Discovering a better way for final days

CALIFORNIA | Mercury News (San Jose) – 29 December 2012 – I want to build on our conversation and prescribe a cure – a new way of considering end-of-life medicine – in the final installment of our year long examination of the emotional and financial cost of dying [writes Lisa Krieger]. It is not a drug or a device, a test or therapy. It is a different way of organizing our ending – so that we live our last days better and pass more gently. Powerful lessons have emerged from the stories of suffering and triumph we have shared – not only through the reporting but from dozens and sometimes hundreds of emails and phone calls from readers. Together, we’ve met Bay Area people like Ray Brown, who showed how agonizing it can be when a loved one's end-of-life wishes are unknown. And doctors like Jessica Zitter, who insists it's the doctor's job to help families decide whether it's time to quit. We admired the resolve of Bill Newman, who wears his end-of-life wishes on a homemade "Do Not Resuscitate" badge, and marveled at caregivers like Susan Meyers who sacrificed her own well-being to allow her be-


Study finds spiritual care still rare at end of life


1. 'Why is spiritual care infrequent at the end of life? Spiritual care perceptions among patients, nurses, and physicians...’ Journal of Clinical Oncology; 17 December 2012. [Noted in Media Watch, 24 December 2012.] http://jco.ascopubs.org/content/early/2012/12/13/JCO.2012.44.6443.abstract
Of related interest:

- CALIFORNIA | Mercury News (San Jose) – 27 December 2012 – “How we can change end-of-life medicine?” A gift Americans owe to themselves and their country in 2013 is lessons on how to die. Teachers know this. They don’t spend their final hours like the other 2.4 million Americans who die every year. They’ve seen patients hooked up to tubes in hospital beds, suffering unnecessary pain and indignity, while tens of thousands of dollars are spent on every medical option to extend lives that are clearly near the end. [Source](http://www.mercurynews.com/opinion/ci_22272501/mercury-news-editorial-how-we-can-change-end?source=pkg)

N.B. Links to the articles in the Mercury News series on the emotional and financial cost of dying:

Positioning non-profit hospice

Hospice unveils marketing campaign

INDIANA | The Republic (Columbus) – 29 December 2012 – Faced with more competition from for-profit medical chains, the Hospice of South Central Indiana is making a simple tweak to its name and unveiling a new logo in a bid to stand out from the crowd. Its goal is to drive home the idea that the non-profit hospice acts as a good neighbor for Columbus residents with medical needs. The agency, which offers end-of-life care, will become known as Our Hospice of South Central Indiana. Adding the single word "our" to the agency's long-time name and coupling it with a colorful logo showing the outline of four homes is meant to depict a diverse neighborhood that cares. Debby Pratt, marketing director for Our Hospice, hopes to cut through what the agency sees as consumer confusion about competing hospice services. "There's a lot of confusion in the community, and we are looking for a way to differentiate ourselves from other providers," Pratt said. [Source](http://www.therepublic.com/view/local_story/Hospice-unveils-marketing-camp_1356835757)

End-of-life care and the economy

Bedford Hospice House temporarily suspends operations

VIRGINIA | Smith Mountain Eagle (Bedford) – 27 December 2012 – With Bedford Hospice House regulations redefined in 2007, the organization originally thought it could best serve the community under the Commonwealth's Assisted Living licensure provision, so they immediately began pursuing that credential in mid-2011. Through that process, Bedford House began to realize that the initial mission of Bedford Hospice House ... would have to be compromised to meet the assisted living guidelines. Patients and families who could most benefit from what Bedford House offers might not meet the criteria for an assisted living facility. Residents admitted to an assisted living facility can be hospice patients, but they must be at an early enough stage that they fit the requirement for "assisted living" rather than nursing care. After much thought and consideration, the organization's board of directors made a unanimous decision: abandon pursuit of an assisted living facility license and focus solely on the mission of providing a residence exclusively for hospice patients under the care of local and regional hospice care providers. [Source](http://www.smithmountaineagle.com/news/article_3d6620fc-5033-11e2-8ec8-0019bb2963f4.html)
Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NATIONAL PUBLIC RADIO (NPR) | Online report – 28 December 2012 – 'Americans support physician-assisted suicide for terminally ill.' Results from the latest NPR-Truven Health Analytics Health Poll show most Americans favor physician-assisted suicide for people with less than 6 months to live. Overall, 55% of respondents favored it, and 45% were opposed. Those proportions were unchanged from July 2011, when Truven asked the same questions. Support for the idea varied by age and income. Fifty-six percent of people 65 and older opposed physician-assisted suicide for the terminally ill; 44% supported it. Among people younger than 35, the results were reversed: 59% for and 41% against. [http://www.npr.org/blogs/health/2012/12/27/168150886/americans-support-physician-assisted-suicide-for-terminally-ill]

  N.B. "Doctor-assisted suicide" emerged as the most controversial cultural issue in Gallup's 2011 Values & Beliefs poll with Americans divided 45% vs. 48% over whether it is morally acceptable or morally wrong. Gallup's 2010 poll indicated almost an identical division in public opinion.

