



IHO Update

Bi-weekly News for Hospice Professionals in Iowa

April 8, 2005

Register today for the IHO Annual Meeting

There is still time to register for the Iowa Hospice Organization Annual Meeting set for Wednesday, April 13, 2005 at the Hotel Fort Des Moines in Des Moines.

Judi Lund Person, Vice President, Division of Quality End-of-Life Care with NHPCO, will keynote. Bruce Anderson, Geriatric Nurse Practitioner with Mercy in Iowa City will discuss fall preventions and Debbie Fisher, President of the Iowa Assisted Living Association and colleague Sandy Wilson will talk about assisted living and hospice care.

You don't want to miss this informative day. To register and for more detailed information, see the attached program brochure or download it from the IHO Website at www.iowahospice.org. Registration questions should be directed to Noel Beemer at 515.243.1056.

District 4 Meeting Set for April 13

The District 4 Quarterly Meeting will be held immediately following the IHO Annual Meeting on April 13 in the room designated for the Annual Meeting. Questions about the District 4 meeting can be e-mailed to Marcia Gowdy at mgowdy@mcmh.org.

CMS Solicits Rural Hospices for Demonstration Project

A five year demonstration project for rural hospices with a 20-bed or less facility is being offered by the Centers for Medicare & Medicaid Services (CMS). The demonstration is designed to test if hospice services provided to Medicare beneficiaries who lack an appropriate caregiver and who reside in rural areas result in wider access, improved hospice services, benefits to the rural community, and a sustainable pattern of care.

The demonstration project was authorized with the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (MMA). The project focuses on Medicare beneficiaries who are unable to receive hospice care at home for lack of an appropriate caregiver. The project will allow demonstration hospices with a facility of 20 or fewer beds to offer, within its walls, the full range of services provided by hospice programs yet will not require the agency to offer services outside of the hospice facility or to meet the 20-percent cap on inpatient care days.

CMS plans to make up to three awards; applications are due on or before June 6, 2005.

Further details and complete solicitation and supporting information are available on the CMS Web site at: <http://www.cms.hhs.gov/researchers/demos/rmbh/default.asp>. A FAQ and general questions will also be posted on this Web page. Interested hospices can also contact: Cindy Massuda at (410) 786-0652 or RURALHOSPICEDEMO@cms.hhs.gov for more details.

Advocates Training Medicare Prescription Drug Coverage

The 2005 Medicare Modernization Act introduced prescription drug coverage for people on Medicare, a coverage that begins January 1, 2006. Everyone on Medicare must make a decision about enrolling in Medicare drug coverage. In addition, people with limited income and resources can get help paying for some of the costs of this program. Those wanting help with their costs can start applying July 1, 2005.

Training will be available through 19 ICN network sites on Tuesday, May 10, and repeated Thursday, May 12, from 9 a.m. to noon. To register to attend the training, click onto: www.shiip.state.ia.us/dtraining.html. Select the site and date you wish to attend and complete the online enrollment. Space at each site is limited and registrations will be accepted on a first come, first serve basis. You will receive a confirmation notice when your registration is accepted. Materials for the training will be available on the following web site beginning May 4. Please print the materials and bring them to the training. Copies of the materials will not be available at the ICN site.

Questions about the training? Please e-mail the shiip.registration@iid.state.ia.us

The Social Security Administration (SSA) and Senior Health Insurance Information Program (SHIIP) are hosting a free training for professionals who work with people on Medicare. Come and learn about the Medicare Prescription Drug Coverage and the extra help available.

The seminar will take the combined efforts of professionals across the state to make people aware of this new Medicare coverage and the extra help available to them. Following this training you will be able to share information and assist your clients in completing the application for the extra assistance for low income individuals.

Second Meeting of EOL Stakeholder Group is Facilitated by IHO

Fifteen individuals representing a variety of organizations involved in end-of-life issues met for a second time on April 5 at the IHO office in Des Moines. The idea for organizing the meeting grew out of IHO's strategic planning session last summer and the ending of the Iowa Partnership, a three-year statewide initiative funded by the Robert Wood Johnson Foundation.

The group is in a formative stage and time was spent discussing and identifying the needs of each organization represented that would determine their ongoing participation. The group reviewed discussions and issues identified in the first meeting for further exploration and decided to distribute them to participants for ranking of the top 2-3 issues under each topic. The topics identified include;

- Support for family caregivers
- Advance care planning; out-of-hospital DNR
- Pain management
- Veterans

The next meeting of the group will be May 24 at the IHO office from 10-3:00 p.m.

