

## Patient Refusal of Therapy

As Christians, we believe that human life is a gift from God and that all individuals are accountable before God for their lives. This accountability includes decisions to accept or refuse therapy.

As Christian physicians and dentists, we will assist patients, families, and clergy in making decisions within the framework of patients' values and beliefs. A patient may refuse therapy that violates his or her moral values or religious beliefs. However, the right to refuse therapy is limited by the harm it may cause to innocent third parties.

For the Christian, to be absent from the body is to be with the Lord. Physical death need not be resisted at all costs. In certain circumstances, medical treatment only prolongs pain and suffering and postpones the moment of death. It may then be appropriate for a patient with decision-making capacity to refuse medical interventions.

The patient's decision should be made after thoughtful consideration of his or her responsibilities to God, family, and others. When the patient refuses life-prolonging therapy, we will respect that choice and compassionately support his or her medical, social, and spiritual needs.

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### Explanation

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#### Background

Prior to the 1960's, whether a particular patient with a particular condition should be treated with a particular treatment was a decision made primarily by that patient's physician or dentist. The professional stance was paternalistic in that the clinician benevolently imposed his or her values on the subordinate patient. This was not only common practice, it was accepted by both patients and professionals as the way things were and the way they ought to be. Several things have happened in our culture which has changed that acceptance, including: (a) the development of more treatment options, many of which are invasive, burdensome, and expensive, and some of which have less than ideal efficacy; (b) the emergence of the legal doctrine of "informed consent"; and (c) the rise of individual rights as manifested by increased emphasis on minority rights, consumer rights, patient rights, etc. One of the results of the social ferment of the 1960's is that "medical paternalism" has become a pejorative term and "patient autonomy" has become dominant. The individual patient's values now most often take precedence over the values of the individual clinician or the profession as a whole. Thus at the same time that there are more (and more difficult) decisions to be made, the ultimate authority for making those decisions has shifted from the physician or dentist to the patient. As will be discussed later, this shift has been a mixed blessing.

#### Patient Refusal of Therapy

During this time of transition, there was a public perception that physicians were often too aggressive in treating patients beyond the time when it was reasonable to limit treatment and accept the inevitability of death. In the 1970's, patients and families began to not only question the wisdom of prolonged aggressive treatment, they also began to challenge some treatment decisions in court. Karen Quinlan's family was the first (1976) to go to an appellate court level (New Jersey) to request the discontinuation of treatment

which was felt by physicians to be necessary to sustain life. That landmark court decision to accede to such a request was the first of 50 or more handed down from appellate judges over the next 15 years which eventually established several legal precedents including: (a) competent patients have the right to refuse even life-sustaining treatment; (b) incompetent patients have the same right, and that right may be exercised by a surrogate; (c) the family is the presumptive surrogate for an incompetent patient; (d) there is no legal difference between withholding and withdrawing a treatment; (e) it is not necessary to go to court to make these decisions; (f) a physician or hospital, acting in good faith, will not be held liable for following such requests; and (g) artificially administered fluids and nutrition are treated the same under the law as any other treatment modality. Of course, everything legal is not necessarily ethical from a Christian perspective.

## **Advance Directives**

Most of the contentious cases have involved patients who had lost their decision-making capacity because of illness or injury. Advance directives have been devised as a way for persons, while still competent, to communicate to family or physician what they would want to have done if they should become unable to make their own decisions. These directives may address treatment goals, the values underlying treatment decisions, specific treatment modalities, or who should act as surrogate decision-maker.

In 1967, Louis Kutner proposed a written document he called a Living Will in which a person could express his or her treatment wishes. His proposal attracted little attention or support until 1976 when the public discussion of Karen Quinlan caused many to desire a way to record their wishes. In 1976, California became the first state to enact a law (The Natural Death Act) recognizing the validity of an advance directive. Subsequently nearly all jurisdictions have passed such enabling legislation. Many states have prescribed wording, others merely give legal recognition to the concept. The completion of Living Wills has been encouraged by many medical and lay organizations, including The Society for the Right to Die (now called Concern for Dying).

Living Wills are documents giving instructions about goals of treatment. Most are written in a negative tone, e.g., "... If I should be in an incurable or irreversible mental or physical condition with no reasonable expectation of recovery, I direct my attending physician to withhold or withdraw treatment that merely prolongs my dying ...". Some include instructions about specific treatment modalities which the patient declines. Some are worded in a positive way to say what treatments the person would want to have under certain conditions. One format called the Medical Directive, is designed to allow the person to choose which of 12 different treatment modalities he or she would or would not want to have in each of 4 different clinical situations.

