
HOSPICE NEWS NETWORK

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

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CAREGIVERS OFFER TIPS ON CAREGIVING

Stacey Burling, staff writer for the *Philadelphia Inquirer*, says that the most helpful information she got about caring for her husband came from a woman whose husband had recently died of the same cancer. Burling says, "I wished that someone had condensed end-of-life caregiving wisdom for me before Jeff got so sick." Burling has now done that for other caregivers, and here are some of the suggestions from her and others who contributed.

- * Hospice aides only are at your home a short while. You may need additional help.
- * Ask the nurses and home aides to teach you caregiving tips.
- * Learn about draw sheets before your patient is bedridden.
- * Twin sheets don't fit hospital beds, which are themselves "surprisingly uncomfortable."
- * Liquids can be thickened to help with swallowing by using Thick-It powder.
- * Pick the funeral home early – last minute shopping isn't fun.
- * Decide whether you want to see the morticians remove the body in a body bag.
- * Find a palliative care team early.
- * Give family members roles where they have skills to fit.
- * Use a wireless doorbell for the patient to call you. You keep the ringer and leave the button for the patient.
- * Make your end-of-life wishes known.
- * Try to keep your sense of humor – funny things happen when you're caregiving.
- * Bed pads that are cotton on top and waterproof on the bottom don't wrinkle as bad and may help prevent bedsores.
- * Dress the patient in a hospital gown.
- * If the patient wears a bra, get a surgical one that closes with Velcro.
- * Stock up on latex gloves.
- * Use a waterproof mattress cover.
- * Egg-crate foam pads may make the bed more comfortable.
- * You can make ice chips by putting ice cubes in a blender.
- * If the patient has difficulty walking, place chairs along the route so there'll be someplace to sit.
- * Ask the care team to help you anticipate problems.
- * Give people specific things to do, like walking the dog.
- * Dress the patient in loose clothing that's easy to get on and off.
- * Family conflicts are common. It's not a time to try to change anybody.

The end-of-life feature, which appeared April 4, has other articles:

- * **"The Price of Not Talking About Death,"** which says that "ignorance makes caregiving harder";
- * **"What is Hospice?";**
- * **"The Process of Death: A Topic Often Avoided,"** and

* **“The Last Month: A Husband’s Final Days,”** the story of Burling’s husband’s last days. (*Philadelphia Inquirer*, 4/4, articles.philly.com/2011-04-04/news/29380447_1_palliative-care-team-sheets-esophageal-cancer; www.philly.com/philly/health_and_science/20110404_The_price_of_not_talking_about_death.html; www.philly.com/philly/health_and_science/20110404_What_Is_Hospice.html; www.philly.com/philly/entertainment/20110404_The_last_month_A_husband_s_final_days.html)

RESEARCH & RESOURCE NOTES

* **The Hospice Foundation of America’s newest video, “Paying for Hospice Care,”** says that **there’s almost certainly a way to pay for hospice if someone needs it. “Hospices work hard to provide access, not to deny it,” according to the organization’s blog.** The video is available at the link below, and other Hospice Information Center videos are available at www.hospicefoundation.org/watch-videos. (*Hospice and Caregiving Blog*, 4/4, blog.hospicefoundation.org/2011/04/paying-for-hospice-care.html)

* **A presentation at the 2011 American College of Cardiology meeting reported the results of a University of Pennsylvania study of end-of-life preferences of patients with implantable cardioverter defibrillators.** The study’s senior author said, **“ICD patients agree that discussions about ICDs and end of life are important. The majority of the patients we polled also support the concept of an ICD-specific advanced directive and post-mortem donation for product improvement or reuse, but have not considered or discussed these topics.”** Half the respondents wanted their devices deactivated if they were terminally ill, but only 17% had considered the issue before the survey, and only two had specific instructions in their advance directives. Over 80% of the respondents would donate the device for product improvement studies or for reuse by other patients or in animal studies. (*Red Orbit*, 4/5, www.redorbit.com/news/health/2024868/penn_study_sheds_light_on_end_of_life_management_of/)

* **AMD3100, an orphan drug originally used for treating HIV, “has been found to short-circuit the process that results in additional sensitivity and pain from opioid use.”** Originally published in the March 25 issue of *Brain, Behavior and Immunity*, the study suggests that “the finding in animal models may ultimately make morphine a safer and more effective drug.” Morphine use can cause opioid-induced hyperalgesia, which one researcher calls “the drug itself producing its own new pain.” AMD3100 interrupts the signaling to and from the nerves which “contributes to a neuroinflammatory response.” (*Indiana University School of Medicine News*, 3/24, communications.medicine.iu.edu/newsroom/stories/2011/a-safer-more-effective-morphine-may-be-possible-with-indiana-uni/)

