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The Ethicist Is In

by Albert R. Jonsen, Ph.D.

Remember Lucy in "Peanuts"? From time to time, she set up a booth and hung out a shingle, "The psychiatrist is in." She charged 5¢ for advice. The ethicists at Ethical Times offer advice for free. We encourage you to ask us a question, by letter or email, and we will try to answer it. The answers will come from our experience, the combined experience of ethics scholars and the literature of the field. Here is our first question. It was prompted by our article, "The Scoop on Advance Directives" in the Fall 05 Ethical Times.

"I found the article on Advance Directives thought provoking and informative as far as it went. By the end of it I had the sense that even if I prepared and discussed with my physician the various documents mentioned, my wishes might be ignored when the time came to implement them. Perhaps a follow up commentary on what a person could/should do to provide the best possible utilization of their expression of their wishes would be helpful."

Gerry Brinton, Sonoma, CA

Dear Gerry,

The original article did end on a negative note. It stated that advance directives often fail to guide medical care in the direction intended by the writer. Failures in communication, in clarity, in meaning often contribute to this failure.



Objection by family members may prevent the fulfillment of the writer's wishes. Disagreement by the doctor may block the patient's preferences. A lot can go wrong to frustrate the best intentions.

What can be done "to provide the best possible utilization" of these documents. First, those who prepare them must realize that they are words on paper. Some words on paper are intended to have a definite effect on behavior: the words of a contract or a law. Others convey ideas from one mind to another, as in a letter or a novel. The typical Advance Directive is more like the second than the first. It is not a formal

contract or a law. It expresses the preferences and desires of one person to others. This kind of document is a very inefficient way to convey ideas, since the reader can, and will, interpret them according to circumstances or personal inclinations. What can be done? Talk about what is written! An advance directive is something like a rough script. It lays out some general directions that must be explained, exemplified, emphasized. Advance directives that remain on paper and are never talked about with the writer's family, physicians or designated surrogate, are very likely to be more of a problem than a solution.

ETHICIST, continued inside

First Phase of Staff Ethics Survey Completed!

The Program in Medicine and Human Values recently completed a survey of the CPMC clinical staff to learn their perception of ethical healthcare practices at California Pacific. This information will help us guide local quality improvement projects in the near future. California Pacific will become the first community hospital in the United States to do this (the Veterans hospitals have done it; we used the survey instrument that they developed). We are now analyzing the results. We will report them in late January on our website, www.cpmc.org/ethics, and in the next issue of *Ethical Times*.

We awarded those who completed our survey with a Peet's card for a complementary coffee. We thank Brian and the staff of Peet's Coffee & Tea on Fillmore & Sacramento Streets. They prepared all of the Peet's cards and even gave us a huge discount! The survey surely wouldn't have been nearly as successful without their help.



The Program intends to start a series of public events devoted to explanation and discussion of ethical issues in health care. Watch for the announcement.



Dr. Albert Jonsen, Co-director of The Program, has just published *Bioethics Beyond the Headlines: Who Lives? Who Dies? Who Decides?* (Rowman & Littlefield) This book addresses the major topics of bioethics, such as euthanasia, genetic diagnosis and therapy, experimentation with humans and with animals, cloning and stem cell research, and organ transplantation in a way that introduces the general reader to the science and the ethical reasoning behind the headline stories that appear regularly in the media.

The Program's Inaugural Annual Report, *Ethics: Inspiring Excellence*, has been completed and is available on our website at www.cpmc.org/ethics. Click on publications.

Stop Talking Medicalesse!

Patients and their families often meet with doctors and nurses to discuss the medical issues that arise during a hospital stay. Often, the clinicians use terms that may not be clear to patients. We have prepared a list of some of the more commonly used terms and defined them in patient friendly words (we hope). The following three terms are the beginning of this list; the others will appear in subsequent issues of *Ethical Times* and on our website.

1. **Brain death:** This term describes a person whose brain has ceased to support all essential functions of the body, including thinking, feeling, breathing, and most other bodily functions. People with this condition, even if their heart is beating, never recover. If the brain dead person is attached to a breathing machine, some signs of life, such as heart beat and skin color, will be present but the person is actually physically and legally dead.
2. **Persistent vegetative state (PVS):** This term describes the physical destruction of those parts of the brain that support thinking, perception and feeling, leaving only those parts of the brain that support breathing, digestion, heart regulation and other metabolic functions; "persistent" refers to the medical judgment that the destruction is so severe that recovery will not occur. Unlike patients pronounced "brain dead", persons in PVS are not legally dead, but they are completely and permanently unaware of their surroundings.
3. **Terminal Condition:** There is no formal or strict medical definition of "terminal." It literally means "at the end," but gives no information about how close to the end the patient may be. Doctors use the term cautiously: only when their experience suggests strongly that a patient has so seriously deteriorated that death is likely within hours or, at best, a few days. Its use is usually the signal to suggest to patient or family that aggressive measure of life-support have become more of a burden than a benefit to the patient.

Our questioner fears that her “wishes might be ignored when the time comes to implement them.” It is exceedingly rare, in our experience, that wishes expressed in an advance directive or in conversation with the doctor are ignored. In contemporary medical care, they receive attention. Instead of being ignored, it is more usual that they are difficult to interpret in the situation due to the vagueness of the words or the complexity of the situation.

