

*Health Care Law*

*Mid-Atlantic Ethics Committee Newsletter*

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University of Maryland Francis King Carey School of Law    *Year 2004*

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Mid-Atlantic Ethics Committee  
Newsletter, Summer 2004

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# MID-ATLANTIC ETHICS COMMITTEE

N E W S L E T T E R

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia  
Published by the Law & Health Care Program, University of Maryland School of Law  
and the Maryland Health Care Ethics Committee Network

Summer 2004

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## The Living Will – Admit Failure?

**A**re the living will (LW) and subsequent Patient Self-Determination Act (PSDA) policy failures? Should we admit this and move on? That's what Angela Fagerlin and Carl Schneider conclude in a recent article in the Hastings Center Report.<sup>1</sup> For LWs to function as hoped, the authors write, people would have to have them, they would have to decide and clearly state what treatment they would want if incapacitated, and the LW would have to be available and understandable to people making treatment decisions. Based on a comprehensive review of hundreds of studies of living wills, end-of-life decision-making, and the psychology of making choices, Fagerlin and Schneider (F&S) conclude that living wills don't work and should be abandoned in favor of durable powers of attorney (DPOA) for health care.

### Why do so few people have living wills?

On average, only about 20% of the U.S. population has a LW. The low numbers are a result of people procrastinating, hesitating to plan for/talk about death, not thinking a LW is needed, and preferring family members and/or their physician to make decisions for them. In addition, the LW may be incompatible with certain cultural traditions. F&S point out that efforts to address each of these barriers has not increased the number of persons who have LWs. They ask, if "after so much propaganda so few of us have LWs, do we really want them, or are we just saying what we think we ought to think and what investigators want to hear?"

The Mid-Atlantic Ethics Committee Newsletter is a publication of the Maryland Health Care Ethics Committee Network, an initiative of the University of Maryland School of Law's Law & Health Care Program. The Newsletter combines educational articles with timely information about bioethics activities in Maryland, D.C., and Virginia. Each issue includes a feature article, "Network News," a Calendar of upcoming events, and a case presentation and commentary by local experts in bioethics, law, medicine, nursing and related disciplines.

Diane E. Hoffmann, JD, MS  
Editor

### Can people really know what they will want?

Research shows that most people can't accurately identify their future preferences—they answer differently based on how a treatment question is framed, change their minds,<sup>2</sup> and have trouble recognizing that their views have changed. This makes it less likely they'll amend their LW and more likely the LW will "treasonously misrepresent their wishes." This inability to clearly express future treatment preferences is partly due to health care providers' poor performance in effectively explaining key information. But

# NETWORK NEWS

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is not intended to provide legal advice  
or opinion and should not be acted  
upon without consulting an attorney.

## MARYLAND HEALTH CARE ETHICS COMMITTEE NETWORK (MHECN)

On Thursday, May 27, MHECN and the Greater Baltimore Medical Center (GBMC) co-sponsored a Journal Club discussion that focused on the Florida case of Terri Schiavo. Schiavo, who is in a persistent vegetative state (PVS), is the subject of a lawsuit in which her parents are trying to stop her husband, Michael, from discontinuing Terri's tube feedings. The spirited discussion included debate about the definition of persistent vegetative state; the role of the courts and the legislature in this type of case; challenges to a health care surrogate's stewardship; and related issues. Many thanks to GBMC for hosting this event! If your institution is interested in hosting a Journal Club discussion, please let us know.

Don't forget to register for MHECN's fall conference, "Still Hazy After All These Years; The DNR Order: Problems & Solutions," to be held on Wednesday, November 17, 2004, at Charlestown Retirement Community in Catonsville, MD (see Calendar).

MHECN welcomes Ellen Agler to its Board. Ellen is the Director of Project Management for Erickson Health Plan, and brings to the Board a wealth of experience in long-term care and assisted living.

Ethics committee members and/or employees of MHECN member institutions who would like to receive MHECN e-mail announcements directly, please send us your email address and the name of your institution, and we will add you to our e-mail distribution list.

If you would like to join the MHECN e-mail discussion listserv, you may do so by sending a blank e-mail message to [join-mhecn@list.law.umaryland.edu](mailto:join-mhecn@list.law.umaryland.edu).

Contact MHECN at (410) 706-4457; e-mail: [www.MHECN@law.umaryland.edu](mailto:www.MHECN@law.umaryland.edu).  
MHECN Coordinator: Anita J. Tarzian, PhD, RN

## THE METROPOLITAN WASHINGTON BIOETHICS NETWORK

The Metropolitan Washington Bioethics Network continues to work with the D.C. Superior Court Probate Division, which has been sponsoring training sessions for guardians on bioethics issues. The most recent training was held on June 23 and attended by more than 150 guardians. Panelists included John Lynch, MD, Andrea Sloan, Esq., RN, Fiona Druy, RN, NP, Michelle Grant-Ervin, MD, and Barbara Soniat, PhD. Another session is being planned for the fall (date TBA). In addition, the DC Bar has established a working group to attempt to update and upgrade DC law on probate issues, including guardianship, self-neglect and related topics. MWBN continues to extend ethics and health law resources to its members. Joan Lewis, long-time MWBN Coordinator, has recently moved from the DC Hospital Association to serve as Executive Director of IONA Senior Services. She will continue to serve as MWBN Coordinator from her new post.

Contact: Joan Lewis, Executive Director,  
202-895-9408, [jlewis@iona.org](mailto:jlewis@iona.org).

### The Living Will

Cont. from page 1

it's also a psychological phenomenon—people are poor predictors of their future preferences. F&S conclude, "[G]iven this rich stew of research on people's missteps in predicting their tastes generally, we should expect misapprehensions about end-of-life preferences. Indeed, those preferences should be especially volatile, since people lack experience deciding to die."

### Can people effectively articulate what they want?

Even if patients knew what future care they wanted, articulating it effectively in a LW is exceptionally difficult. If the directive

*Cont. on page 3*

is too general (e.g., a ‘values history’), it precludes drawing useful conclusions about how to apply it to specific clinical scenarios. If it’s too specific, it forces patients to “address more questions than they could comprehend.” Does a patient who forbids use of feeding tubes in a LW mean in *any* circumstance, or only if (s)he were imminently dying? What is ‘imminent’? If (s)he requests artificial feeding at the end of life, does that person understand what this might entail if (s)he were severely demented and unable to meaningfully interact with others?