Online Grief Assistance Course Available

Health care professionals who have an understanding of the basic concepts of grief and knowledge of different coping strategies are equipped with the tools necessary to guide and comfort those who need their care. The goal of the careLearning.com course, "Assisting Grieving Patients and Families", is to provide an overview of the grieving process. Topics to be discussed include:

- Leading theories on grief
- Role hospice plays in the life of the dying patient
- Holistic care and bereavement care
- Caring for patients with chronic illness
- Chronic sorrow and various coping strategies
- This course has been approved for 0.3 nursing CEUs under the self-study category. To register for this course, go to www.carelearning.com and click on “Courses” and “Nursing” then scroll down to this course. For more information on this series of courses or any careLearning.com offering, contact Kara Bylund (bylundk@ihaonline.org) at 515/288-1955, ext. 342.

careLearning.com is a non-profit organization owned by more than 40 hospital associations including the American Hospital Association. The sole purpose of this organization is offer quality online education programs for health care professionals.

NH *Union Leader*: ‘How Do Hospice People Stay So Cheerful?’

The Union Leader in Manchester N. H., ran a March 27 story, “In hospice, she’s prepared to go,” about cancer patient Madeline Urbach’s decision: “No chemotherapy, no radiation. And when the time comes, no respirator, no feeding tube. So there will be no artificial means to prolong her life. At 88, she is surrounded instead by the most natural of life supports: Her family’s love.”

Right after she received her diagnosis, Urbach decided that, when the time came, she would move out of her Manchester home into an area hospice house. She had cared for her husband at home with hospice during his last struggle, with lung cancer eight years ago. Her son Bill said hospice “was a very bright experience.” His father’s reaction to chemotherapy “was just awful. Really, really bad....He decided he wasn’t going to do any more” after the first.

The son marveled at hospice, “I think we were all stunned. How do you have people who do this, knowing what the end is, who are so cheerful?” (www.msnbc.msn.com/id/7306654)

NBC’s Today Show Features Five-Part Series on Pain

The NBC News “Today Show” is airing a five-part series this week on pain. Anchor Matt Lauer (who taped public service ads for NHPCO several years ago) interviewed two board members of the American Pain Foundation (APF): Dr. Russell Portnoy of New York City’s Beth Israel Medical Center and Dr. Scott Fishman of the American Academy of Pain Medicine.

Fishman noted that we have become “a victim of our own success” in that America’s unprecedented success in curative treatment has caused us not to do “as much on quality of life issues like pain.” Portnoy pointed out that “Pain itself is an illness” chronically suffered by 50 million Americans. Lauer asked Fishman the six questions about pain found at the APF website www.painfoundation.org.

NY Times: Federal Prosecution of Physicians Hurts Patients

The New York Times “Editorial Observer” for March 26 opined on “Weighing the Difference Between Treating Pain and Dealing Drugs.” Noting the federal government’s prosecution of Dr. William Hurwitz, convicted of 50 counts of distributing narcotics, “His behavior was in some cases inexcusable. Patients for whom he freely provided large prescriptions should...have been given more close supervision. But malpractice should be cause for loss of license. Instead, Dr. Hurwitz has been prosecuted as a drug kingpin because some patients sold their pills....That sends a chilling message to doctors who treat people with extreme pain.” Federal prosecutors are seeking a life sentence for

Hurwitz. “This might marginally reduce the amount of opioids on the street,” the Times story ended, “but in the process it will sentence hundreds of thousands of people to suffer needlessly.”

President’s Family Has Living Wills

President and Mrs. Bush have living wills, according to the March 30 New York Times. Speaking to reporters while en route to Afghanistan, Mrs. Bush said, “I hear the numbers of people inquiring about living wills or writing living wills increased dramatically,” with the Schiavo case, “and I think that is really good. The president and I have living wills, and of course our parents do, and they wanted us always to be aware of it. I think that is important – for families to have an opportunity to talk about these issues.”

New Consumer Engagement Campaign Debuts Soon

It’s About How You LIVE, the outreach campaign being developed by NHPCO’s Caring Connections team will be unveiled the beginning of May. There’s still time for your organization to join many of your colleagues in supporting this exciting free initiative. If you haven’t signed up, click onto http://www.nhpc.org/files/public/Caring_Connections_Partner_Signup.pdf download a Founding Partner registration form and return it by April 30!

