



FLORIDA HOSPICES AND PALLIATIVE CARE

THE HOSPICE E-NEWS

WEEK OF FEBRUARY 24, 2009

## FAMILIES, PATIENTS SOMETIMES DISAGREE ON EOL CHOICES

Dr. Luann DePodesta cares for terminally ill patients in Boston, and “more than once, ... has witnessed elders changing course and undergoing more medical intervention solely to ease the emotional pain of a distraught son or daughter.” “People don’t make decisions in a vacuum,” she said. “They make decisions at the end of life based on the people they care about and how it’s going to affect the people they love.”

A recent *NEJM* article explored the same phenomenon, where three times in one week, physicians in one ICU encountered children pressuring their dying parents to choose more aggressive treatment than the parents wanted. **The article cites studies which show that while most Americans would not choose to “be kept alive at any cost,” they also do not tell their families about that choice while they are still healthy.** In Massachusetts, a 2005 end-of-life care survey found that 83% of respondents didn’t want to be a burden to loved ones at the end of life, but only slightly more than half had discussed that with spouse or family.

**One Boston hospital, Beth Israel Deaconess, has established a protocol for handling disagreements about stopping treatments for terminally ill patients.** If a doctor thinks that continued treatment would not be effective or would be harmful, and the patient or the family disagree, the family “is offered the opportunity to seek transfer to a facility willing to provide that treatment. They also are advised that they can seek legal intervention.” The whole process is reviewed by a social worker, a member of the clergy, and physicians who are not involved with the case. **Boston’s Brigham and Women’s Hospital has policies similar to Beth Israel Deaconess.**

In Cincinnati, palliative care nurse Karla Kay Shearer says that she often finds that “aging parents will say they want to receive more treatments, even if they don’t, in order to shield a son or daughter who is unable or unready to face the parent’s death.” When she encounters such cases, Shearer “tells anguished sons and daughters that aggressive interventions may keep a parent breathing, but not experiencing what makes life worth living — as she puts it, ‘doing everything to live may actually take everything that is living away from their loved one.’”

Christine McCluskey, executive director of Better Ending Partnership, does community presentations on end-of-life planning and decision-making. “I always tell people ... that you have to get all your family members involved because it’s the daughter or son from California who hasn’t seen Mom in years who will say mom wants to fight on,” McCluskey said. “You need to engage the whole family so there aren’t surprises.” (*The Boston Globe*, 2/16)

## HEALTH CARE SYSTEM IGNORES THOSE WITH CHRONIC CONDITIONS

Author Gail Sheehy, writing in Newark's *The Star Ledger*, says, "Our health care system excels at treating people with acute illnesses in hospitals, but it virtually ignores those with chronic conditions who end up being looked after by family members with no professional training, no financial support and rarely any respite."

Sheehy expresses concern that President Obama's discussion of the nation's health care crisis "rarely if ever mentions the staggering cost and family burden of long-term care for the chronically ill." According to the article:

- \* Between 90 and 133 million Americans have at least one chronic disease.
- \* More than 75% of the nation's \$2.2 trillion spent on health care is spent on chronic disease costs.

After four bouts with cancer, Sheehy's husband, Clay Felker, wanted to die at home. But, Sheehy writes, "Our healthcare system makes it all but impossible for people like Clay to achieve this goal except at exorbitant cost and effort. Medicare covered his acute hospitalizations, expensive tests and procedures, and trips to multiple specialists. What it didn't cover was what he really needed to be cared for at home: a cash benefit to be spent on a medically trained nurse to visit and help relieve distressing symptoms, a doctor on call, and ongoing physical therapy."

Sheehy cared for Felker by stopping work herself and paying privately for the costs of his home care. She writes, "But under our current system, most people could never afford this solution. If the family can't bear the full costs of care, and nobody can give up a job and survive, the family spends down all their savings until they become eligible for Medicaid. That usually only buys a nursing home stay for the rest of the elder's life. Middle-class families face stark choices during a grim chapter of their lives."