Related to the problem of difficulty articulating future preferences is the problem of accurately interpreting the LW. One study found no difference in agreement about the patient’s treatment preferences between surrogates and patients who had and who had not completed LWs. This was true even if surrogates had discussed the LW with the patient just before being asked their prediction of what the patient would have wanted. Other studies have shown that physicians are not helped by LWs in determining the patient’s wishes. F&S assert that the “failure to devise workable forms is not a failure of effort or intelligence. It is a consequence of attempting the impossible.”

### **Do living wills alter patient care?**

LWs have not altered patient care, research shows, whether evaluating diagnostic testing, hospital and ICU lengths of stay, or health care costs. Patients have surrogate decision-makers identified in the medical record who are not who was appointed by their advance directive (AD), and receive care that is inconsistent with their LW. This may partly be due to the LW not being where it needs to be when it needs to be. In one study, only 26% of hospital charts accurately recorded information about ADs, and only 16% of the charts contained the form. In another, only 35% of nursing home patients transferred to a hospital had their LWs with them.

F&S present three reasons to explain why LWs do such a poor job influencing patient care. First, their content is vague and difficult to apply in specific situations. F&S believe this exacerbates the interpreter’s tendency to read the documents in light of his or her own preferences. Second, patients are not seen as being hopelessly ill or actively dying, so

the LW is not invoked.<sup>3</sup> Third, surrogate decision-makers are often not available, or are “ineffectual or [are] overwhelmed with their own concerns and do not effectively advocate for the patient.”

### **Do living wills have beneficial side effects?**

Even if LWs don’t work as well as intended, proponents argue that their secondary benefits make them worthwhile. These include: (1) stimulating conversation between doctor and patient about end-of-life treatment; (2) reducing costs of terminal illness (i.e., not having to administer expensive therapies that would otherwise have been administered if the patient’s wishes to avoid them hadn’t been known); and (3) bringing comfort to patients and surrogates. Research findings have challenged the first two,<sup>4</sup> but Fagerlin and Schneider cite some research to support the third benefit (e.g., reduced stress/unhappiness of family members who authorized withdrawing a patient’s life support in accordance with a patient’s LW). However, because this comfort is apparently unrelated to the accuracy of the surrogate’s decision, F&S conclude that “we are left with the irony that one of the best arguments for a tool for enhancing people’s autonomy is that it [the tool] deceives them [the declarant] into confidence.”

### **Repeal the PSDA and admit failure of the LW?**

F&S conclude:

*LWs fail not for want of effort, or education, or intelligence, or good will, but because of stubborn traits of human psychology and persistent features of social organization ... If, as we have argued, patients sign LWs without adequate reflection, lack necessary information, and have fluctuating preferences anyway, then LWs will not lead surrogates to make the choices patients would have wanted.*

Citing the costs of implementing the PSDA and the evidence that it has “promoted the execution of uninformed and under-informed advance directives, and has undermined, not protected, self-determination,” they recommend repealing it. In addition, they believe patients should be told the truth—that

LWs have a “faint chance of achieving their intended effect.” Patients who want control over future medical decisions should be counseled to appoint an agent via a DPOA. Although these documents are not perfect, the appointed agent (likely to be a family member) will “probably know more at the time a decision needs to be made than patients can know in advance.” Unlike LWs, the authors concede that DPOAs are “simple, direct, modest, straightforward, and thrifty.”

### **NOTES**

1. Fagerlin, R. & Schneider, C. (2004). *Enough. The failure of the living will. Hastings Center Report, 34(2), 30-42.* Research studies referred to in this article are referenced in Fagerlin & Schneider’s article.

2. A meta-analysis of 11 of 16 studies regarding the stability of individuals’ preferences for life-sustaining treatment found a stability of preference of 71%, on average (range: 57-89%). F&S also cite a study that found that “Only 10-14% of individuals who survive a suicide attempt commit suicide during the next 10 years, which suggests that a desire to die is inherently changeable.”

3. For example, on the day before death, the median prognosis for patients with heart failure is 50% that they will live 6 more months; these patients typically die quickly from arrhythmia or infection. Patients with heart failure who have advance directives (LW or DPOA not specified) have not been shown to be different in timing of DNR or utilization patterns from those without.

4. Regarding the ability of the LW to stimulate physician-patient communication about end-of-life care, research shows that conversations about LWs don’t take place often, and when they do, are generally unsatisfactory. “...[D]octors commonly ‘did not explore the reasons for patient’s preferences and merely determined whether they wanted specific treatments’.” Physicians used vague language to describe end-of-life scenarios, and “conversations tended to ignore the more common, less clear-cut predicaments surrounding end-of-life care.” In a study examining how doctors explain advance directives, patients generally thought doctors did a good job, but F&S conclude that it’s “likely patients didn’t know how little they were told.”



## A challenge to Fagerlin & Schneider

F&S concede that the minority of individuals who have clear ideas of what they want at the end of life and desire control over future medical interventions should still be able to complete a LW, but F&S don't think the LW, as policy, should be promoted for the general population. They present compelling evidence that people poorly predict their future preferences, which precludes crafting LWs that achieve the intended goal of directing future treatment. However, LWs are only one form of advance directive addressed by the PSDA. Repealing the PSDA because of recognized failings of the LW ignores the alternative of shifting focus from promoting LWs in their current form to that of DPOAs, or to alternative advance directives like the "Five Wishes"<sup>1</sup> document. However, promoting the DPOA as an alternative to the LW doesn't solve the other problems F&S elucidate, such as agents or surrogate decision-makers not being available (physically or emotionally) to advocate for patients when needed, advance directives being absent from patients' medical charts, and health care providers failing to effectively communicate with patients and families about end-of-life planning and treatment options. Whatever takes the place of the LW will inherit the same set of challenges: flawed human psychology, prognostic uncertainty, death aversion, faulty communication/information exchange, and institutional inefficiency. With this list of barriers, it's no surprise that improvements are so incremental. But all the more reason not to repeal legislative incentives like the PSDA—instead, we should more effectively implement the law based on what we've learned thus far, which is so aptly summarized by Fagerlin & Schneider.