Medical situations are often extremely complex. Frequently, the signs and symptoms that the doctor sees are ambiguous, even to the best observer. One physician may interpret the situation as curable, while another sees it as a terminal condition. The future quality of life that can be predicted during a critical episode is obscure even to experienced physicians. These difficulties sometimes make family and physicians hesitate about the course of action. The question that they ask is, “is this present crisis or its possible outcome just what our loved one, or our patient, meant when they directed that life-support be discontinued?” The words of a written document may shed little light on an answer to this question. At this point, the physicians and the family must join together to provide the most reasonable interpretation. That interpretation is informed by the words of the document, by prior discussion and explanation by the patient, and by the knowledge that family members have of the patient’s values, beliefs and hopes.

Another difficulty that may arise is disagreement among the family members about the patient’s wishes or about some other factor, such as religious principles. These disagreements often become bitter arguments. The patient’s wishes are then “ignored” because the concerns of family become primary. At times like this, an ethics consultation is advisable. This brings a new, neutral party, the ethics consultant, into the situation. The ethics consultant may guide the discussion, defuse anger, clarify the medical or social or religious situation, and point toward a reasonable resolution that seems to honor the patient’s wishes.

Thus, we answer our questioner: do prepare a written advance directive, make it as clear as

you can on paper and discuss it with your doctor, your appointed surrogate and your family, and indicate that, in case of dispute, you desire an ethics consultation. If this has been made clear, it is unlikely that your wishes will be ignored.

Often it happens that no written document is available. We will write about how “surrogate” or “proxy” decisions should be made in our next issue.

A second question has come to us from several of our readers. What is a “DNR order”?

“DNR” stands for “Do Not Resuscitate,” that is, do not carry out the procedures that are used to try to restore a dangerously irregular heartbeat. A regular heartbeat is a blessing we are not even conscious of. We notice our heartbeat when it is exaggerated, as after a vigorous jog, or when it goes wildly out of control. A heartbeat out of control, called “fibrillation” may kill us. Fortunately, there are ways to pull a fibrillating heart back into regular rhythm. A technique called “cardiopulmonary resuscitation” (CPR) was devised some fifty years ago. It consists of blowing air into the lungs, pumping hard on the chest, injection of heart stimulating drugs, applying electric shocks to the heart, and the insertion of a air tube into the throat. The most basic of these techniques, mouth-to-mouth breathing and chest compression, are taught to lay persons. A small machine to apply the electric shocks, called an automatic defibrillator, can now be found on the walls of airports and football stadiums. The sight of a trained emergency technicians crowded around someone fallen on the sidewalk is familiar to city dwellers. In hospitals, a voice on the message system urgently announces “Code Blue” to summon the team of doctors and nurses to the room of a patient whose heart has gone awry.

Resuscitation is an urgent matter. The longer the heart fails to beat rhythmically, the more the brain is damaged by deprivation of oxygen. The longer it is silent, the less likely it is to return to normal rhythm. Death or serious brain damage is the result. The procedures and

treatments that are administered are well worked out and practiced in advance according to a CPR protocol. There is no time to think about what to do. Inaction means certain death.

The public perception of resuscitation is that it is often successful. One study reviewing the success rate of CPR, as portrayed on popular television programs, showed that 3/4 of the time, patients were up and about shortly after being resuscitated. The truth, however, is quite different. When CPR is administered out of the hospital, 85% of the patients die during the attempt. Half of the rest never leave the hospital. The statistics for in-hospital CPR are not much different. In the best of circumstances, one study documents less than a 1/3 success rate for immediate survival with CPR, but less than 8% of those patients were still living one year later. Community hospitals report that less than 11% of all patients receiving CPR leave the hospital alive.

The success of CPR is also highly dependent on the medical condition of the patient who collapses. Young healthy victims of traumatic accidents and patients suffering heart attacks in a Coronary Care Unit are excellent candidates for the procedure. On the other hand, patients with multiple medical conditions, those suffering an acute stroke, or those who were confined to bed before they came to the hospital, have a dismal prognosis for surviving attempts at CPR. One study of patients with metastatic cancer showed that no attempts at resuscitation were successful. In short, every hospitalized patient on whom CPR is attempted has a 100% chance of dying if the procedure is not initiated, and a 98 to 93% chance of dying if it is.

Given the published statistics on the success of CPR, some may be surprised to find that it is the default treatment for all patients who enter the hospital, unless they specifically opt out by having their physician write what is called a "DNR order" (that is, "do not resuscitate"). It is unclear whether this policy exists because its creators were overly influenced by

Hollywood, or because they felt that the opportunity to save even one life was worth any risk.

The decision to permit a DNR order to be written by the doctor is, of course, a most distressing situation for the patient or for their family to face. The physician must confidently judge that the patient is so seriously ill that death is likely, even if resuscitation succeeds—for example, the patient has cancer that has invaded major organs. If this is the case, the patient will be subjected to the physical stress associated with chest compression, electric shock and insertion of lines and tubes to no avail. In some cases, the patient is very old and very sick. Doctor and family may believe that death would be welcomed.

In addition to terminally ill and dying patients, competent, non-terminally ill patients may initiate discussion of DNR orders with their physicians. For these patients, a DNR order is an important component of advance care planning, allowing them to express preferences about treatment at the end of life. Many of these patients are in the earlier phases of serious diseases, such as metastatic cancer, AIDS or ALS. They are prepared to forgo resuscitation attempts because they are concerned that even if they are "successfully" resuscitated, they may experience anoxic brain damage or some other functional impairment or go on to live through a painful terminal phase of their illness. Physicians should carefully discuss these requests with the patient and honor them.

Deciding to forgo attempts to restart a failing heart or lung is never an easy one to make, but if you have not made it for yourself, the decision has been made for you by hospital policy: without such an order, resuscitation efforts will be made.