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# Ethical Times

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## Make the Most of Your Doctor-Patient Relationship

Wes McGaughey, Research Director

AS A CHILD, I HAD MANY DOCTORS. It seemed as if my mother was always taking me to one. As I got older, I went less frequently. Only when I got miserably sick with a bad case of the flu, or when I received a letter from my health insurance company prodding me to my annual check-up, would I go. It always seemed to be a different doc. When I was sick, I would sit on the table, stare at them, and tacitly say, "Fix me!" After some prodding and poking, the "fix" was usually a prescription for some chalky liquid and some commonsensical advice. With my experiences, I found "the doctor" a waste of time, and wished for a drive-through clinic where one could get a test at the first window and pick up a prescription at the second. Since I have joined the Program in Medicine and Human Values, I've learned more about the doctors' world and how it works. I now know why I never got "fixed" and why I felt my visits were a waste of time. It was because I didn't help the doctor help me. He needed me just as much as I needed him.

I grew up in the late 20<sup>th</sup> century; the age of the physician as technocrat. My doctor wasn't my healer, he was my mechanic. That's the ostensible culture of medicine these days; it's technology driven. The technology consists of new drugs, new imaging machines, new organ support systems and much more. In order to use these systems, medical students are taught to think like computers; to reason from flowcharts and algorithms. In a world filled with electronic devices directed by computers, this techno-



logical thinking might seem an advantage: faster, fault free diagnosis and treatment! But it is more insidious than it appears: it can disrupt the essence of the doctor-patient relationship.

The doctor-patient relationship is a very special. Naturally, patients who like their physicians and physicians who know what they are doing make a good relationship. But, most important for this relationship is the trust that doctor and patient have in each other. Trusting is no easy task. In order for patients and doctors to trust each other, both have to make commitments to each other. Patients have to be honest with their physicians about their values so the physician can

RELATIONSHIP, CONTINUED ON PAGE 3

# The Ethicist Is ...a phone conversation



by William Andereck, M.D.

*Today's Ethicist (E) is Dr. William Andereck. He has just taken a phone call from one of his patients, AS (anxious son):*

**(AS):** Hi, Dr.A. Can I ask a question about my Dad? He had a stroke four weeks ago and is still in the intensive care unit at Mercy Hospital in Chicago. I saw him right after the stroke. He was drowsy but recognized me and my sister. He was just starting to take a little food. The doctors said he was improving. They talked with us about a rehabilitation facility. After I returned to San Francisco, things started to fall apart. He stopped breathing and was put on a respirator. That was almost three weeks ago and he hasn't awakened. This morning someone from the hospital called my sister. They asked if we would like to have my father taken off life support. I am flying back this afternoon. What should I do?

**The ethicist (E):** Tell me more about your father. How old is he? How was he doing in the months before his stroke?

**AS:** Well, he is 78, still living in the home we grew up in. He slowed down after Mom died 3 years ago and then his heart attack last September left him pretty much confined to home and trips to the doctor's office. My sister lives close, but she can't be there all the time. Yet Dad refuses to move to one of these new retirement

centers. He has a caretaker who is there almost all the time, but that may not be enough now.

**E:** The first thing is to determine what his own wishes might be. Have you or your sister ever spoken with your father about what he might want in a situation like this?

**AS:** Gosh no. He was a very optimistic guy and didn't talk about such things.

**E:** Do you know whether your father has an Advance Directive or Living Will that might specify how he would like to be cared for in a situation like this? In almost every state, there is a legal form that allows persons to state their future wishes and to designate someone to make decisions for them. Since many savvy attorneys now include this in their estate planning services, your father's lawyer might know. Check with him.

**AS:** I am not sure Dad ever did this. He never mentioned it to me. Maybe his lawyer has it, along with his will. Maybe he has talked about these things with my sister but she never mentioned any papers.