A Values History is a detailed document through which a person can convey the information necessary to make a treatment decision. For example, a person might indicate that the ability to communicate with others (or to recognize others, or to listen to music, etc.) is more valuable to him or her than continued living.

Another form of advance directive is a proxy statement, i.e. the designation of what individual the person would trust to make medical decisions if he or she should lose decision-making capacity. The most popular form is a Durable Power of Attorney for Health Care. Such documents may or may not include specific directions for the proxy to follow. The assumption behind a proxy statement is that the person named to act as the agent knows the patient's values, goals, and/or specific treatment wishes.

The 1990 Patient Self-Determination Act was passed by Congress as an amendment to the Omnibus Budget Reconciliation Act. It requires all health facilities which accept federal funds to ask each patient on admission if he or she has an advance directive, and then to give information about advance directives to all who do not have one but would like to learn about them.

In spite of enabling legislation and popular support, only 10-15% of the adult population in the U.S. have completed an advance directive. Reasons for reluctance include denial of the need for such documents, suspicion of unnecessary "legal documents", concern that the motive behind societal encouragement of advance directives is to decrease health care costs, and suspicion that Right to Die advocates are trying to impose their values, which are often contrary to a Right to Life philosophy. In addition, some have expressed concern that signing an advance directive requesting some limitation of treatment in some

circumstances may be misinterpreted as a request for no treatment at all, or that it might result in the withholding of measures needed to ensure comfort and dignity.

### **Secular vs Christian Perspectives**

Several assumptions underlie the use of advance directives: (a) treatment decisions require valid consent, (b) not everything that can be done must be done, (c) it is prudent to anticipate loss of decision-making capacity, (d) it is helpful to provide guidance for surrogate decision-makers, (e) both verbal discussion and written documentation are helpful. These assumptions fit squarely and solidly with the secular concept of decision-making where the wishes of the autonomous individual are dominant.

When advance directives were first proposed, many Christians were opposed to them fearing that acceptance of these documents could be used by "right to die" proponents to facilitate the premature withdrawal of treatment from handicapped individuals, or even that they could lead to euthanasia. Upon further reflection, most Christians are now comfortable with these assumptions; none is in conflict with biblical teaching. However, Christians ground these assumptions in a framework also shaped by scripture. Biblical freedom (with the decision-making responsibility that flows from it) is distinctly different from the common contemporary understanding of autonomy. Autonomy today typically means both that decisions critically affecting a patient's life should be made by the patient, and that whatever decision a patient makes is right simply by virtue of the fact that the patient has made it. A Christian perspective challenges both of these claims:

First, the biblical writings do affirm that even the crucial decision for or against Christ with its definitive implications for one's eternal life is a matter of personal responsibility--not to mention important decisions that affect life in this world. However, while affirming and protecting the individual, a biblical outlook also emphasizes the significance of community, which is rarely commended in an autonomy-based approach. The best treatment refusal decisions are typically made together with one's physician, taking into account the well-being of family, friends, and others, and not merely oneself.

Second, while the biblical writings do suggest that we must allow people to refuse even life-sustaining therapy--because it is their decision to make--all such decisions are not necessarily right. Contrary to autonomy-based thinking, a biblically based decision to limit treatment, whether through a patient refusal of therapy or through an advance directive, is constrained by the addition of other assumptions not generally considered in a secular perspective. Added to the assumption of (f) the patient's freedom (properly understood) are such concerns as (g) the sanctity of life, (h) the sovereignty of God, and (i) the stewardship required regarding our bodies and our resources.

Some evangelical Christians remain fearful of advance directives feeling that they are too vague, or that they give too much authority to a surrogate or a physician who might then act differently from what the patient wants. The importance of such worries and the potential for various differences between the secular and the Christian perspectives led the Christian Medical and Dental Society to develop statements on *Patient Refusal of Therapy and Advance Directives*.

### **Abstracts**

#### **Assessing patients' capacities to consent to treatment. Applebaum PS, Grisso T. N Eng J Med 1988; 319(25):1635-1638**

This article is a concise review of the ethical and legal foundations of informed consent followed by practical guidelines on how to assess an individual patient's capacity to consent. In order to honor the patient's right to accept or refuse recommendations, the clinician must be able to carefully assess the decision-making capacity of each patient. Patients must be adequately informed about treatment options and must be given the opportunity to demonstrate their highest level of mental functioning. The legal standards for competence include four skills: communicating a choice, understanding relevant information, appreciating the current situation and its consequences, and manipulating information rationally. Competence is a legal concept which must be formally determined by a court. The clinician's role is to gather enough information to decide whether a formal adjudication of incompetence is required. Sometimes it is possible to restore the patient's decision-making capacity through treatment.