New Consumer Internet Resource

A new consumer focused Web site was launched last week, www.caringinfo.org. This is part of NHPCO’s Caring Connections consumer outreach initiative that will be releasing a number of resources over the coming months. Funded by a grant from the Robert Wood Johnson Foundation, Caring Connections will be supporting the work of providers, professionals, coalitions, and individuals seeking information on end-of-life care. Visit www.caringinfo.org and explore the range of materials available.

Terri Schiavo Update

Due to this extensive media reporting on Terri Schiavo’s death and events leading up to the controversy, it is impossible for IHO to adequately summarize all the coverage. Instead, IHO has selected a few articles that did not receive wide distribution in the popular media. IHO focuses not on the family disagreements of the case, but rather on the favorable coverage hospice and end-of-life issues have received from news media nationwide in the past few weeks. Attached to this week’s IHO Update is the OP/ED piece that IHO distributed to media the week of March 21.

- Issues raised by dozens of publications include fears that hospices and their mission will be misunderstood. To address that concern, hundreds of local hospices and state hospice associations issued statements and invited reporters to write articles about the mission and purpose of hospice. NHPCO said, “As values-based organizations, honoring individual wishes, faith and cultural traditions and the natural cycle of life, hospices across the country help patients and families grapple with difficult decisions and situations every day. It has been said that hospices provide a caring sanctuary, nurturing the dying, supporting the living and caring for the community. We will continue to offer this special care with respect, dignity and compassion.”
- The National Hospice and Palliative Care Organization (NHPCO) noted in a March 25 member update on the Terri Schiavo case that “in a single day” during the heat of the Schiavo controversy, “the NHPCO’s Caring Connections HelpLine staff “fielded 673 calls and processed more than 2,000 e-mails from people requesting copies of state-specific advance directives. NHPCO President Don

Schumacher was taped March 29 at the D.C. studio of ABC News' "Good Morning America" about advance care planning. (E-mail from NHPCO)

- Many writers predict that state legislatures will more actively address end-of-life issues with pressure from an emerging group of conservatives and liberals siding with disability activists to enact more stringent laws governing removal of life support. On the day Schiavo died, the West Virginia House Judiciary Committee voted to kill a bill that would allow physicians to refuse to provide "medically ineffective" treatment. However, they reconsidered the next day and will debate it this week. A New Jersey proposal would encourage persons marrying or divorcing to complete advance directives as part of the process. The Kansas House voted last week to require legal guardians to go to court for approval of ending life-prolonging measures, but the Senate sent it to committee.
- *AP* writer Robert Tanner points out that there is "a slew of legislation around living wills and other end-of-life issues that wouldn't further the aims of this emerging group." But Tanner says chances for laws being enacted at the state level this year are slim—some legislatures have already adjourned and others are submerged in their agendas.
- Additionally, many editors and authors wrote, there will be a concerted effort by the Bush administration and congressional Republicans to place more conservative judges in courts, hoping to create a judiciary more sympathetic to their philosophy, even though a *Time* magazine poll, found that nearly 70% of Americans opposed the intervention of Congress into the Schiavo case.
- The *Philadelphia Inquirer* says the Schiavo case may be additional support for physician-assisted suicide. The theory is that if Americans feel they won't be able to refuse or remove feeding tubes, they will fight for the one option that gives them certain control of how they die.
- A *USA Today* editorial opines that one of the most prominent issues sure to be addressed is whether federal laws should set uniform standards and federal courts should review disputes about the wishes of an incapacitated person. The same editorial raises the question: "Who pays for expensive efforts to keep incapacitated persons alive?" Medicare doesn't cover long-term care and both Medicare and Medicaid have severe financial problems.

(*Akron Beacon Journal*, 4/1; *Herald-Dispatch*, 3/30, 4/2; *Yahoo! News*, 4/3; *USA Today*, 3/31, 4;1; *The Washington Post*, 4/1; *Chicago Tribune*, 4.1; *Philadelphia Inquirer*, 4/1)

How We Die: Choice and Chance

By Anne Applebaum

No matter how you ask the question, most people -- right-wing, left-wing, atheist, religious -- will tell you that they don't want to die like Terri Schiavo. That is, they don't want to spend their final days in a hospital, tied up to a machine, unable to feed themselves, unable to speak. Nine out of 10 Americans have told Gallup pollsters that they don't want to die in an institution. Another poll found that 82 percent of Americans would, upon being told they had very little time to live, prefer simply to go home: They want to die in their own beds, surrounded by family, in a setting that feels natural.