**E:** Have you spoken with your father's doctor recently?

**AS:** Dr. Snipe took care of him for 30 years. He got him through Mom's death, but after the heart attack Dad spent most of his time going back and forth to the heart doctor. Since he has

been in the hospital this time, we haven't seen any doctors he knew before the ambulance brought him to the emergency room. They are all neurologists and lung doctors now. The doctors taking care of Dad are nice, and they certainly seem competent, but they don't know him or us.

**E:** A talk with your father's regular doctor might be helpful. He and your Dad may have had some discussions about these matters, particularly around the time of your mother's death. His years of treating your father may give him a better idea of what he would want and hope for than the doctors in the hospital, who are often strangers.

**AS:** Suppose we don't get much from Dr. Snipe. What do we do then?

**E:** Well, if we can't learn about your Dad's personal wishes, the best I can do is to give you some important things to keep in mind when you return to your father's bedside, and a strategy to make sure that his dignity and personal values are respected.

The first thing to consider is, "What choices are possible?"

Sometimes, there really is no choice to make. Patients who are brain dead, for instance, even though they seem to be breathing on the ventilator, are already dead and no treatment is possible. Likewise, for patients who

**ETHICIST, CONTINUED ON PAGE 4**

work within those values in caring for them. Physicians must manifest their values to patients.

While the relationship often proceeds with technological thinking—patients come with a pain or a problem and the doctor figures out what it is and fixes it—ideally, the goal of the interaction between physician and patient ought to reflect the patient’s health-related values. What’s a health-

protects and promotes the patient’s values. A doctor ought to understand these values as the patient defines them. The doctor, whose values may favor effective and efficient cure, should adapt in light of the patient’s values. Obviously, this meeting of minds takes time, the willingness to be open and to adjust. If the patient is having a hard time defining them, the doctor should encourage the patient

for treatment. Shared decision making, open conversation, value-oriented discussions, respect for autonomy, and recognition of mutual responsibility on both sides, should be the gold standard in all doctor patient relationships.

In an era when contact between patients and doctors is often brief and when doctors change with insurance plans or specialty needs, this gold standard would seem beyond attainment. Doctors are not paid for deep conversation; indeed, they may be penalized for taking too much time with their patients. Still, like all ideals in an imperfect world, the gold standard should be the measure of what patients ask of their doctors (I do!) and what doctors wish to give their patients. It should inspire medical education and motivate health care reform. Values do count!

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I now know why I never got “fixed” and why I felt my visits were a waste of time. It was because I didn’t help the doctor help me. He needed me just as much as I needed him.

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related value? Everyone has values: the things that one appreciates and considers a necessary ingredient for happiness and well-being. “Health-related” values are the features of physical and psychological life that a person wants to preserve and improve. Youthfulness, strength, and vitality are obvious examples. When persons seek the help of doctors, their health related values are usually straightforward. For example, a person in pain wants to be pain free; a person laid low by flu wants to be up and around. Health-related values can be much deeper. For example, persons who appreciate articulate communication may prefer to tolerate pain rather than take drugs that make them fuzzy and drowsy. Persons who value an intense, active life may forgo treatments that might keep them, alive but seriously debilitated. Persons may choose a less effective treatment because the more effective one might compromise their ability to bear a child or cause impotence. In all such cases, the treatment depends, not on the “fix” but on the way treatment

to define them more clearly. The patient’s values are invaluable when the doctor is seeking to understand the patient’s condition and decide on suitable treatment.

Modern medical ethics takes the autonomy of the patient very seriously.

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What autonomy really means is that every person has values that shape and guide their personal life. Respect for autonomy means that the doctor must incorporated those values into a plan for treatment.

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Doctors must respect the autonomy of their patients. However, patients and doctors often oversimplify patient autonomy, viewing it simply the right of patients to select their preferred course of action from a menu of options offered by doctors. What autonomy really means is that every person has values that shape and guide their personal life. Respect for autonomy means that the doctor must incorporated those values into a plan

## ETHICIST, CONTINUED FROM PAGE 2

have entered the persistent vegetative state, such as Terri Schiavo, choices of treatments to improve quality of life are meaningless since such patients have no experience and cannot perceive anything. It seems, however, that your father has not yet advanced to either of these states so you still have to make some tough decisions.