Sheehy cites an American Association of Homes and Services' proposal for a National Insurance Trust, with the estimated cost to contributing citizens possibly less than one dollar per day. If they become disabled or dependent at any age, they would be allowed to "withdraw a daily cash benefit to help pay for their care at home."

Sheehy concludes, "Long-term care is long overdue for change, and solutions are within our grasp. We simply must make it affordable for American families to do right by their aging loved ones without sacrificing their own future security or health." (*The Star-Ledger*, 2/15)

## JANE BRODY WRITES GUIDE TO THE GREAT BEYOND

Jane Brody covers health issues for *The New York Times*, but she's taken this new book one step farther – *Jane Brody's Guide to the Great Beyond*. Reviewer David Kessler, author and co-author of several books on death and grief, quotes Brody as saying, "From the Start

Consider the Finish.” Kessler says Brody leads you from “diagnosis to grief,” even while putting you at ease by saying, “Don't be afraid to face the inevitable, which I hope will be as distant from the present as possible.”

Kessler cites Brody's extensive use of humor, which he calls “never irreverent,” but says she “also asks pertinent questions and provides checklists of things that patients and family members may want to ask, following through on her promise to make this book practical.”

The review points out that Brody is truthful, even if maybe we'd rather she weren't. Brody contradicts “movie-style” CPR, where someone who's had it as a result of respiratory failure is “back, feeling and looking good” a few minutes later. Brody says, “The real life facts, however, are quite different. Fewer than one in one hundred terminally ill patients given CPR recover and half of those who survive do so with profound brain damage. More than 99 percent end up as corpses with broken ribs.”

In *Amazon's* “Editorial Reviews,” early reviewers of the book have posted their comments:

\* Betty Rollin (*Last Wish, Here's the Bright Side*): “We're all going to die some day, so we might as well do it right. Jane Brody, a master of information and storytelling, does that in her wonderful and enjoyable new book. This is for everyone who doesn't like the subject—and for everyone else as well.”

\* Diane E. Meier, MD, Center to Advance Palliative Care: “I didn't think it could be done, but then Jane Brody has always accomplished the impossible—she has demystified and given us real control over the thing we fear the most. This book is a gift to all her fellow humans.”

\* Robert N. Butler, MD, International Longevity Center: “At long last we have a comprehensive, humane book about end-of-life care. This is not a ‘pop’ book but rather a thoughtful, science-based, honest discussion of a topic people want to avoid—and do so at their own risk. While it is facile to speak of a ‘good death’ it is all too easy to mis-plan and end up experiencing a bad one.” (*The New York Times*, 2/21; *Amazon Website Editorial Reviews*)

## PUBLIC POLICY NOTES

\* The new stimulus bill signed into law by President Barack Obama last week contained a one-year moratorium on cuts in Medicare funding for hospices. The group of hospice advocates which has been opposing the cuts will now work with Congress and the Obama administration to reverse the CMS rule which eliminates the budget neutrality adjustment factor. (*NHPCO Press Release*, 2/18; *PR Newswire*, 2/18; *On the Hill*, 2/18)

\* Wisconsin Governor Jim Doyle (D) has proposed a domestic partner registry which would give couples in a committed relationship “legal rights of visitation in hospitals, power to make end of life decisions, and the right to inherit property, pensions and benefits like any married couple.” Doyle said, “It is also time to make sure our state takes some basic steps towards fairness and decency.” (*NBC15 Website*, 2/18)

\* **David C. Leven, executive director of Compassion & Choices of New York, has written *The New York Times* to protest the new FDA limits on narcotic prescriptions.** Leven says that the program “raises serious concerns,” because “the underprescribing of opioid drugs is a far greater problem than their misuse.” Leven suggests that other states should emulate New York, which provides \$4.5 million in grants for medical and post-medical school training in pain management. **He concludes, “If the federal government is going to place limits on the prescribing practices of doctors who lack skills in managing pain or spotting drug abuse, it should help ensure that doctors develop these skills.”** (*The New York Times*, 2/18)

