FLORIDA HOSPICES AND PALLIATIVE CARE

THE HOSPICE E-NEWS

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DOCTORS SHOULD COMMUNICATE PROGNOSES

Dr. Nicholas A. Christakis, author of *Death Foretold: Prophecy and Prognosis in Medical Care*, is a physician and a sociology professor at Harvard. In an op-ed column in *The New York Times*, Christakis says that the well-ingrained "no surprises" rule in hospitals, which reports changes in patient status up the medical ladder, unfortunately "does not extend to seriously ill patients themselves. They and their families are frequently surprised by the sudden imminence -- and the raging authority -- of death."

Christakis says that doctors "contribute to the problem by avoiding making prognoses." When they do make a prognosis, says Christakis, "They typically overestimate the time a patient has left to live, often at least tripling it, perhaps because they feel overconfident." The combative attitude of physicians toward disease can cause problems for patients. "Doctors who wrongly think that patients are going to live much longer wind up recommending needlessly painful and expensive treatments." Christakis cites a "gallows humor" joke: "Why are coffins nailed shut? To keep doctors from administering more chemotherapy."

Christakis asserts that reliable prognoses will have to become a priority of medical research and education before they will become a routine part of medical care. Statistical tools and databases that assist physicians in outcomes prediction are also needed to supplement the physician's clinical judgment.

Christakis concludes by saying, "Doctors often say they worry that predictions about survival may become self-fulfilling prophecies or cause patients to lose hope. But a realistic assessment of how long a patient has to live need not cause either the patient or doctor to become pessimistic. It should only refocus attention on the quality of the patient's life. Sometimes living life to its fullest requires knowledge of its finitude."

In a subsequent issue, *The New York Times* printed several letters in response to Christakis' column. Dr. Michael Katz, of White Plains, wrote, "There is a difference between fanaticism of pre-terminal efforts to save a patient's life … and an optimistic approach to therapy, even when facing decreasing odds of success." Dr. Jeffrey B. Freedman, of New York City, says, "A little denial is healthy. … Hope can keep one's spirits up and lead to acceptance of appropriate treatment for the illness." And one woman, whose mother survived six years after a few months prognosis, says, "Human beings don't come with expiration dates." (*The New York Times*, 8/24, 28)

ALZHEIMER'S ASSOCIATION RELEASES EOL PRACTICES

The Alzheimer's Association recently released its third iteration of *Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes*. The recommendations, which were released in conjunction with the Association's 15th annual Dementia Care Conference, "focus on improving the end of life experience for people with Alzheimer's and other dementias by offering concrete suggestions for addressing issues unique to people with dementia at the end of life."

Topics covered in the practice recommendations include communication, decision-making strategies, psychosocial and spiritual support, coordination and provision of care when the family elects hospice, acknowledgment of the patient's death, bereavement services and staff training.

Other key issues covered by the report include the need for end-of-life planning as soon as a diagnosis is made, the provision of palliative care, the importance of training residential care workers on end-of-life issues as they pertain to dementia patients and staff/patient/family communication. The recommendations also "emphasize the importance of consistency in individualized and person-centered care approaches; development of relationships between staff and residents; and increasing staff knowledge of individual resident needs, abilities and preferences."

The press release and a PDF of the recommendations are online at www.alz.org/media_11127.asp. (*Alzheimer's Association Press Release*, 8/28)

RESEARCH & RESOURCE NOTES

* Two professors from the University of Nevada, Las Vegas School of Nursing have written about the importance of understanding cultural diversity for giving good end-of-life care in critical care units. The article appears in *Dimensions of Critical Care Nursing* and says, "It is common for patients and families to face difficult decisions about end-of-life care in critical care units, and minority cultures do not always believe in the Westerner's core values of patient autonomy and self-determination. Knowledge of these cultural differences is fundamental if critical care nurses wish to provide appropriate and culturally competent information regarding end-of-life decisions." (*Dimensions of Critical Care Nursing*, 2007;26(5):194-198)

* The *Hospice Wage Index for Fiscal Year 2008* has been posted on the CMS website at www.cms.hhs.gov/center/hospice.asp. It can be downloaded as a PDF. (*CMS Website*)

* NCcareLINK, North Carolina's online computerized information system for state services, debuted last week but "appeared to contain errors and inadequate information." The system, designed for both emergency and day-to-day needs, will "guide state residents through the maze of agencies and companies that provides services for families, children, older people and those with disabilities." The website is www.nccarelink.gov. (*The News & Observer*, 8/29)

* The Rhode Island Health Literacy Project is offering a website to help people keep track of medical needs and information. The site, at www.rihlp.org, lets visitors "download a card to help you keep track of your medications, learn about how to prepare for end-of-life decisions, and review a checklist that will make sure you get the most out of each visit to the doctor. For agencies and providers, the Web site also provides advice on cultural competency, tips for communicating with patients, guidelines for written materials and links to other resources." (*The Providence Journal*, 9/3)

* Cahaba GBA is presenting two Webinars (Web seminars) relating to the hospice billing changes detailed in CR 5567. The October 23 seminar is currently full, but the November 14 presentation, which is a repeat of the earlier one, still has slots available. See www.cahabagba.com/apps/course_registration/ia/calendar.jsp for more information. (*Cahaba GBA Website*)