1. For more information about the "Five Wishes" document, visit [www.agingwithdignity.org/5wishes.html](http://www.agingwithdignity.org/5wishes.html).

Anita J. Tarzian, PhD, RN  
MHECN Coordinator

## IMPROVING THE CARE PLANNING PROCESS: NEW MARYLAND LEGISLATION

Mrs. Jones is a nursing home resident and has lost the capacity to make medical decisions, but has already expressed her preferences about the use of life-sustaining medical treatments in a living will. She used Maryland's optional form and directed that her life "not be extended by life-sustaining procedures" once she is in a terminal condition. The living will is meant to speak for her when she cannot.

But, once she is certified to be in a terminal condition, the directions in the living will must be transformed into concrete, operational instructions for those providing hands-on care: What medications are to be given? Is a feeding tube to be used if Mrs. Jones is no longer able to eat normally? If she has a cardiac arrest, is CPR to be attempted? These and other matters would be specified by her attending physician in medical orders, which are to be consistent with the living will.

Now suppose Mrs. Jones needs to go to the hospital for some reason. Maybe her living will would be sent with her, and maybe not. Even if it were, a new physician, who probably doesn't know Mrs. Jones, would have to figure out how the living will should affect the medical orders that the new physician will write. The change in the site of care increases the risk that Mrs. Jones' preferences will not be honored.

A variety of studies show a gap between patients' preferences about end-of-life care and the interventions actually performed in health care facilities. Although many reasons for this disparity have been identified, one has to do with the problem of information flow across care settings. A patient might move, for instance, from an assisted living facility to a nursing home, then to a hospital, then to a rehabilitation facility, then back to a nursing home. There is currently no systematic way for a plan of care to be established that honors the preferences

of the patient or the patient's proxy and that remains in effect, unless changes in the patient's condition require a modification, no matter where the patient is receiving care.

House Bill 556, which becomes effective on October 1, 2004, addresses this problem through an amendment to the Health Care Decisions Act. A new section 5-608.1 of the Health-General Article instructs the Attorney General's Office to develop a document called a "Patient's Plan of Care" Form. In general, the "Patient's Plan of Care" Form will be a summary of the overall plan of care, including the use of life-sustaining treatments, that has been decided upon by, or on behalf of, a patient. Although its use is voluntary, once the AG's Office has developed the new form after a public consultation process, it can be expected to gain increasing use over time in a range of clinical settings.

The new form is intended to complement, not supplant, the decision-making processes already recognized by the Health Care Decisions Act. H.B. 556 recognizes that patient or family decisions about the goals of care are not self-executing. A patient will receive care that fits these goals only if health care providers actually know about and follow a plan of care that is consistent with the patient's overall goals. The "Patient's Plan of Care" Form will be a tool for embodying and communicating the plan for each patient.

### *Relationship Between "Patient's Plan of Care" Form and Physician's Orders*

As introduced, H.B. 556 would have enacted a "Physician Orders for Life-Sustaining Treatment" (POLST) form, a standard order form that health care providers would have been required to follow. Although this method has been successfully used in a handful of other states, opposition to the POLST approach in a legislative committee resulted in a significant set of amendments. As amended, the bill does not provide for any kind of physician's order. That is, a "Patient's Plan of Care" Form is not itself a physician's order, though ordinarily the contents of the form will shape the orders to be written.

The bill contemplates a patient-centered process. First, the patient or the patient's proxy (health care agent or surrogate) will have agreed to complete

the form, as attested by the appropriate signatures. Once completed, the form becomes the primary means of communicating how the use of life-sustaining treatments fits within the overall plan of care. Presumably, the physician who signed the form will write orders that reflect its contents.

The original "Patient's Plan of Care" Form, and the corresponding physician's orders, would remain in effect until something significant happened, as identified in the form itself or as otherwise having obvious potential impact on future clinical care. Then, the attending physician should revisit the plan of care with the patient or proxy and, if appropriate, cause a new "Patient's Plan of Care" Form to be completed and write new orders.

When a patient with a "Patient's Plan of Care" Form is transferred to a different health care facility, the form is to accompany the patient. When the attending physician at the new facility is considering orders for a patient with a form, the physician is required to review it. If, after reviewing the form in light of the patient's current clinical condition, the physician concludes that the patient's condition has not changed in any material way from when the plan was formulated, the review should result in clinical orders that are consistent with the plan. If, however, the plan has been overtaken by events and no longer serves the patient's best interest, the new attending physician's orders can properly depart from the plan.

#### *Relationship Between "Patient's Plan of Care" Form and Advance Directives*

The "Patient's Plan of Care" Form is not a new type of advance directive. Rather, it will serve as a bridge between the decisions made in an advance directive and treatment-specific medical orders. Nothing in the bill changes the current statutory right of an individual to make a written or oral advance directive. The making of an advance directive means that the individual, in anticipation of a future loss of capacity, has decided about the use of life-sustaining medical procedures, designated a health care agent, or both. If a patient who has lost capacity has an advance directive containing decisions,

like a living will, a "Patient's Plan of Care" Form for that patient must be consistent with those decisions. Likewise, if an individual had made an advance directive naming a health care agent, a "Patient's Plan of Care" Form for that patient must reflect the agent's decisions.

#### *Relationship Between "Patient's Plan of Care" Form and EMS/DNR Order*

The "Patient's Plan of Care" Form will not substitute for an emergency medical services "do not resuscitate order," anymore than an advance directive now does. If a "Patient's Plan of Care" Form reflects the patient's or proxy's decision that CPR not be attempted in the event of cardiopulmonary arrest, the form would be a basis for the patient's attending physician to write the appropriate order. The form itself, however, is not such an order and cannot directly affect the actions taken by EMS personnel.

#### *Nursing Home's Obligation and the "Patient's Plan of Care" Form*

The "Patient's Plan of Care" Form is expressly stated to be voluntary, and no patient is ever required to have one. Nursing homes, however, will be required to offer new residents the opportunity to prepare the form. If a resident is incapable of making an informed decision, the opportunity should be presented to whoever is making health care decisions on behalf of the resident. The exact manner in which this opportunity is to be presented is left to the reasonable discretion of the facility administrator. A nursing home's failure to present this opportunity, like other deprivations of resident rights, could potentially lead to sanctions through the licensing and survey process.

