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# HOSPICE NEWS NETWORK

*What the Media Said about End-of-Life Care This Week*

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## PHYSICIANS LEARN TO DEAL WITH PEDIATRIC DEATH AND DYING

As part of an increasingly widespread initiative to better the care that children with serious medical conditions are receiving throughout the nation, many hospitals and educational programs for physicians are implementing programs to promote “relational care” capacity of those in the medical field. An article in the *Wall Street Journal* details the use of tutorials specializing in the personalized care of families dealing with the loss or potential loss of a child. Such programs are becoming more and more prevalent throughout the country. The primary goal of these programs is to help physicians and other healthcare professionals feel more comfortable with dealing with families suffering an enormous loss.

**There are few situations as devastating to a family as the loss or potential loss of a child, but, the article reports, the latest investigations indicate that the experience and preparedness of many of those in the healthcare profession are significantly lacking.** Physicians desire to be sensitive to the needs of those in their care but do not want the immense emotional strain of becoming deeply emotionally affected by each tragic event that they encounter in their work. Unfortunately, **this often leads to doctors not feeling able to undertake the most difficult conversations with their patients and, when they do so, carrying them out unsatisfactorily** – often contributing to long-term emotional damage for the families they serve.

To help healthcare professionals become more sensitive, many organizations are now beginning to provide their staff with specialized training. **These trainings include the use of actors playing the part of families and children who find themselves with bleak hopes for recovery.** This provides professionals the chance to practice delivering devastating news to the most vulnerable patients. One scenario, for example, involves a teenage girl who is informed that her leukemia has returned and that she does not have much time left. Another scenario involves a family that needs to be informed that their five year old son has been left brain-dead in a drowning accident. The goal in all of this is to prepare physicians to provide sensitive care in the worst of circumstances.

One organization, the Education Development Center, Inc., a nonprofit based in Massachusetts, is using this program in its nationwide **Initiative for Pediatric Palliative Care (IPPC)**. **IPPC works with children’s hospitals and pediatric professional associations to facilitate better treatment and interactions with the families of the tens of thousands of children who die in hospitals in the United States every year**, as well as the thousands of others who live with conditions that threaten to kill them. IPPC director David Browning says, “While tutorials offer no single ‘right’ way to deal with families, there are specific guidelines, such as asking what the family knows and understands, speaking slowly and without using

medical jargon, turning off beepers...” In the past year, around 100 hospitals, pediatric hospices and other organizations have taken part in trainings.

**Researchers at New York Presbyterian Hospital recently found that pediatric residents of all levels of experience and training are often left feeling unprepared when confronted with the terminally ill patients in their care and informing children and their families of the severity of the child’s condition.** Indeed, studies have shown doctors to be generally reticent about using the words “dying” or “dead” and this is especially true in the case of children and adolescents. Jargonized terms, such as “terminal” or “critical,” can often yield negative reactions on the part of families. (*The Wall Street Journal*, 5/3)

## POLICY NOTES

\* **NHPCO is currently monitoring S. 1955, “The Health Insurance Marketplace Modernization and Affordability Act,” sponsored by Senator Mike Enzi (R-Wyoming).** This bill is an effort to make health insurance benefits more affordable to small businesses. One of the effects of this bill, however, would be to eliminate state insurance mandate for chiropractic services, mental health services, diabetes and hospice coverage. NHPCO notes that the bill does not impact Medicare Hospice Benefits. States that currently have mandated hospice coverage include Arizona, California, Colorado, Kentucky, Massachusetts, Maryland, Michigan, Nevada, New York, Virginia, and Washington. To view the text of the bill online, visit [thomas.loc.gov](http://thomas.loc.gov), enter “S. 1955” (without the quotes) in the Search box, and click the Search button. (*NHPCO Public Policy Alert*, 5/3)