## RESEARCH & RESOURCE NOTES

\* **An article in *The New York Times* reports on a study published in the current *JAMA* that examines rates of employment among American and European survivors of cancer. The study found that cancer survivors “are at significantly higher risk for joblessness than healthy counterparts.”** In the United States, the risk is even higher than in Europe, because insurance is provided through a person’s place of employment. The study’s chief author thinks that disability may play an important role in a patient’s difficulty in finding a job, and suggests that “businesses and other employers ... adopt policies more accommodating to cancer survivors, like additional breaks and flexibility in work hours and tasks.” (*The New York Times*, 2/17; *JAMA*, 2009;301(7):753-762)

\* ***Waiting for Rick: A Caregiver’s Dilemma* is the story of Rick Duffy’s experiences in caring for his mother, who suffered from dementia and cancer.** Duffy wrote the book to “reveal strategies and resources for better end-of-life caregiving,” and intends the book “to serve as both a tribute to her life and a how-to manual for families experiencing the unique challenges of saying goodbye to an elderly loved one in failing health.” More information is available at [www.waitingforrick.com](http://www.waitingforrick.com). (*MMD Newswire*, 2/19)

\* **Hospice Partners on Call<sup>SM</sup>, created by Hospice of Palm Beach County, “assures hospice providers that an after-hours team is available to provide answers, offer clinical instruction, or immediate interventions for patients and families who are in need of acute care or immediate intervention over the phone.** A team of professionally trained and skilled customer service representatives and RNs combined with state-of-the-art information tracking technology is dedicated to providing a seamless care experience, 24/7.” (*South Florida Hospital News*, 2/2009)

## HOSPICE & END-OF-LIFE NOTES

\* **Executives of the Denver Hospice recently announced that the new federal economic stimulus bill will result in \$800,000 of benefit to them.** (*Denver Post Website*, 2/19)

\* **VITAS Vice President Bob Miller says that patients with implanted cardioverter defibrillators (ICDs) “need to be informed of the positive and possible long-term negative effects of these devices,” whether it’s done by “the patient’s attending physician or cardiologist, or it’s the hospice physician, or all working in tandem.”** The medical director for VITAS points out that **“once an ICD starts to shock a dying patient’s heart, there is nothing anyone can do to stop it or to ease the patient’s pain.”** “These problems,” Miller says, “could be avoided if patients were fully educated about the devices and, once they are admitted for hospice care, if they were able to discuss their wishes about using or disabling their ICD,” but that doesn’t always happen. (*South Florida Hospital News*, 2/2009)

## OTHER NOTES

\* **“The Long Goodbye,” by Meghan O’Rourke, is a chronicle of what it’s actually like to grieve.** O’Rourke recently lost her mother, age 55, to cancer. **In the next installments, O’Rourke will examine what it means to grieve in a culture that “has few ceremonies for observing it,” and what it’s actually like to grieve.** She also plans to survey the literature of grieving. The first installment is online at [www.slate.com/id/2211257](http://www.slate.com/id/2211257). (*Slate*, 2/16)

\* **When Carole Dunham knew she had only a few months to live, she began looking for an eco-friendly alternative to a traditional burial. She decided on Eternal Reefs, which molds cremated remains into concrete shapes to form artificial reefs. Another “green” alternative is offered by the UK’s Eco Coffins Ltd, which allows customers to design their own biodegradable cardboard coffins. The Green Burial Council is working with the Texas Parks and Wildlife Department to offer cremation-based green burials. For those still living, the founder of Coffin Couches purchases unwanted or damaged coffins from funeral homes and turns them into furniture. See [www.coffincouches.com](http://www.coffincouches.com).** (*CNN Website*, 2/17)

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