#### *"Patient's Plan of Care" Form and Statutory Immunity*

Health care providers who will use the "Patient's Plan of Care" Form, including physicians who write medical orders in good-faith reliance on a "Patient's Plan of Care" Form, are protected in doing so by the immunity provision in the Health Care Decisions Act.

#### *"Patient's Plan of Care" Form and Medically Ineffective Treatment*

The "Patient's Plan of Care" Form will not be used to reflect the attending physician's judgment (with a consulting physician's concurrence) that a particular life-sustaining treatment would be "medically ineffective," as that term is used in the Health Care Decisions Act. The "Patient's Plan of Care" Form is a documentation of the care planning decisions of the patient or the patient's proxy, based on the patient's expressed wishes, the proxy's inference about the patient's wishes, or the patient's best interest. The certification that a treatment is medically ineffective is based on none of these criteria, but rather criteria of physiological ineffectiveness. Consequently, a certification that a treatment is medically ineffective is unrelated to the "Patient's Plan of Care" Form.

#### *Conclusion*

The care planning process has three phases: the patient's thinking about health care issues and preferably discussing them with family, friends, and health care professionals; the patient's documenting his or her decisions in an advance directive; and the health care system's provision of care that is consistent with the patient's advance directive. When the patient has not engaged in care planning, as the vast majority have not, still some kind of care planning by proxy ought to occur: the proxy's thinking about health care issues in terms of what the patient would want done or the patient's best interests; and the health care system's provision of care that is consistent with the proxy's goals for the patient. In either case, a serious medical error occurs if the care that is delivered is inconsistent with the patient's goals and values, as reflected in the patient's own words or the proxy's interpretation. The Maryland Legislature and Attorney General's Office hope this type of medical error can be reduced if health care providers make effective use of the new "Patient's Plan of Care" Form.

Jack Schwartz  
Director of Health Policy  
MD Office of the Attorney General

# OREGON PAS SURVIVES CHALLENGE FROM ATTORNEY GENERAL ASHCROFT

In May of 2004, the United States Court of Appeals for the Ninth Circuit decided *State of Oregon v. Ashcroft*, 368 F. 3d 1118. In its ruling, the court ordered the continuation of an injunction that prevents federal enforcement of Attorney General John Ashcroft's directive that criminalizes physician-assisted suicide in Oregon. The court held that Ashcroft exceeded his authority in trying to regulate physician-assisted suicide, which is authorized in Oregon under the state's Death with Dignity Act.

The background of this case begins with the passage of the Controlled Substances Act (CSA) in 1970. This statute was enacted by Congress to address the problems of drug abuse and illegal drug trafficking in the United States. The CSA provides regulations for production and distribution of controlled substances (i.e., drugs that have the potential for abuse). The statute states that "a prescription for a controlled substance may be issued only for a legitimate medical purpose by a practitioner acting in the usual course of his professional practice."

In 1994, the State of Oregon enacted the Death with Dignity Act (DDA), becoming the only state to legalize physician-assisted suicide. Under the DDA, adult Oregon residents suffering from an incurable disease likely to result in death, are eligible to receive prescribed medication that would end life. A physician may prescribe, but not administer, the medication to the patient. Since its enactment, approximately 70 terminally ill patients have taken their lives following the stipulations of the DDA. In all cases, patients used medications listed as controlled substances under the CSA.

Beginning in 1997, several attempts were made by certain legislators to interpret the CSA in a way that would make it illegal to prescribe controlled

substances for the purpose of assisting with suicide. Janet Reno, Attorney General from 1993–2001, reviewed the issue and concluded that the federal government did not have the authority to prosecute Oregon physicians who were in full compliance with the DDA, although they were prescribing controlled substances for the purpose of assisting with suicide. She explained that "the CSA was not intended to displace the states as the primary regulators of the medical profession, or to override a state's determination as to what constitutes legitimate medical practice."

In November 2001, after John Ashcroft became Attorney General, he issued a statement (known as the "Ashcroft directive") specifically addressing physicians in Oregon acting under the Death with Dignity Act. The directive states that assisting with suicide is not a legitimate medical purpose, and that prescribing, dispensing, or administering a controlled substance for the purpose of assisting with suicide is not in the public interest. Any physician assisting with suicide under the DDA would be in violation of the CSA and could face criminal prosecution and termination of their ability to prescribe a controlled substance.

In response to the Ashcroft directive, the State of Oregon, along with an Oregon physician, pharmacist, and several terminally ill patients, filed a lawsuit against the Attorney General to prevent enforcement or application of the directive. A temporary restraining order, preventing implementation of the directive, was granted by a U.S. District Court Judge Robert Jones (District Court of Oregon.) The Judge ruled that the CSA was not intended to overrule a state's decision on what constitutes "legitimate medical practice" and found that the Attorney General and the DEA went beyond their authority in trying to control state physicians acting under the DDA.

The case was appealed to the U.S. Court of Appeals for the Ninth Circuit for a final decision. The Court held that the Ashcroft directive interferes with Oregon's authority to regulate medical care within its borders, which is an area traditionally reserved for state authority. In addition, the Court of Appeals determined that the Ashcroft directive conflicts with the CSA, which addresses problems associated with drug abuse and addiction—not

medications prescribed by physicians to assist with suicide.

The ruling of the Ninth Circuit supports state regulation of medical practice. The decision in this case will be significant for any other states that seek to address the issue of physician-assisted suicide and other issues related to the administration of controlled substances.