* A study of proactive palliative care consultations on the length of stay of medical ICUs found that those in the proactive group had an average length of stay of 8.96 days, while those in the control group stayed an average of 16.28 days. An article in *Critical Care Medicine* says, "There were no differences between the two groups on total length of stay in the hospital or length of stay from MICU admission to hospital discharge" and no significant differences in discharge disposition or mortality rates. (*Critical Care Medicine*, 2007;35(6):1530-1535)

* The *Journal of the American Osteopathic Association* is offering a "refreshed series of four supplements" on pain management, the first of which focuses on the elderly and end-of-life care. The five articles in the issue cover pain management in older adults, the use of methadone in pain management, patient education and the use of opiates at the end of life, and an article on the perspective of an osteopathic physician working in hospice. Also included are reprints of two policy statements on end-of-life care. The issue is online at www.jaoa.org/cgi/content/full/107/suppl_4/ES1. (*Journal of the American Osteopathic Association*, 2007;107(Suppl 4):1-2)

PAIN NOTES

* South Carolina primary care doctors are often not prescribing any Schedule II drugs, says an article in *The Post and Courier,* leaving pain management specialists to deal with additional patients who have chronic pain. Most are afraid of DEA charges, and those who do prescribe narcotics are careful to protect themselves by making "stringent agreements" between themselves and their patients about the use of the drugs. Others refuse to rewrite prescriptions for lost medication, such as Dr. Marc Dubick of Roper St. Francis' Pain Management Center. "People who really need it to function don't lose it," he said. (*The Post and Courier*, 8/27)

* Fentanyl patches have been "implicated in scores of deaths," as people are being killed by accidental overdoses. Other drugs are being marketed in patch form, "including other painkillers, contraceptives and medications for children with attention deficit disorder."

Newer, high-tech patches will soon enable even more drugs to be administered that way. The patches have many advantages, as well as disadvantages. No one knows what dose of a drug administered through the skin corresponds to an oral dose, different thicknesses of skin absorb the drugs at different rates and heat affects the absorption rate. The FDA has recommended that fentanyl patches "should be prescribed at the lowest practicable dose, should not be used to treat short-term pain or pain after an operation, and should only be used by patients already established on opioid drugs." (*Los Angeles Times*, 8/27; *Inside Bay Area*, 8/27)

* Growthhouse, a website dedicated to improving care for the dying, has made available full-text extracts in their online edition of Dr. Joanne Lynn's new book, *The Common Sense Guide to Palliative Care*. See www.growthhouse.org. (*Growthhouse Website*)

OTHER NOTES

* An article addressed to emergency medical service personnel on ethical issues involved in treating terminally ill patients lists several reasons why EMS responders often have difficulty in deciding what to do: 1) Medical associations have "made limited attempts" to address palliative care outside the hospital; 2) Very few EMT and paramedic training programs include enough discussion of hospice and treatment of the terminally ill for responders to "become knowledgeable and act appropriately; 3) Only 6% of the 200 largest cities in the US have "a clear, definitive palliative care protocol," and in those that did, "there was much confusion about their implementation among field staff." The article discusses when to initiate care, and clinical considerations of medications and transport. The authors suggest that terminally ill patients may need a "treat and release" protocol instead of a "treat and transport" one. (*Emergency Medical Services*, 9/2007)

* The *Tucson Citizen* warns of solicitations by the U. S. Veterans Hospice Foundation, an organization that purports to create hospices for homeless veterans with chronic illnesses. The paper's opinion editor says that the organization is not listed as an IRS 501(c)3 organization, nor with the Arizona state departments that regulate solicitations. According to the article, the Foundation "claims to be part of The Ark Foundation Inc., formerly the At-Risk Kids Foundation, and, earlier still, the Bob Wiggins Evangelistic Association Inc." The editor says that The Ark Foundation is not listed as a charitable organization by the IRS or several websites that list charities and that the tax-exempt status of the Bob Wiggins Evangelistic Association was suspended in 1982. (*Tucson Citizen*, 8/28)

* Senator Max Baucus (D-Montana), chairman of the Senate Finance Committee, says, "Cracking down on charitable abuses or imposing new regulations on nonprofit groups" isn't at the top of his list of things to do. Baucus succeeded Charles E. Grassley (R-Iowa) as chairman of the committee and says that he and Grassley have different priorities. (*The Chronicle of Philanthropy*, 8/23)

* Two hundred Alzheimer's patients in Palm Beach County will receive a free identification microchip implanted in their arms. The chips, which were approved as a medical device in

2004, are provided by VeriChip Corp., and the arrangement was made through West Palm Beach's Alzheimer's Community Care. The chips contain a 16 digit number that can be read by a small handheld device, and enables a lookup on a secure online database that contains the patient's identifying information. (*Palm Beach Post*, 8/30)

* Guest essayist Mary Jane Milano, formerly co-director of the Rochester Community-Wide End of Life/Palliative Care Initiative, wrote of the "deplorable" behavior of several members of the media after her son Jeff collapsed and died at a lacrosse practice. One reporter tried to sneak into the pediatric ICU as the Milano family waiting for Jeff's organs to be harvested. A TV reporter called the hospital room and other members of the media contacted Jeff's 14-year-old teammates within an hour or so after Jeff's death. Milano wrote, "We, as human beings, have a right be left alone. Intrusive invasion of privacy is defined as intrusion upon solitude and seclusion of someone or into his or her private affairs. Our rights in this situation were completely ignored." (*The Democrat and Chronicle*, 8/29)