**Christian Faith, Health, & Medical Practice. Bouma J, Diekma D, Langerak E, Rottman T, Verhey A. Grand Rapids, MI: Eerdmans, 1989**

In this book, these scholars from the Reformed tradition attempt to "discern the shape of Christian obedience and integrity in the midst of the dilemmas and problems of medical care." Chapter 10, entitled "Death and Covenantal Caring", includes the following four biblically-grounded general principles which Christians can use in addressing dilemmas of life and death: (1) a Christian need not regard the mere prolongation of biological life as intrinsically beneficial; (2) a Christian need not strive to endure irremedial and intense suffering when it eclipses the good of relationships with God, self, and others; (3) a Christian should not be devastated by the state of dependency that sometimes characterizes sickness and dying; and (4) end-care decisions Christians make for themselves must not be grounded exclusively in how these decisions affect them personally. They then go on to discuss the question of competence, Living Wills, a Christian Living Will, and the advantages and possible disadvantages of a Christian Living Will. They conclude the chapter by distinguishing between allowing to die and killing (including the special issue of fluids and nutrition) and give a covenantal basis for caring.

**Autonomy, religious values, and refusal of lifesaving medical treatment. Wreen MJ. Journal of Medical Ethics 1991; 17(3):124-130**

Autonomy is the value most often offered as justification for honoring a rational patient's refusal of therapy. There are some cases, however, where we intuitively question the validity given to the primacy of autonomy (e.g. when the patient refuses for trivial, whimsical, or irrelevant reasons). Some attempt to justify over-riding such refusals by questioning the rationality of the patient, and others would honor the refusals by adding to autonomy the values of privacy and bodily integrity. The author then proposes and defends his thesis that religious values are different from individual autonomy, privacy, or bodily integrity, and they are "special" when offered as reasons for refusal of treatment.

**Securing patients rights to refuse medical care: in praise of the Cruzan decision. Emanuel EJ. American Journal of Medicine 1992;92(3):307-312**

After outlining the legal history and background, the author summarizes the decisions of the Missouri Supreme Court and the U.S. Supreme Court and their implications. He concludes that "[t]he Cruzan decision (1) definitively recognizes the right to refuse medical care as a constitutionally guaranteed right, (2) ensures this right applies to artificial nutrition and hydration, (3) strongly implies that living wills, durable power of attorney, and other clear statements of patient preferences are protected as necessary to the exercise of a fundamental right, and (4) does not mandate extensive state regulation of surrogate decision-making for incompetent patients."

**"Playing God" and the removal of life-prolonging therapy. Paris JJ, Poorman M. Journal of Medicine and Philosophy. 1995;20:403-418**

From the conclusion: "In our society it is not the physician 'playing God' who decides when, if ever, life-sustaining treatments may be withheld or withdrawn. It is the individual patient (or proxy) who assesses the proportionate benefits and burdens of the proposed treatment and then determines if it should be undertaken or foregone. as the long and unbroken tradition of [Roman Catholic] moral theology established, such action is not 'playing God', but a reasonable acknowledgment that there are limits on what humans have to endure to preserve life. When God created us 'a little lower than the angels', we were not endowed with immortality. Moreover, the unfortunate expression playing God implies that by determining the proportionate use and the disproportionate abuse of technology, a physician or other decision-maker idolatrously assumes the omniscience or the omnipotence reserved to God alone. But the cornerstone of moral theology - the natural law tradition - allows ample room for human participation in God's 'eternal law'. We do that by the exercise of *recta ratio*, a right reason which carefully weighs all of the moral dimensions of a possible course of action in the sincere and faith-filled hope of doing good and avoiding evil.... "

**Death and Dying, in Dignity and Dying: A Christian Appraisal. Dunlop, John T. Ed. Kilner, John F., et al. Grand Rapids, Mich.: Eerdmans; and United Kingdom: Paternoster, 1996.**

While acknowledging the biblical foundation for the reverence of human life, the author contends that such a reverence for life may actually incite us to take inappropriate measures in resisting death. He asserts that, "[w]hile we should indeed oppose euthanasia, we must also present a thoroughly biblical and

ethical approach to death. Otherwise, a 'pro-life' orientation will mistakenly become 'anti-death' . We must complement our theology of life with a clearly articulated theology of death." Central to such a theology is the belief that death, although an enemy, has been defeated in Christ; as a result, one must not fervently hold on to this life at all costs but may instead accept the inevitability of death by embracing the hope of eternal life in Christ. In making the decision not to receive aggressive medical care, the author maintains and demonstrates that one must consider both the medical context and the associated spiritual and emotional factors involved.