The vast majority, of course, will not die at home. Perhaps they won't be on a feeding tube, but they will almost certainly be in a hospital or a nursing home. Perhaps their relatives won't be battling one another in the national media, but they are statistically more likely to be at odds with one another, or with their doctors, than ever before. Many will be surrounded by strangers and hooked up to machines, even if they've written living wills that say they don't want to be. Many will die, in other words, in a setting that doesn't feel natural at all.

Along with all of its unexpected political implications, the Schiavo case has had the effect of exposing the enormous gap between what Americans imagine death should be like and what death actually is like for most people in the 21st century. A hundred years ago, when average life expectancy was 47, people who got sick either recovered or died quickly. Now that life expectancy is 75, most Americans will spend at least two years of their lives too disabled, one way or another, to care for themselves without help.

Yet, although we see video images of death all the time -- movie shootouts, scenes of faraway warfare -- we don't much like dwelling on the medicalized environments in which most people in our society actually pass away, and we don't like thinking about the murky ethical dilemmas that their deaths often present. In some sense the Schiavo case has attracted so much attention precisely because it brings, almost for the first time, a very common, very painful, but usually very private dilemma into the public sphere. This case is unusual only in that the family has such a relatively clear set of choices, or at least knows with some degree of certainty what will happen when the tube is removed. More often, the decisions are extraordinarily delicate medical and ethical judgment calls. When is someone's health so frail that the risks of an operation -- or the price of an operation -- become too great? Who decides when the pain that will result from a particular cancer treatment is going to outweigh the benefits?

But because we don't dwell on it, and because we haven't thought about it, the system that has sprung up to care for the elderly and the terminally ill is neither medically nor ethically consistent. In different regions of the country -- even among hospitals rated the best in the country -- there are huge variations in the kind of treatment given to dying patients. In one study -- carried out over several years, in five different hospitals in five different regions -- nurses were trained to conduct constant conversations with the ill and dying, trained to respect their wishes, and trained to allow those who wanted to die at home to do so. Even so, there was a wide range of outcomes. In one region, a third of the patients died in a hospital despite their wishes. In another, the figure was 66 percent.

These variations couldn't be explained by medical necessity or patient preferences. On the contrary, it seems that the most important factor in determining whether a particular region has a high rate of medical intervention on behalf of the terminally ill -- risky operations, respirators, artificial feeding -- is not local religious practices but the local availability of hospital beds and the number of local doctors. There are, for example, a lot of both in Miami. As a result, Medicare spending on a patient in the last six months of life was twice as high in Miami as in Minneapolis. Dying patients in Miami spent four times as many days in intensive care units and saw at least twice as many specialists, too. Yet another study, conducted by the Dartmouth medical school, found no correlation between the amount of treatment given to dying patients in particular regions and that region's overall mortality rate: Just because you see more specialists doesn't mean you'll live longer.

In this sense, the Schiavo case is not only unusual but actually misleading. All of the commentary makes it sound as though these momentous decisions are not only crystal clear but are ultimately made on moral grounds, as if there were something important at stake: the sanctity of human life vs. the right to die, or the wishes of the dying person vs. the wishes of the family. But in practice, we've designed a health care system in which the fulfillment of one's wishes on this matter depends on serendipity. You will die at home -- or not -- because of where you live. You will be kept on a respirator -- or not -- because that's how your local hospital does it. And until we and our politicians are able to focus more thoughtfully on the realities of 21st century death, serendipity, not ethical debate, will remain the ruling principle.

Member-Abilia

- InTrust Hospice has changed its name to Iowa Health Hospice and its Web site to www.iowahealthhomecare.org.
- Hospice of Monroe County, a department of Monroe County Hospital, is actively searching for a full-time and part-time RN to join our team. The part-time RN will work weekends (Friday, 4 p.m. to Monday, 8 a.m.) Requirements include a current Iowa RN license. Hospice or home care experience preferred, but not required. Interested individuals can apply by faxing their resume to 641-932-1671 or e-mailing to bflickinger@mchalbia.com. The selected candidate will be required to complete a pre-employment physical which includes a drug screen.

Attachments:

IHO 23rd Annual Meeting Registration
IHO OP/ED