\* **The Florida Senate passed a bill which, if signed by Gov. Jeb Bush, will allow for-profit hospice organizations to compete with non-profits for Florida’s Medicare and Medicaid funds.** The bill, HB 1417, sailed through the Florida Senate, opposed by only 28 of the body’s 160 members. State Senator Nancy Argenziano criticized her colleagues and says that the bill will allow for-profit corporations to exploit the dying and put in danger the long-term viability of non-profit organizations. Senate sponsor Jeff Atwater claimed that the bill would provide more options for families, open the door for competition and force non-profits to give the best care possible. Other speakers and committees had testified that the quality of care had not decreased when for-profits began operations in 49 other states. The bill, said Atwater, would put non-profits “on notice that the best in the business” are on their way to Florida. A similar bill did not get passed by legislators last year, following a campaign by the state’s non-profit hospices to prevent its passage. (*Citrus Times*, 4/29; *Palm Beach Post*, 4/28)

## BOOK NOTES

\* ***Why People Die by Suicide*, a recently released book by Thomas Joiner, explores the factors that increase facility of suicide.** Joiner, says a *JAMA* reviewer, draws on hundreds of academic sources, his clinical experience and his own father’s suicide. The book includes both a theory of suicidal genesis and clinical prevention strategies. Joiner notes that successive self-injury is a regular precursor among those who go on to fatal suicide, hypothesizing that such self-inflicted damage reduces the individual’s fear of bodily injury, thereby removing one of the key resistances to suicide. The lack of a sense of belonging and of connection to others, he

notes, is a primary motivator of suicide. Age is also a critical factor, he observes; and suicide incidence increases with age and becomes most common among those 65 or older. Joiner discusses prevention and intervention, detailing interpersonal psychotherapy, which aims to help the suicidal patient with one issue that causes him or her great distress. The goal is to help the patient find relief on this one issue in the hopes that this success could have positive resonance throughout the patient's life. Joiner also describes cognitive behavioral analysis, as well as his own therapeutic approach, which targets the patient's perceived burdensomeness and lack of belonging. (*JAMA*, 2006; 295:2082-2083)

**\* *In Patient Autonomy and the Ethics of Responsibility*, physician Alfred I. Tauber primarily blames physicians themselves for submitting to economic and organizational influences and allowing a culture that promotes a legal-contract model of the patient-physician relationship.** "Law appears when trust fails," he notes. Tauber seeks to correct the way law has come to overemphasize the right of the patient to determine the course of treatment, often at the expense of the patient's need for compassionate treatment from his or her physician. Tauber details a strategy, says a *NEJM* review, to include greater sensitivity to moral values, increased ethics education and the creation, by institutional providers, of an ethical component to be included in the personal record of every patient. (*NEJM*, 2006;354:1966-1967)

**\* *Death's Door – Modern Dying and the Ways We Grieve: A Cultural Study* is written by Sandra Gilbert, a professor of English at the University of California, Davis.** Inspired in large part by the death of her husband, says a *JAMA* reviewer, Gilbert relives her own experience of loss and American society's meticulous evasion of an acknowledgement of death. Gilbert recalls the words of a surgeon who attended her dying husband. "I arrived when he was just terminating," said the surgeon. "I arrived before he terminated, but he had not responded at that time." Gilbert remarks upon our society as one that, having witnessed the massive scenes of death of the 20<sup>th</sup> century, has become a culture in which death is administered, timed and orchestrated. She cautions against the effect of medical technology as a distancing agent between doctor and patient. Gilbert's book, says the *JAMA* reviewer, invites the reader to confront the reality of death and to deal with it honestly and humanly. (*JAMA*, 2006;295:2079-2080)