* **Two articles in the current *JAMA* address opioid use in pain management. “Curbing Diversion and Abuse of Opioid Analgesics Without Jeopardizing Pain Treatment”** recommends enhancing and updating “clinical teaching and training practices for physicians, nurses, dentists, and pharmacists in the areas of pain management, opioid pharmacology, and abuse/addiction.” The authors also recommend the adoption of guidelines recently developed by the American Academy of Pain Medicine. **“Association Between Opioid Prescribing Patterns and Opioid Overdose-Related Deaths”** says that **higher opioid doses in prescription medications were associated with an increased risk of opioid-related deaths.** (*JAMA*, 2011, 305(13):1315-1321, dx.doi.org/10.1001/jama.2011.370; *JAMA*, 2011, 305(13):1346-1347, dx.doi.org/doi:10.1001/jama.2011.369)

* **“A study by Capital Hospice found that in the District of Columbia, African-Americans over 65 who are eligible for hospice care are 34 percent less likely than white people to use it.”** Capital Hospice, which is changing its name to Capital Caring, presented information on the study during a meeting of the National Press Club. (*The Washington Post*, www.washingtonpost.com/national/leading-hospice-provider-says-blacks-in-dc-34-percent-less-likely-to-use-hospice-care/2011/04/06/AFPIw2mC_story.html; *Reporters Notebook*, 4/7, www.newsline.umd.edu/blog/index.php/2011/04/)

* **Resources to help you in your participation in National Healthcare Decisions Day, April 16, are available at the link below. New Jersey Hospice & Palliative Care Organization’s 5-minute video on NHDD is online at www.youtube.com/watch?v=spiq4K6m2Fk.** (*National Healthcare Decisions Day Website*, www.nhdd.org/p/organize-your-community.html; *New Jersey Hospice & Palliative Care Organization*)

PUBLIC POLICY NOTES

* **US Senators Ron Wyden (D-Oregon) and Pat Roberts (R-Kansas) have introduced the Hospice Evaluation and Legitimate Payment (HELP) Act. The bill “would require any changes to hospice Medicare reimbursements be tested for two years in a pilot program to ensure they do not harm hospice centers in a way that would limit access to those who need it most.”** (*Senator Ron Wyden Press Release*, 5/5, wyden.senate.gov/newsroom/press/release/?id=26bfbd2f-dbb1-499c-b627-79ab88497b18)

* **John K. Iglehart, national correspondent for *NEJM*, discusses at length the current views on Medicaid by the Republican and Democratic parties. He writes, “Republicans seek to cap open-ended federal funding for Medicaid, provide states greater flexibility in managing their Medicaid programs, and repeal the ACA, which includes a large Medicaid expansion scheduled for 2014. Democrats, meanwhile, defend Medicaid as a crucial safety net that benefits millions of people at a cost far lower than what Medicare and private carriers pay for similar services. The debate over Medicaid’s future will engage Congress and state legislatures nationwide this year.” He concludes, “Medicaid stands at a crossroads. With policymakers poised to address large budget deficits, the program is vulnerable because of controversies surrounding it and states’ inability to sustain its rapid growth. Ultimately, policymakers will revisit the decision Democrats made in the last Congress to greatly expand the program — thereby offering another answer to the question of the politically acceptable level of public support that the United States should provide to its poorest citizens.”** (*NEJM*, 4/6, www.nejm.org/doi/full/10.1056/)

* **Connecticut’s proposed requirements for inpatient hospices (changes in medical staffing levels, onsite pharmacies, required qualifications for administrators and medical staff, spiritual counseling and arts programming) brought a large turnout to a Department of Public Health meeting about the changes. All but one of the state’s 29 hospices support the proposals, but Connecticut Hospice “says the new rules would compromise care and put its finances at risk,” and would reduce “the state’s current standards to the minimum required by Medicare.”** (*The Hartford Courant*, 4/4, www.courant.com/health/connecticut/hc-hospice-wars-0404-20110404,0,1657876.story)

* A bill before the Maryland legislature would create a new prescription drug monitoring system that “would require pharmacies to log each filled prescription in a database, allowing prescribers in doctors’ offices, emergency rooms or urgent care facilities to check before writing prescriptions for the same medications.” A spokesman for the American Pain Foundation responded to the article, saying that the organization “would like to remind legislators that in addition to helping curb abuse and misuse of prescription pain medication in this state, they must be careful not to diminish access to pain care.” (*The Baltimore Sun*, 4/2, www.baltimoresun.com/health/bs-hs-prescription-drugs-20110330,0,1122265.story; 4/6, www.baltimoresun.com/news/opinion/readersrespond/bs-ed-0405-prescription-drugs-letter-20110406,0,4207699.story)