**Forgoing Treatment, in Dignity and Dying: A Christian Appraisal. Kilner, John F. Grand Rapids, Mich.: Eerdmans; and United Kingdom: Paternoster, 1996.**

In consideration of the question of whether forgoing treatment is an ethically defensible option for patients, the author contends that an appeal to the Bible yields a manner of thinking which is instructive for decision-making in this area. He asserts that a biblical focus is inherently "God-centered," "reality-bounded," and "love-impelled." He maintains that such a focus may serve to counter the common pressure to overtreat or undertreat by providing a biblically-based, ethically sound model for end-of-life treatment decisions. He envisions two questions as being central to the decision to forgo treatment. Because the biblical notion of freedom holds that individuals must be free to make choices which shape their lives both now and in eternity, one key question is whether or not the patient is indeed willing to forgo a treatment option. A second key question is whether a desire to forgo treatment indicates that a patient is accepting the prospect of a death which is unavoidable or is actually intending death. This distinction is important, as the Bible indicates that although we are not to fear death, neither are we to choose it as a means to avoid suffering.

### **Bibliography**

**Ramsey P. On (only) caring for the dying. Chapter 3 in The Patient as Person. New Haven, CT: Yale University Press, 1970**

This book by a conservative Protestant theologian has become a classic in medical ethics, and this chapter on palliative care is one of the best pieces written on really caring for people as they die. His analysis of moral questions in terminal care includes a good discussion of "ordinary vs extraordinary" treatments, and his assertion that some things are morally obligatory and others are not. His thesis is that people need only comfort and company during this process.

**McCormick RA. To save or let die: The dilemma of modern medicine. Chapter 17 in How Brave a New World. Washington, DC: Georgetown University Press, 1981**

This Catholic theologian urges that we face our awesome responsibility of making decisions. He invokes the Judeo-Christian tradition as he attempts to steer a middle ground between medical vitalism (that preserves life at any cost) and medical pessimism (that kills when life seems frustrating, burdensome, "useless").

**Culver CM, Gert B. Philosophy in Medicine. New York: Oxford University Press, 1982**

A psychiatrist and a philosopher give clear descriptions of valid consent and competence, then present a useful distinction between rationality and competence.

**The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Making Health Care Decisions. Washington, DC: U.S. Government Printing Office, 1982**

The introduction to this 200-page classic gives a good description of valid consent and its underlying values, followed by 13 well thought out implications. These are then explained and expanded in the chapters that follow.

**Katz J. The Silent World of Doctor and Patient. New York: Free Press, 1984**

The author examines the history and practice of "one-way trust" in the doctor- patient relationship and criticizes doctors for encouraging patients to relinquish their autonomy. He encourages more open and honest communication which respects the rights and needs of both sides.

**Drane JF. Competency to give an informed consent. N Eng J Med 1984; 252(7):925-927**

Rather than selecting a single standard of competency, the author suggests and describes a sliding scale that requires an increasingly more stringent standard as the consequences of the patient's decision embody more risk.

**Lantos J. Treatment refusal, noncompliance, and the pediatrician's responsibility. Pediatric Annals 1989; 18(4):255-260**

This pediatrician-ethicist assesses the problems of treatment refusal by parents and offers advice to physicians who must balance the child's best interest against the parents' right to make decisions for their children.

**Culver CM, Gert B. The inadequacy of incompetence. The Milbank Quarterly 1990; 68(4):619-643**

The authors use their concept of rationality to defend some situations when it may be ethically justified to over-ride the refusal of a seemingly competent patient when he or she makes a seriously irrational decision.

**Morreim EH. Impairments and impediments in patients' decision making: reframing the competence question. Journal of Clinical Ethics 1993; 4(4):294-307**

The author suggests that the traditional yes-or-no concept of competence be reconceived in terms of the conditions that are necessary for patients and physicians alike to be fully responsible for their decisions.

Miller R. The ethics of involuntary commitment to mental health treatment.

**Chapter 13 in Psychiatric Ethics, 2nd ed. Bloch S, Chodoff P, eds.; New York: Oxford University Press, 1993**

The author addresses the difficult question of treating the mentally impaired individual against his or her will.

**McCullough LB, Chervenak FA. Management of ethical conflict and crisis in gynecologic and obstetric practice. Chapter 7 in, Ethics in Obstetrics and Gynecology (same authors); New York: Oxford University Press, 1994; pp 241-265**

After discussing a framework for defining ethical issues in OBGYN and describing efforts at prevention of conflict in earlier chapters, the authors address the question of how the clinician should respond when fetal best interests suggest an intervention which the pregnant woman refuses.