

The Scoop on Advance Directives

by Albert R. Jonsen, Ph.D.

ADVANCE DIRECTIVES? Designated decisionmaker? Life-support? Nutrition and hydration? Persistent vegetative state? Diminished capacity? A conversation filled with those words can make heads spin. Worse, that conversation can be very uncomfortable, for it may be about the death of a loved one. Imagine that you visit your mother who lives in a retirement community. She tells you that she has just heard a lecture about Advance Healthcare Planning. She wants you to be her "designated decisionmaker." When you ask what that involves, she gives you the handout from the lecture. It is an attractive brochure but filled with the words that open this paragraph. What are you being asked to do? Is it wise to do it?

Advance Healthcare Planning is a rather new idea in the world of medicine. For centuries, planning for one's death was urged more by preachers than by doctors. It was prudent to prepare one's soul for eternity. Now, as medical technology can sustain life through serious illnesses and even maintain life when hope for cure is gone, doctors need to urge their patients to consider how they want to live at the end of their lives. Advance care planning does that in a systematic way.

The idea of a Living Will was the first step. In the 1967 it occurred to a Chicago lawyer, Luis Kutner, that people had no way to direct their medical care after they had become so sick that



they could not express themselves. He wondered why a sort of Will could not give those directions to be carried out before death, unlike the Last Will and Testament that takes effect only after death. He drew up a document that said, "If I become unable, by reason of physical or mental incapacity, to make decisions about my medical care, let this document provide the guidance and authority needed to make any and all such decisions...if there is no reasonable hope of my recovery from a seriously incapacitating or lethal illness, I do not wish to be kept alive by artificial means." Mr. Kutner had a flare for promotion. He persuaded

the most popular television figure of the era, Catholic Bishop Fulton J. Sheen, to introduce the Living Will on his television program. The Bishop and Joe DiMaggio signed it on the show.

The Living Will was a clever idea but there was a catch (that a lawyer should have caught). Unlike its testamentary relative, it had no legal force. Doctors could, and did, simply ignore it. Another lawyer, California legislator Barry Keene, decided to remedy this after a difficult death in his own family. He introduced into the State Assembly, the Natural Death Act, which gave some legal force to the document. But even then doctors ignored it. They commonly said that it was too vague to be of any use in a real

ADVANCE DIRECTIVE, continued on back



Advance Directives: Terri Schiavo Didn't Have One. DO YOU?

California Pacific Medical Center's
Program in Medicine & Human Values &
the Community Health Resource Center present an

ADVANCE CARE FAIR

October 8, 2005

10:00 A.M. to 2:00 P.M.

California Pacific Medical Center

Pacific Campus, Lobby

2333 Buchanan Street

San Francisco, CA

These programs will present a half day of dialogue, lectures and consultation to help patients and their families understand Advance Healthcare Directives. You'll have a chance to personally meet and consult with experts on the topic and attend lectures by faculty, including California Pacific Medical Center's resident bioethicist **Albert R. Jonsen, Ph.D.** and **Bernard Hammes, Ph.D.** of the Gunderson Lutheran Clinic in La Crosse Wisconsin.

Advance Healthcare Directives and Advance Care planning come in many forms. Patients are often confused about how to go about planning. We'll walk you through the essentials of **Advance Care Planning**. We'll help you talk to your loved ones and your doctor about these things and we'll even help you decide what is right for you.

We'll have consultants from California Pacific, St. Luke's Hospital, Catholic Healthcare West and the California Medical Association.

Schedule of Events
on next page.

The event is free of charge. You can also make a 10–15 minute appointment (time permitting) to speak to one of our consultants to have some specific questions answered. Follow-up appointments can be scheduled at the Community Health Resource Center (CHRC). To schedule an appointment, call the CHRC at (415) 923-3155.

Schedule of Events

The schedule of events is set up so that you can attend lectures at your leisure. When you're not in lectures, you can talk to consultants and have specific questions answered in the hospital lobby.

Consultations and Information Exhibits

10:00 a.m. – 2:00 p.m.

Lectures

10:00 – 10:30 a.m.

“What is Advance Care Planning?” Bud Hammes, PhD; Enright Room

“What is Good Care for the Dying Patient?” Marsha Nunley, MD; Level A Conference Room

11:00 – 11:30 a.m.

“What is Advance Care Planning?” Carol Bayley, PhD; Enright Room

“What is Good Care for the Dying Patient?” William Andereck, MD; Level A Conference Room

12:00 – 12:45 p.m.

“What Happened to Terri Schiavo?” Albert R. Jonsen, Ph.D and Panel, Enright Room

1:00 – 1:30 p.m.

“What is Advance Care Planning?” Bud Hammes, Ph.D.; Enright Room

“What is Good Care for the Dying Patient?” Marsha Nunley, MD; Level A Conference Room

1:30 – 2:00 p.m.

“What is Advance Care Planning?” Carol Bayley, PhD; Enright Room

“What is Good Care for the Dying Patient?” William Andereck, MD; Level A Conference Room

Special Guest: Bernard J. Hammes, Ph.D.

