administration of blood and blood products. This refusal arises most frequently on religious grounds and is usually asserted by Jehovah's Witnesses. An individual's freedom to act in accord with personal religious values is one aspect of autonomy, and the right of Jehovah's Witnesses to refuse blood should be recognized. However, as with nonreligious aspects of autonomy, the right of self-determination is not absolute. For example, the right to forgo treatment may sometimes be restricted on the grounds that it will cause harm to specific others. These exceptions include parents making decisions for a child, or when the patient is pregnant or has dependent children. The decision-making process for refusal of blood and blood products may occur when serious bleeding is expected but has not yet started, when such bleeding occurs (if there is enough time to go through

the entire decision-making process), or when treatment for bleeding has started and the question is whether to continue. If it is medically indicated, patients should receive treatment for bleeding in an emergency, except when the patient, while capable of making decisions, has given direction refusing blood and blood products.

Antibiotics and other medications

Some patients who are terminally ill or in a severely debilitated and irreversible condition may determine that treatment with antibiotics or other medications will only prolong their pain and suffering. Decisions about using antibiotics and other medications, like decisions about other forms of life-sustaining treatment, require patients or other surrogates to balance carefully the potential burdens against the benefits. Respecting the considered choice of the patient or the patient's surrogate to forgo life-sustaining medication does not violate the ethical mandates of health care professionals. Only when it is necessary to override a patient's refusal of antibiotics or other life-sustaining medications for public health reasons should a patient's wishes not be upheld.

Nutrition and hydration

Medical procedures for supplying nutrition and hydration treat malnutrition and dehydration; they may or may not relieve the hunger and thirst that can occur. Conversely, hunger and thirst can be treated without necessarily using medical nutrition and hydration techniques. For instance, dehydrated patients may have their thirst relieved by having their lips and mouth moistened with ice chips or lubricants. Patients in their last days before death may spontaneously reduce their intake without experiencing hunger or thirst. Indeed, clinical experience indicates that dehydration may offer benefits for certain dying patients. Dehydration can reduce secretions and excretions, thus decreasing breathing problems, vomiting, and incontinence. Dehydration can also produce a sedative effect on the brain, making death more tolerable. Forgoing nutrition and hydration is one of the most difficult treatment termination decisions because of the association of nutrition and hydration with

basic needs and human caring. Individual cases should be decided by balancing these basic human needs and their potential benefits with the burden to the individual of the technology needed to provide artificial nutrition and intravenous hydration. The artificial provision of nutrition and hydration is a form of medical treatment and may be forgone when requested by a patient and a family. Provision of nutrition and hydration may be technologically possible but not an ethically mandatory means of prolonging life. As with other life-supporting treatments, decisions about using or discontinuing nutrition and hydration require carefully balancing the potential burdens against the benefits.

Pain relief

Pain relief is an extremely important aspect of providing humane care to dying individuals. Although the majority of dying patients do not feel substantial pain, most fear the possibility of pain, perhaps more than death itself. Since the primary goal of caring for dying patients is to relieve pain and suffering unless the patient chooses otherwise, measures involving substantial risk may be considered, although they might not be undertaken to relieve the discomfort of patients with a reasonable chance of survival. Examples of such measures include percutaneous cordotomy or neurolytic blocks. The proper and adequate use of analgesics, especially narcotics, is critically important to alleviate pain for patients who are dying. Concerns about addiction or physical dependence are irrelevant to the dying patient. Likewise, psychological dependence on narcotics is most often the result of under-medication rather than overmedication. Patients are less likely to become psychologically dependent when narcotic agents are given on a prophylactic schedule to prevent pain, rather than in response to request after pain is experienced. The health care professional should ordinarily seek to give sufficient medication to relieve pain while enabling the patient to remain as mentally alert as the patient wishes. Continuous intravenous infusion of narcotics is appropriate therapy to alleviate pain and suffering in a dying patient, even when given to the point of unconsciousness (with the consent of the patient or surrogate), and even though alleviation of the pain and suffering may hasten death.

REFERENCES

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