Iyanrick John, MPH  
University of Maryland  
School of Law, '06

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## 'DEADLY MEDICINE' – HOLOCAUST MUSEUM EXHIBIT OPEN THROUGH OCTOBER 16, 2005

*"It is a rare and special good fortune for a theoretical science to flourish at a time when the prevailing ideology welcomes it, and its findings can immediately serve the policy of the state."*

Eugen Fischer, leader of the German eugenics movement, 1943

*"It is certainly not the fault of eugenics, if godless and criminal misuse occurred in National Socialism without any knowledge of the genetic facts, and through the destruction of all human dignity."*

Eugen Fischer, 1955

The new Holocaust Memorial Museum exhibition "Deadly Medicine: Creating the Master Race," chillingly chronicles the use and abuse of science in the name of Nazism. This exhibit demonstrates how scientists and physicians crossed the fine line between objectively generating data and contributing to torture and murder in the name of science and 'social policy.' The museum's director, Sara J. Bloomfield, says in the catalogue to the exhibition, "[d]uring the Holocaust, every institution established to uphold



civilized values failed—the academy, the media, the judiciary, law enforcement, the churches, the government and, yes, the medical and scientific disciplines as well.”<sup>1</sup> While the tendency is to distance oneself from Nazi ideology, the exhibit reminds attendees that the ‘Final Solution’ was arrived at through a series of small steps. Most people recognize the horror of the gas chambers and inhumane Nazi experiments. Fewer dwell on the more subtle moral thresholds that were crossed en route. For example, American eugenics (which were endorsed up until the 1960’s) inspired Adolf Hitler, who praised them in ‘Mein Kampf’ and skillfully promoted eugenics policies in Nazi propaganda films and movies. Nazi eugenics led German citizens, scientists, and physicians to see the logic and compassion of euthanasia as a humane response to ending the suffering of individuals deemed as having a ‘life not worth living.’ Our modern-day aversion to health care rationing may stem from early eugenics policies, which were commonly concerned with the social cost of illness (for example, a wall display by the American Eugenics Society in the 1920’s reads, “Every 15 seconds \$100 of your money goes for the care of persons with bad heredity”). These everyday health and social concerns were the starting point for well-intentioned German scientists and physicians. This exhibit demonstrates how their moral compasses became frighteningly misdirected, and offers lessons to others who think they’re not apt to lose their moral bearings.

**The U.S. Holocaust Memorial Museum is open 10 a.m. to 5:30 p.m. every day except Christmas and Yom Kippur. Admittance is free and no passes are required for the “Deadly Medicine” exhibition. The museum is at 100 Raoul Wallenberg Place SW, near the Smithsonian Metro stop. The exhibition runs through Oct. 16, 2005.**

#### NOTE

1. As cited in “The Seduction of Science: To Perfect an Imperfect Race” by Philip Kennicott, *The Washington Post*, Thursday, April 22, 2004; Page C01.

## THE POPE AND ARTIFICIAL NUTRITION

On several occasions over the last 50 years, representatives of the Catholic church have explicitly stated that withdrawing life support, including artificial nutrition and hydration (ANH), is permissible “if it does not offer hope of benefit or imposes an excessive burden.” These statements were made by Pope Pius XII in 1957, the Catholic Congregation for the Doctrine of the Faith in 1980, and Pope John Paul II in 1995. Determinations of “hope of benefit” were to be made by the patient or the patient’s proxy, and could be applied to persons in persistent vegetative states (PVS). Until recently, this view has been supported by Catholic bishops, conferences of bishops, and Catholic medical ethicists. However, contrary opinions were expressed at the March 2004 international congress, “Life-Sustaining Treatments and the Vegetative State: Scientific Advances and Ethical Dilemmas,” sponsored by the World Federation of Catholic Medical Associations and the Pontifical Academy for Life, and attended in Rome by 350 physicians and medical ethicists. During this meeting, Pope John Paul II asserted that the administration of ANH is “a natural means of preserving life, not a medical act,” particularly for patients in a PVS.<sup>1</sup> Bishop Elio Sgreccia, vice president of the Pontifical Academy for Life, avowed that artificial hydration and nutrition for patients in a PVS is “simply care,” and not medical intervention. And Eugene Diamond, director of the Catholic Medical Association’s Linacre Institute, said that the provision of nutrition and hydration through tubes was not an “extraordinary” intervention but obligatory care.<sup>2</sup>

James Walter, professor of bioethics at Loyola Marymount University in Los Angeles, reacted by countering, “We normally understand ‘care’ to mean washing the patient’s body, turning the patient so they don’t get [bedsores], things of that sort, and you could include providing a tray of food to a patient ... But when you start artificially delivering this, it is now a matter of treatment.”<sup>3</sup> Walter pointed to inconsistencies in the current “Ethical and Religious Directives

for Catholic Health Care Services.” The introduction to Part 5 says ANH can be discontinued if the patient is imminently dying or if the patient cannot assimilate the nutrition and hydration, while Article 58 says there’s a presumption favoring providing ANH, but that ANH can be withdrawn if there’s not sufficient benefit to outweigh the burdens to the patient. Walter believes that the Schiavo case in Florida has triggered this latest examination of ANH in Catholic doctrine.

Indeed, the Pope voiced concerns about respect for patients in PVS that likely reflect the attitudes underlying Catholic conservatives’ changing views toward ANH. For example, the Pope stated, “[B]eing in the presence of a living person already imposes the obligation of full respect and of abstaining from any act that aims at anticipating the person’s death.” The Pope has also recently stated, “[d]eath by starvation or dehydration is, in fact, the only possible outcome as a result of ... withdrawal [of ANH]. In this sense it ends up becoming, if done knowingly and willingly, true and proper euthanasia by omission.” Dominican Fr. Kevin O’Rourke, professor at the Neiswanger Institute of Ethics and Public Policy and the Stritch School of Medicine at Loyola University, Chicago disagreeing with this view, clarified that those who believe ANH for PVS patients is a medical treatment and offers no hope of benefit or that it imposes an excessive burden still view the PVS patient as a person, but one for whom there is no moral mandate to prolong life.

Part of this debate centers on interpretation of Catholic moral tradition determining whether an intervention is ordinary or extraordinary. Shannon and Walter<sup>4</sup> refer to the “proportionate-disproportionate means test,” described in the 1980 Congregation for the Doctrine of the Faith’s “Declaration on Euthanasia,” stating, “In any case, it will be possible to make a correct judgment as to the means by studying the type of treatment to be used, its degree of complexity or risk, its cost and the possibilities of using it, and comparing these elements with the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources” (paragraph 4). Examples are given, including “when

*Cont. on page 8*



## The Pope and Artificial Nutrition cont. from p. 7

inevitable death is imminent in spite of the means used, it is permitted in conscience to make the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted.” Shannon and Walter point out that ordinary and extraordinary forms of treatment are determined by their effects on the patient or on those who have the responsibility to care for the patient, which requires knowledge of a specific patient and his or her own wishes. Furthermore, they counter the charge that surrogates acting according to a family member’s wish to forego ANH (e.g., communicated through an advance directive) are not attempting to end the patient’s life because the patient is a burden to them. Shannon and Walter express concern that the Pope’s recent statements represent “an elevation of biological or physical life to an almost absolute value,” which is counter to other declarations, such as in the encyclical *Evangelium Vitae*, in which the Pope states, “Certainly the life of the body in its earthly state is not an absolute good for the believer, especially as he may be asked to give up his life for a greater good.”