The day prior to our Fair, we are very pleased to announce the participation of a guest teacher, Professor Bernard Hammes, Director of Medical Humanities at Gundersen Lutheran in La Crosse, Wisconsin. Dr. Hammes will be leading a Tutorial for a variety of staff both from CPMC and other medical institutions here in San Francisco. His training will provide these staff with the skills to consult patients on how to complete a Directive, and raise their awareness of the importance that Directives have on the lives of patients and their loved ones.

Staff Ethics Survey

In October and November, CPMC's Program in Medicine & Human Values will be asking some staff to complete a very important survey on ethical healthcare practices. This survey, the Staff Ethics Survey (SES), was developed by the VHA National Center for Ethics in Health Care. It is designed to gather information about staff members' experiences and thoughts about ethical healthcare practices at our hospital. The results will be used to guide local quality improvement projects.

Invitation letters will be sent to randomly selected CPMC staff members within the next few weeks. The survey covers six topics related to healthcare ethics, including the healthcare environment, shared decision making, end of life care, privacy and confidentiality, professionalism and resource allocation.

This is a unique opportunity for staff to share their perceptions of ethical healthcare practices. The survey is voluntary and anonymous and staff members are encouraged to complete it during their normal working hours.

Please direct your questions to the project coordinator, Wes McGaughey, (415) 600-1480 or email ethics@sutterhealth.org. CPMC Resident Bioethicist gives prestigious lecture!

CPMC Resident Bioethicist gives prestigious lecture!

Dr. Albert Jonsen gave the Pitts Lecture in Medicine and Society at the Medical University of South Carolina. His subject was The God Squad: The Origins of Transplant Ethics.

What Else Should I Know About Advance Health Directives?

Below is a list of resources of information, websites, books, etc.

Websites:

For Advance Directive Forms in several languages, visit:
California Pacific Medical Center
<http://www.cpmc.org/learning/advdir.html>

For Catholics:
Florida Catholic Conference
<http://www.flacathconf.org/Publications/Comment/Comm298.htm>

For the Jewish family:
The United Synagogue of Conservative Judaism
<http://www.rabbinicalassembly.org/docs/medical%20directives.pdf>

For information, visit:
California Medical Association
<http://www.cmanet.org/publicdoc.cfm/7>

California Coalition for Compassionate Care
http://www.finalchoices.calhealth.org/advance_health_care_directives.htm

California Attorney General
http://ag.ca.gov/consumers/general/adv_hc_dir.htm

Books:

King, Nancy. *Making Sense of Advance Directives*. Washington, D.C.: Georgetown University Press, 1996.

Fulton, Gere B. *Perspectives on Death and Dying*. Boston: Jones and Bartlett, 1995.

clinical situation. In recent years, efforts have been made to bring this advance planning both to patients and to doctors in ways that are helpful and meaningful. Here are some basic ideas.

Persons who are in good health rarely contemplate how serious disease or disability might affect them. In medicine, the guiding principle of autonomy urges that persons have the responsibility and the right to make decisions about how they should be treated during serious illness. However, serious illness often deprives the patient of the abilities to make decisions on their own behalf. In recent years, the concept of "advance planning" has been widely promoted as one solution to that problem. Advance planning encourages individuals to make known to physicians how they would wish to be treated at a future time when they might be unable to participate in decisions about their care and also to inform the physician about the persons they most trust to decide on their behalf. The most important features of advance planning are discussions with one's family and with one's doctor. The physician will document this conversation in the patient's record where it will be available at all times. Advance planning has become more common in routine medical care and is especially important in terminal care.

In addition to this conversation, the wishes of the patient should be stated in legally acceptable documents, generally called "advance directives." There are several forms of advance directives: (1) the "durable (or medical) power of attorney for health care;" (2) the legal instrument entitled "Directive to Physicians" in the natural death acts enacted by various states; (3) the less formal "living will." Each of these forms is explained in the following paragraphs.

The idea of advance directives has become both familiar and accepted in ethics and in law. Medicare regulations require hospitals to provide patients with information about their rights under state law to accept or refuse recommended care and to formulate advance directives. In 1990, Congress passed the Patient Self-Determination Act requiring that all hospitals and other healthcare facilities receiving federal funds, such as Medicare and Medicaid payments, must ask patients at the time of admission whether they have advance directives. If they do, patients are asked to submit copies for their records; if they do not, they are to be informed that they have the right to sign such a document and be given information about it. Physicians should encourage their patients to prepare advance directives; they should become familiar with the provisions of advance directives that are legally valid in their locale.

Although the legality of advance planning has been formalized by legislation and upheld by courts, medical practice has been slow to respond to the preferences of terminally ill patients for less aggressive end-of-life care. Several empirical studies document that physicians are reluctant to discuss end-of-life issues with patients. Physicians often failed to write DNR orders for patients who had requested them to do so. Systematic attempts to improve communication, information, and conversation between patients and physicians met with little success. Nor did the use of outcome data or patient preferences influence physician practices. End-of-life care, at least in the intensive care setting, is currently driven more by traditional hospital and physician practices to prolong life than by patient preferences which are often difficult to discern when the patient is critically ill.