**AS:** You're right. There are definitely some decisions to be made. What do think I can expect?

**E:** Patients spend a lot of time in intensive care because they are very sick. ICUs exist because we have good data to show that the aggressive medical and surgical treatments employed can be life saving in many cases. Popular media would have you believe that these miraculous outcomes are the norm. Unfortunately, especially for elderly individuals with multiple problems, like your father, the outlook is often not bright. He may survive Intensive Care but a return to independent living is not a likely outcome. If he survives, he will probably be discharged to a nursing home. It's with that prospect in mind that someone from the hospital called about taking him off life support.

**AS:** But don't the doctors know what to do? Why should we be asked to make this decision?

**E:** You and your sister must be the decision makers. You must form a decision based on what you believe he would want, not based on what you want. This is a really important distinction. Your own emotions will be very strong. They can easily confuse your own desires and hopes with what is best for your father. So, the first thing you should do is to sit down with your sister and talk about the kind of person your father is.

Enlist input from the person who has been taking care of him at home. Was he making plans for the future, was he enjoying his daily activities? Make sure you both have a common understanding of his values and preferences. Essentially, you are trying to formulate an idea of what would be in his best interest.

**AS:** I've always found it hard to understand what "best interest" means—and I'm a lawyer.

**E:** It is a vague idea but, in these medical decisions, it stands for our best idea of what a person appreciates about life, based on what we know about their past and about their hopes. Strange as it may seem, death can sometimes be in a person's best interest, when they no longer can live in accord with their hopes. You and your sister should be ready to discuss these difficult matters when you meet with his doctors.

**AS:** What do I say when the doctor comes in?

**E:** That won't be a problem. They usually talk first. They might explain things in fairly technical terms, so don't be afraid to ask for clarification if you don't understand something. Doctors may give you a lot of statistics and percentages, a 20% chance of this happening and a 30% chance of that happening. This is not very helpful to you. Ask them for their best opinion as to what will happen. Say you recognize they are human and could still be wrong. You want to know the diagnosis (what is wrong), and the prognosis (what is expected to happen), both with a particular treatment (the respirator will support his lungs while we wait to see if his brain recovers), and without it (he will die if we take him off the respirator now).

Ask whether everyone on the med-

ical team is on the same page about these matters. Sometimes the doctors and nurses are conflicted among themselves about the right course of action. They recognize the difficult issues and that there are different approaches reasonable people might pursue. Hospitals now appreciate the difficulties inherent in many of these decisions and have instituted measures to assist the staff in dealing with them. In cases of severe disagreement between doctors, or between doctors and families, hospital ethics committees, now required by law, can often provide guidance.

**AS:** I hope it doesn't come to that!

**E:** It probably won't. Usually, agreement can be achieved when there is clear, honest communication, even when emotions run high. In all this ask yourself whether your input is acknowledged. Does the staff show an appreciation for your father as a person with further goals and aspirations beyond another day in the ICU? Does the medical team seem consistent and in agreement with the treatment plan? Most of all, do you feel like you can trust the people who are taking care of your father?

If the answer to all of the above questions is "yes," you are probably on the right track. Things won't be easy, but with a respect for your father's values, thoughtful medical care and good communication, things usually work out with the least amount of tragedy, conflict and pathos.

**AS:** Thank you, Dr.A, you have given me a lot to think about on the plane.

**E:** Good luck.



# On the Calendar

## On the Calendar

Dr. Al Jonsen has been invited to give the Charles Bodemer Annual Lecture at the University of Washington, May 1, 2007. Dr. Bodemer was the founder of the Department of Medical History and Ethics, of which Dr. Jonsen was chairman for 13 years until his retirement in 1999. His lecture is entitled "Cultural Sensitivity and Ethical Relativity: Doing Biomedical Research in Other Climes."