Shannon and Walter ask several questions: What is the level of magisterial authority with which the Pope’s statement about ANH is made? Does it apply only to patients in a PVS, or does it also extend to other categories of patients who need permanent feeding tubes inserted but are not in a PVS? If not the latter, then on what grounds do we argue that it is always required of patients in a PVS?

It has yet to be seen how this issue will unfold within the Catholic church, and how Catholic health care facilities, providers, patients, and families will respond to these recent Vatican statements. There have been ample statements from U.S. bishops countering the Vatican’s views.

Brian Yanofchick, a local senior vice president of Bon Secours Health System’s three Virginia hospitals, says the Pope’s statements (which did not

mention living wills but have implications for honoring living wills) have prompted questions, but no immediate changes at Bon Secours hospitals.<sup>5</sup> For now, Yanofchick says they will continue to honor living wills as written by patients. But he expects much more discussion before resolving the debate stirred by John Paul II, explaining, “In the Catholic world, when the Pope says something, that’s the beginning, not the end.”

### NOTES

1. Yet later, the Pope stated that use of ANH must be considered “ordinary and proportionate,” which made some wonder whether he considered ANH a type of treatment (though an “ordinary and morally required one”).
2. “Extraordinary” refers to interventions that do not offer hope of benefit or that impose an excessive burden, while “ordinary” refers to interventions that offer some hope of benefit and no excessive burden (i.e., ‘care’).
3. U.S. ethicists counter Vatican view; artificial hydration, feeding: normal or extraordinary care? Arthur Jones, *National Catholic Reporter*, March 26, 2004. <http://ncronline.org/mainpage/healthbeatarchives.htm>.
4. Artificial nutrition, hydration: Assessing papal statement. Thomas A. Shannon, James J. Walter, *National Catholic Reporter*, April 16, 2004. <http://ncronline.org/mainpage/healthbeatarchives.htm>.
5. Three local hospitals weigh Pope’s words on feeding tubes. Steven Vegh, *The Virginian-Pilot*, May 4, 2004. <http://home.hamptonroads.com/stories/story.cfm?story=69859&ran=193307>.

## CASE PRESENTATION

*One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee and an analysis of the ethical issues involved. Individuals are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information about patients and others in the case should only be provided with the permission of the individual. Unless otherwise indicated, our policy is not to identify the submitter or institution. Cases and comments should be sent to: Diane E. Hoffmann, Editor, Mid-Atlantic Ethics Committee Newsletter, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201, or [dhoffman@law.umaryland.edu](mailto:dhoffman@law.umaryland.edu).*

## CASE STUDY FROM A MARYLAND LONG-TERM CARE FACILITY

Mr. Silvers is a 66-year-old male with a diagnosis of a meningioma, which has required surgery and radiation to his brain. Although meningiomas are benign brain tumors, due to the location and size of Mr. Silvers’ tumor, it compresses on various parts of the brain adjacent to it. Mr. Silvers underwent surgery in 1989 and the meningioma was partially removed. More extensive removal could not be done due to its location. Radiation treatments to shrink the tumor caused ‘panhypopituitarism’ (lack of pituitary hormone production), and subsequently requires Mr. Silvers to take cortisone pills, without which he would die. He also began to

develop some cognitive deficits after these treatments. This slowly worsened, and in 1999 he developed normal pressure hydrocephalus, or excessive buildup of fluid in the brain. This required the placement of a shunt to alleviate the pressure and allow the fluid to drain. Since then his cognitive and physical abilities have continued to decline, due to a combination of the tumor pushing on the surrounding brain tissue, the post-radiation effects and the hydrocephalus. In March of 2003, he had deteriorated to the point that he required twenty-four hour care for all his needs, at which time he was admitted to a long-term care facility. A few months later he developed pneumonia and respiratory failure. He was hospitalized, and placed on a ventilator for a short period of time. After hospitalization he was discharged back to the nursing home and enrolled in hospice. He could no longer swallow well and his caretakers believed he would die from the respiratory infection. He survived this, however, and slowly began to recover and eat. His cognitive function deteriorated to the point that he had only brief periods of lucidity; his thoughts were generally scattered. He was no longer able to walk. He needed to be fed. He recognized his wife, but not his child.

His wife of over forty years had cared for him at home for as long as she could. Mr. Silvers had no living will or advance directive. Mrs. Silvers is her husband's agent (as designated in his power of attorney for financial matters) but not his appointed health care agent. Once Mr. Silvers was enrolled in hospice, Mrs. Silvers was comfortable with the decision to no longer treat his future infections, such as pneumonia, with antibiotics, or to hospitalize him if he had a major change in condition. She based her decisions on what she felt he would want. Since Mr. Silvers stabilized and no longer appeared to be actively dying, it became very hard for her to see him in this state of total dependency. He had traveled all over the world as a consultant, was highly educated, and his hobbies were all in the intellectual realm. It was disheartening for his wife to see her once articulate and passionate husband reduced to complete dependence for daily functions. He could no longer read or participate in discussions. Mrs. Silvers wanted to

explore the possibility of stopping all his current medications. What was the point of prolonging his life, she wondered, when it had none of the qualities her husband had cherished? She felt he had lost all his dignity. The issue of stopping his medication was discussed, specifically his hormone replacement.

Due to his adrenal insufficiency, he could not survive without the cortisone pills as replacement hormones. Mr. Silvers' physician, however, feared that stopping the cortisone would cause Mr. Silvers to experience pain or discomfort (for example, nausea, vomiting, abdominal cramps, or severe hypotension). If steroids were to be avoided, even for palliative reasons, his physician wondered if palliative sedation would be necessary to control Mr. Silvers' symptoms. The physician asks, is it ethical to choose a course of treatment that might *require* palliative sedation as an option? Does Mrs. Silvers have the right to decide that the cortisone be discontinued?