## RESEARCH NOTES

**\* *Chronic pain is a problem for both workers and their employers*, says Florida State University associate professor Wayne Hochwarter.** Hochwarter says that research shows that chronic pain – lasting for at least six months – affects as many as 50 million Americans and most of them are full-time workers. Apart from the effect upon the individuals themselves, there is an enormous economic impact upon their employers, who lose thousands of dollars in productivity each year as a result. Social stigmas and fears of losing employment may hide the true extent of the problem. One study found that chronic pain cost employers more than \$5,000 per employee per year. Adding indirect costs could triple that amount. (*Law and Health Weekly*, 5/6)

**\* *A study of healthcare preferences and changes in preferences in older adults* reveals that "the acceptability of treatment resulting in certain diminished states of health increases with time." As health declines, persons may become more willing to accept what**

**others see as a poor quality of life, because they do not perceive it as such.** The study was conducted via in-home interviews with 226 elderly, community-dwelling persons with advanced cancer, congestive heart failure or chronic obstructive pulmonary disease. The interviews were conducted at least every four months for up to two years. Patients rated whether treatment for their illness would be acceptable if it resulted in 1 of 4 health states. These changes in health care preferences, say the study's authors, pose a challenge to advance care planning. (*Archives of Internal Medicine*, 2006;166(8):890-895)

**\* A new study indicates that most physicians are willing to discuss religion with patients, but only half actually initiate such conversations.** The survey, which was carried out by researchers at the University of Chicago, suggests that it is unlikely that a doctor will recommend prayer and highly unlikely that he or she will pray with the patient. Farr Curlin, the author of the study, found that there was "no consensus among physicians about what is customary or appropriate" and that the approach of each individual doctor is likely to vary greatly. More than 90% of those who responded to the study (1,140 of the 2,000 contacted) said it was appropriate to discuss religious or spiritual issues when a patient brings them up. Only half said that they inquire, occasionally or more often, about a patient's faith. Only 10% said that they routinely mentioned their own faith, and fewer than one in three endorsed praying with patients. The study found that physicians' personal religious convictions tend to guide their responses. While 76% of religious doctors inquire as to their patients' beliefs, only 23% of minimally religious physicians do. Protestant doctors were the most likely to discuss such matters and to pray with patients. (*Livescience Website*, 5/1)

## OTHER NOTES

**\* MayoClinic.com provides public education that stresses the importance of preparing for emergencies by gathering important medical information about loved ones.** There are a number of things that one should know about the health of one's aged parents or others who are at risk for medical emergencies, says the site. In order to help doctors in providing care, the site suggests that information be readily available, including the names of the person's doctors, the person's birth date, a list of allergies, major medical problems, a list of medications, religious beliefs (for example, in the case of blood transfusions), insurance information, prior surgery and lifestyle information – such as whether the person smokes or uses alcohol. The site also suggests that patients and families complete advance directives. (*MayoClinic Website*, 5/5)

**\* The Broadway production, "Night Mother," portrays a family dealing with the impending loss of one of its members and their interaction with hospice.** The production, with Mia Farrow playing the lead, is interspersed with dark humor and addresses how children react to their parents' end-of-life concerns. (*New York Magazine*, 5/2)

**\* Dr. Joseph Civetta, in the inaugural lecture of the Rowe Lecture Series at the University of Connecticut, highlighted issues in end-of-life care.** Civetta, a surgeon who has written extensively and taught at Harvard Medical School and the University of Miami School of Medicine, told participants that we live in a society that has a "problem facing both life and death." **Civetta criticized a pervading culture that views death as "unnatural" and "a failure," and argued that, "We should not be preventing death, but we should be**

**preventing bad dying.” Civetta focused on the meaning of a “good death,” suggesting that it is one that is focused above all upon the needs of the patient, not upon those of the family or health insurance companies.** He called on his audience to become familiar with right-to-die cases and to consider futile vs. worthwhile care, as well as what constitutes “quality of life.” Civetta encouraged caregivers to spend as much time developing good relationships with their patients as they do mastering new technology. Despite all recent medical advances, Civetta noted, “The death rate remains the same: one per person.” (*Advance*, 4/17)

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