## Summer Workshop

Our Program will produce a Workshop in Clinical Ethics June 1 and 2, 2007. The Workshop will be devoted to understanding

how diverse ethnic communities and cultures understand ethical issues that arise in clinical care, such as decisions about dying, consent to treatment and participation in research. Dr. John Stone, former director of the Bioethics Center at Tuskegee University, Dr. Henry Perkins, Professor of Medicine at University of Texas, San Antonio and Dr. September Williams of Laguna Honda Home will lead discussions of African-American and Hispanic views on clinical ethics. All members of ethics committees, and other professional staff, from the Sutter Hospital system and from Catholic Health Care West are invited to attend. Call Program in Medicine and Human Values, 415-600-1647 or our home page at [www.cpmc.org/ethics](http://www.cpmc.org/ethics)

## International Bioethics Retreat 2007

Invited bioethicists from around the world will meet in England June 18-22 at Saint Catharine's College, University of Cambridge, for the PMHV-sponsored International Bioethics Retreat. An annual event, the goal of the Retreat is to establish an international community, composed of health professionals, policy makers and academics, committed to furthering research in bioethics.



# After Action Report

## Schwartz lectures at Noon Conference

Professor Robert Schwartz returned as a follow up to his November Talk Ethics presentation, "Should Doctors Obey the Law?" This discussion was specifically for our medical residents, a lecture on Terry Schiavo from a legal perspective. He explained the myths versus facts of the case, and contrasted public perception versus legal reality. He elegantly presented the key issues of the case, the most important of which was the notion of quality of life versus sanctity of life. This was an important bridge to the resident's own daily experiences, and helped them take a nationally publicized case and apply it to their own daily experiences in the hospital. Finally, Professor Schwartz asked the residents how

they as physicians will approach the next Schiavo case, and the discussion proved to be fascinating.

It should be noted that one resident approached a staff member afterwards and said she felt like she was back in college, thinking about things from an academic standpoint. For that, we thank the Professor for his continued contributions to ethical work.

## Journal Editors Meeting:

February 15-17 marked an important event in that PMHV sponsored the first meeting of editors representing leading bioethics journals for the purpose of developing publication guidelines. Topics discussed included: Editorial Standards and Processes, Confidentiality,

Transparency, Authorship, Scholarship, Human Subjects and Social Responsibility. The next meeting of the group will be hosted by the British Medical Journal in London in the Fall.

## Dr. Jonsen speaks at events

Dr. Al Jonsen was the opening speaker at a conference in Mexico City organized by the National Health Service of the Mexican government. The conference was the first event in developing a program in clinical ethics for Mexican doctors. Dr. Jonsen also was the opening speaker at Stanford Medical School Conference on Ethics and Neuroscience.

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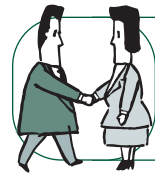
# Stop Talking Medicalese

**Ethics Committee:** An official committee of the hospital medical staff which reviews and advises physicians, patients and families on difficult ethical decisions such as withdrawing life-support, by applying the concepts of ethical literature, legal precedents and hospital policy to particular cases that are referred to them.

**Quality of Life:** A judgment that the experience of living, in whole or in part, is worthwhile or satisfying to the person living that life.

### **Transplant / Organ donation:**

Certain major organs of the body, such as heart, lungs, livers, kidneys and pancreas, can be removed from one person and placed in body of another person, substituting for their failed organ. Organs must be donated by deliberate choice of the donor or their family and can be taken at death or, in case of kidneys and partial livers, during life.



# New Additions

PMHV is pleased to announce our first full time clinical ethicist. Dr. Katrina Bramstedt. Dr. Bramstedt's special interest is in issues surrounding transplantation and the use of life sustaining medical devices. Her primary responsibility

will be serving as the Clinical Ethicist in the upcoming Proactive Ethics Intervention Project. This project will evaluate the utility of early attention to ethical issues in patient care in the ICU over a 3 year period.

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