OTHER NOTES

* BJC Hospice, in St. Louis, created a “program called Lumina that helps patients leave statements that go beyond a simple goodbye.” *NPR’s Weekend Edition* featured a story about the program. The founder of the program, Suzanne Doyle, told of her experiences with Courtney Strain, a patient who died last year, at the age of 25, from cancer. Strain shared with Doyle that she felt like an outcast because, as her health deteriorated, people did not know what to say. Doyle invited Strain to work with her to create a teaching tool, and together they created a guide titled *What You Can Do When a Friend (Like Me) Faces the End of Life*. The program has 25 volunteers. “They’re storytellers who learn how to interview dying people so they can help them leave tangible statements of values and legacy — books, CDs, photo albums, letters.” The story is available for listening at the link below, and suggestions from the guide were posted online on 4/10 at awareofyourcare.com/blog/. (*NPR*, 4/9, www.npr.org/2011/04/09/134463410/for-dying-people-a-chance-to-shape-their-legacy)

* The emergency department at St. Joseph’s Regional Medical Center in Paterson, New Jersey is one of just a few in the country with a palliative care program. The team helps “20 to 30 chronically or terminally ill patients a month by offering relief of pain, nausea, delirium and other symptoms without the high-tech wizardry of advanced medicine.” Dr. Mark Rosenberg, palliative care specialist who created the ER program, says, “For many of these patients, we know deep in our hearts that it’s their last admission. In the past, we never communicated this. We’re trained to cure disease. But we’re trying to communicate this knowledge with patients so they know they have choices.” (*The Record*, 4/4, www.northjersey.com/news/119164764_Hospital_breaking_the_cycle_for_terminally_ill.html)

* San Diego’s Sharp HospiceCare has developed an advance care planning consultation (ACP) program to help patients with advance directives. Drs. Rebecca Sudore and Terri Fried say, “The main objective of advance care planning, rather than advance treatment decisions, should be to prepare patients and surrogates to work with their clinicians to make the best possible in-the-moment medical decisions.” The ACP model targets patients at three stages of life – relatively healthy, with chronic progressive illness, and limited life expectancy. The article, in NHPCO’s *Newsline*, concludes, “The demand for this type of service has exceeded all expectations. Plans are under way to develop a comprehensive “train the trainer” model that can be used system-wide and will be recognized as a best practice for end-of-life care planning.” (*NewsLine*, 4/2011, www.nxtbook.com/nxtbooks/nhpco/newsline_201104/#/10)

* If you want the Catholic sacrament of anointing the sick when you’re reaching the end of life, you need to plan ahead, says retired Cleveland Bishop Anthony Pilla. The shortage of

priests means that one isn't always available when needed. Pilla recommends asking for the sacrament whenever a person is ill, and says that the sacrament isn't just for the dying, but also for the sick and recovering. Many hospitals and hospices have a priest on call, but Catholics living in rural areas may find it more difficult to find a priest in time of need than those living in urban areas. (*USA Today*, 4/6, www.usatoday.com/news/religion/2011-04-06-dying-Catholic-priest-05-ST-N.htm)

* **The Joint Commission has announced that accredited hospitals may seek the Advanced Certification in Palliative Care.** The requirements emphasize “a formal, organized palliative care program led by an interdisciplinary team whose members possess the requisite expertise in palliative care; leadership endorsement and support of the program’s goals for providing care, treatment and services; a special focus on patient and family engagement; processes which support the coordination of care and communication among all care settings and providers; and the use of evidence-based national guidelines or expert consensus to guide patient care.” (*The Joint Commission Press Release*, 3/25, www.jointcommission.org/the_joint_commission_launches_advanced_certification_in_palliative_care_program/)

* **The *Zen Buddhism Examiner* cites the April 6 issue of the *Journal of Neuroscience* as saying that meditation can “reduce your sensitivity to pain.”** Participants in the study practiced a style of meditation called Shamatha, or focused meditation. The results of meditation after 120 degree burns on their calves showed “that the participant’s sensitivity to pain drastically decreased after about a 20 minute meditation session.” (*Zen Buddhism Examiner*, 4/5, www.examiner.com/zen-buddhism-in-national/new-study-shows-meditation-is-a-natural-remedy-for-pain; *Third Age*, 4/7, www.thirdage.com/news/chronic-pain-management-through-meditation-4-7-2011)

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