## COMMENTS FROM A PALLIATIVE CARE NURSE ETHICIST

The physician in this interesting case asks two questions. The first is whether it is ethically appropriate to choose a course of treatment that will probably cause such painful symptoms that palliative sedation will be required. The second is whether the wife of this decisionally incapacitated patient has the "right" to request that the cortisone pills, necessary for his survival, be stopped. Although it is not clear whether the physician is referring to a legal or a moral "right," the second question ought to be addressed first because, if Mrs. Silvers has no legal right to speak for her husband, it could be argued that the physician has no obligation to consider her request.

Despite the fact that Mr. Silvers did not complete an advance directive prior to losing decisional capacity, the Maryland Health Care Decisions Act (HCDA) recognizes the spouse as a legally appropriate surrogate decision-maker if the incapacitated patient meets one of

three qualifying conditions: is terminally ill, is in a persistent vegetative state, or has an end-stage condition. According to the HCDA, a patient is terminally ill if death is 'imminent' from an incurable condition. The fact that Mr. Silvers' brain tumor continues to grow, his condition is incurable, and he was deemed hospice-eligible, provides support for a prognosis consistent with being terminally ill, although his recent rally, stabilization, and improved ability to eat suggest a less predictable dying process (assuming he continued receiving the cortisone). Nevertheless, his condition meets the HCDA-definition of being 'end-stage' ("an advanced, progressive, irreversible condition caused by injury, disease, or illness: (1) that has caused severe and permanent deterioration indicated by incompetency and complete physical dependency; and (2) for which, to a reasonable degree of medical certainty, treatment of the irreversible condition would be medically ineffective"). Thus, Mr. Silvers' wife should be legally recognized as his surrogate for health care decision-making.

If we agree that Mrs. Silvers has the legal right to make treatment decisions for her husband, the next question to ask is whether she has the moral right to make this particular request - that the cortisone pills be discontinued. We might ask whether there are decision-making standards that would preclude or limit the kinds of decisions that surrogates can make. This might be what concerns the physician in the first question - should Mrs. Silvers be permitted to choose an action (e.g., request the withdrawal of the cortisone pills, a life-sustaining treatment) when as a consequence, Mr. Silvers might experience such distressing symptoms that palliative sedation would be necessary to control those symptoms.

There are two well-recognized standards for surrogate decision-making, "substituted judgment" and "best interests." Both standards focus on the patient. Respect for personal autonomy is the basis for the substituted judgment standard, which requires the surrogate to decide as the patient would if he or she were capable. When the patient's treatment wishes are unknown, the surrogate is expected to make treatment

*Cont. on page 10*

## Case Study

Cont. from p. 9

choices that promote the patient's overall well being, and choose the treatment that furthers his or her best interests. In this case, Mr. Silvers' wife of over 40 years is well placed to answer the question, "What would Mr. Silvers choose if he could speak to us now?" She asks, what is the point of prolonging her husband's life when it has none of the qualities he has cherished? One could also ask, what is the point of providing interventions that serve only to prolong his dying?

Surrogate decision makers have a well recognized legal and ethical right to decide to withhold or withdraw medical treatment, whether or not it is life-sustaining, as long as the decision is consistent with the patient's personal wishes, life values, or beliefs. Similarly, hospice and palliative care clinicians have an obligation to effectively manage the symptoms experienced by their dying patients, whatever the cause of those symptoms. Just as palliative care clinicians would manage any distressing symptoms caused by the forgoing of other life-sustaining treatments like nutrition and hydration when such decisions are made by competent patients, so should the physician in this case be prepared to use palliative sedation in the event that Mr. Silvers experiences intractable symptoms caused by stopping the cortisone pills. Doing so demonstrates respect for Mr. Silvers and his previously held values and beliefs, as articulated by his surrogate – who knows well that he would not want to continue living in his current state. If Mrs. Silvers requested withdrawing the cortisone pills but refused interventions to palliate any subsequent pain or discomfort her husband might experience, this case would take a different turn. But with the facts presented here, there is no reason to question Mrs. Silvers' stewardship as surrogate decision-maker for her husband.

Judith Kennedy Schwarz, RN, PhD  
Consultant, Ethics and End of Life Care  
New York, NY

## COMMENTS FROM A PALLIATIVE CARE PHYSICIAN

The case of Mr. Silvers reminds us that "benign" is a treacherous term indeed. Although Mr. Silvers' brain tumor (a clivus meningioma?) may be benign by histology, his clinical course is anything but. Treatment of Mr. Silvers' brain tumor has extended his life but at an ironic cost: progressive neurological deterioration and ever diminishing capacity. In this way, his condition is analogous to that caused by other progressive neurological diseases like Alzheimer's Dementia, Parkinson's Disease, and Huntington's Chorea. The common thread to all of these diseases is the gradual, continual loss of neurological function that leads to a decreased ability to coordinate one's movements, to respond meaningfully to others and the environment, and to make one's wishes known. Death results from complications of the patient's diminished mental and physical capacity. Unable to effectively fight infection or to swallow properly to avoid aspiration, the patient may die from subsequent pneumonia or other infections to which the neurologically impaired are susceptible. If we recall the mortality of end-stage neurological degeneration, i.e., that of the bedfast, immobile, nearly non-verbal, totally dependent patient, Mr. Silvers is likely to die within six months, irrespective of corticosteroid replacement therapy. Indeed, he meets the Medicare Hospice Benefit eligibility criteria.

At issue is Mrs. Silvers' right to stop all life-prolonging measures, including Mr. Silvers' cortisone medication. Although not her husband's legally appointed health-care agent, she is recognized in law by the Maryland Health Care Decisions Act as a surrogate decision-maker and is presumed, by ethical tradition, to be the person who best knows his wishes. Mrs. Silvers essentially believes that her husband would prefer to die rather than continue his present diminished existence. While physicians are barred from actively and intentionally causing a patient's death, discontinuing unwanted medical

treatment has a solid legal and ethical foundation. Viewed in this way, Mr. Silvers' case is little different from withdrawing unwanted dialysis in a patient with end-stage renal disease, or withdrawing unwanted mechanical ventilation from those irretrievably ventilator dependent.

Such actions are sometimes justified using the "doctrine of double effect" (DDE), in which a negative effect (death) is ethically allowed as long as it is unintended and unavoidable in achieving the good effect (relieving pain or suffering). In this case, however, the DDE is of limited value: death for Mr. Silvers is, if not a *prima facie* good, then the lesser evil when compared to the alternative: continuing a slow decline from his present diminished state. The fact that stopping it may actually *cause* pain or discomfort does not categorically bar the action nor does potential for discomfort make the action clinically unique—many medical interventions cause discomfort. Side effects of medical therapies or their withdrawal can, and should, be managed. Mr. Silvers' physician is obligated to palliate any symptoms that may develop after stopping the cortisone. Sedation is not an uncommon side effect of palliative medications. Sometimes pain and symptom management can be achieved while minimizing sedative effects. Other times sedation is unavoidable but acceptable to the patient and/or family members as a "least bad" alternative to conscious suffering. Mr. Silvers' physician should do what is necessary to make Mr. Silvers comfortable through his dying process, including allowing sedation—whether as an unintended side effect or as a tool for palliation.

Charles M. Harrison, MD  
Vice President for Medical Services  
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Rockville, MD

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*We welcome comments to this case study, including how cases such as this are handled at your institution. Please e-mail your comments to [MHECN@law.umaryland.edu](mailto:MHECN@law.umaryland.edu).*

# CALENDAR OF EVENTS

## SEPTEMBER\*

- 9-10 The President's Council on Bioethics Meeting, Washington, D.C. Contact: <http://www.bioethics.gov/meetings/>.
- 23 Portrayals of Physicians in Art and Literature: From Hippocrates to the House of God, Rhonda L. Soricelli, MD, The University of Maryland Medical Systems' Medical Humanities Hour, UMMC Shock Trauma Auditorium, 4PM. Contact: [hsilverm@medicine.umaryland.edu](mailto:hsilverm@medicine.umaryland.edu).
- 23-24 African American Perspectives in Bioethics, Georgetown University Medical Center, Research Building Auditorium. Contact: <http://clinicalbioethics.georgetown.edu/calendar/index.html>.
- 30 – Creating Pathways For Care at the End of Life, 19th Management and Leadership Conference, Washington, DC, USA.  
Oct. 2 Sponsored by the National Hospice & Palliative Care Organization. Contact: <http://www.nhpc.org/MLC2004>.

## OCTOBER\*

- 1 Futile Care: When & How Can Healthcare Providers Say 'No,' sponsored by Sentara Center for Healthcare Ethics, Norfolk, VA. Contact: [jmwest@sentara.com](mailto:jmwest@sentara.com) or (757) 668-4263.
- 5 "I'm demented and I want to vote," addressing the ethical, legal and social issues raised by voting by persons with dementia. Speaker Jason Karlawish, MD. The Emanuel & Robert Hart Lecture Series, sponsored by the University of Pennsylvania Center for Bioethics, 3401 Market St., Ste. 320, Philadelphia, PA. (12N-1PM). Contact: 215-898-7136 or visit: <http://www.bioethics.upenn.edu>.
- 14 Talking to Patients/Surrogates about Dying: Clinical Approaches, Ethical Obligations, and Maryland State Law. Evan DeRenzo, PhD, Steve Selinger, MD, and Jack Schwartz, JD. The University of Maryland Medical Systems' Medical Humanities Hour, UMMC Shock Trauma Auditorium, 4PM. Contact: [hsilverm@medicine.umaryland.edu](mailto:hsilverm@medicine.umaryland.edu).
- 14-16 Humanity, Technology, and Perinatology: Good Ethics Based on Good Information. A conference on perinatal ethics, including palliative care, pain and symptom management. Sponsored by the National Perinatal Association. La Jolla Marriott Hotel, San Diego, CA. Contact: Anita Catlin, [catlin@sonoma.edu](mailto:catlin@sonoma.edu), or visit <http://www.nationalperinatal.org>.
- 17-20 Spotlight on Quality, Focus on Residents, sponsored by Last Acts and the National Citizens' Coalition for Nursing Home Reform (NCCNHR), Hilton, Crystal City, Arlington, VA. Contact: Jennifer Hirsch, 202-332-2275, [jhirsch@nccnhr.org](mailto:jhirsch@nccnhr.org), or visit <http://www.lastacts.org>.
- 22 WV Center for End-of-Life Care Bi-Annual Summit - Ethical and Legal Issues in Respecting Patients' Choices at the End of Life. Speakers include Jack Schwartz, JD, Maryland Attorney General's Office, and Bud Hammes, PhD, Gundersen Lutheran Medical Center. Marriott Charleston Town Center, Charleston, West Virginia. Contact: Cindy at 877-209-8086.
- 28-31 6th Annual Meeting of the American Society for Bioethics and Humanities, Marriott Philadelphia, Philadelphia, PA. Contact: <http://asbh.confex.com/asbh/2004/>.

## NOVEMBER\*

- 10 Georgetown Fall Bioethics Colloquium, Sponsored by the Center for Clinical Bioethics, Warwick Evans Conference Room, Building D at Georgetown University. (4:30PM). Contact: Marti Patchell, 202-687-1671.
- 17 Speaker Dominick L. Frosch, PhD, Robert Wood Johnson Health and Society Scholar, University of Pennsylvania (topic TBA), The Emanuel & Robert Hart Lecture Series, sponsored by the University of Pennsylvania Center for Bioethics, 3401 Market St., Ste. 320, Philadelphia, PA. (12N-1PM). Contact: 215-898-7136 or visit: <http://www.bioethics.upenn.edu>
- 18 Medicine in an Unjust World: Neglect of Easily Preventable Diseases as an Abuse of Human Rights. David Hilfiker, MD. The Dr. and Mrs. Howard B. Mays Lectureship in the History of Medicine and Ethics. University of Maryland Medical Center, Shock Trauma Auditorium, 4PM. Contact: [hsilverm@medicine.umaryland.edu](mailto:hsilverm@medicine.umaryland.edu).

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\* The 7th Annual Lecture Series in Palliative Care begins September 27th, and is held every Monday and Thursday until November 4 at Johns Hopkins Hospital, Hurd Hall, 5-6PM. Visit [www.hopkinscme.net](http://www.hopkinscme.net) for a list of topics and CME registration information.



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