International

Controversial Liverpool Care Pathway 'a fantastic step forward,' says Jeremy Hunt

U.K. (ENGLAND & WALES) | The Daily Telegraph – 30 December 2012 – The pathway, designed to ease the suffering of patients in their last hours or days of life, has come under intense scrutiny in recent months. It can involve the removal of drugs, nutrition and hydration if they are judged to be of no benefit to the patient. But a number of families have complained that their loved ones were put on the pathway without their knowledge, while some doctors have claimed it can hasten death. The Health Secretary [Jeremy Hunt] insisted the protocol was far better than alternative arrangements and allowed those close to death to be comfortable and to spend their last hours with their families. A national audit recently disclosed that almost half of dying patients who were placed on the controversial pathway were not told that life-saving treatment had been withdrawn. The study suggested that about 57,000 patients a year are dying in National Health Service hospitals without being told that efforts to keep them alive have been stopped. It also revealed that thousands of dying patients were not given drugs to make them more comfortable. [http://www.telegraph.co.uk/news/politics/9771659/Controversial-Liverpool-Care-Pathway-a-fantastic-step-forward-says-Jeremy-Hunt.html]

Of related interest:

- U.K. | The Guardian – 29 December 2012 – 'A thirst for palliative care: The Liverpool Care Pathway and withholding sustenance.' Caring for the dying through the controversial Liverpool Care Pathway involves crucial questions about how to see them humanely through their last moments. [http://www.guardian.co.uk/lifeandstyle/2012/dec/30/controversial-liverpool-care-pathway-palliative]

  N.B. See Media Watch of 3, 10 & 17 December 2012 (pp.6, 8 & 3, respectively) for a representative sample of press coverage of the controversy surrounding the LCP.
Elder and end-of-life care

Germany 'exporting' old and sick to foreign care homes

GERMANY | The Guardian (U.K.) – 26 December 2012 – The move, which has seen thousands of retired Germans re-housed in homes in Eastern Europe and Asia, has been severely criticised by social welfare organisations who have called it "inhumane deportation." But with increasing numbers of Germans unable to afford the growing costs of retirement homes, and an ageing and shrinking population, the number expected to be sent abroad in the next few years is only likely to rise. Germany's chronic care crisis – the care industry suffers from lack of workers and soaring costs – has for years been mitigated by eastern Europeans migrating to Germany in growing numbers to care for the country's elderly. But the transfer of old people to eastern Europe is being seen as a new and desperate departure, indicating that even with imported, cheaper workers, the system is unworkable. Germany has one of the fastest-ageing populations in the world, and the movement here has implications for other western countries, including Britain, particularly amid fears that austerity measures and rising care costs are potentially undermining standards of residential care. http://www.guardian.co.uk/world/2012/dec/26/german-elderly-foreign-care-homes

Palliative care in Ireland

Hospice home care for children

IRELAND | The Independent (Dublin) – 26 December 2012 – An estimated 1,400 children in Ireland are living with life-limiting condition; about 350 children die from these each year, 11% of them at home. The Irish Hospice Foundation has raised €2.5m to launch the Hospice Home Care for Children programme and needs to raise €1m more to keep it going. The Foundation provides five children's outreach nurses, who support families with seriously ill children in their homes. It also funds Ireland's only Consultant Paediatrician specialising in palliative care. http://www.independent.ie/lifestyle/hospice-home-care-for-children-the-facts-3335862.html

Palliative care in Africa

Palliative care allays end-of-life pain

UGANDA | AllAfrica.com (Kampala) – 25 December 2012 – Palliative care providers have called for expansion of their services in all the districts of Uganda. This was during the launch of 'Documentation of Palliative Care Development in Uganda.' Rose Kiwanuka, President of Palliative Care Association of Uganda, said currently only 61 districts are covered by palliative care providers with others lagging behind despite having the need. "Much as there is a life limiting illness, there is need to bring hope to those who are battling with such infirmity to cover up for the pain," Kiwanuka explained. http://allafrica.com/stories/201212260788.html
Shanghai promotes burials at sea

CHINA | China Daily (Shanghai) – 24 December 2012 – A shortage of land has prompted the municipal government to offer a larger subsidy to promote sea burials. The local authority has announced a fivefold increase, from 400 yuan ($64) to 2,000 yuan, in subsidies to encourage Shanghai residents to consider the sea option. Starting next year, Shanghai will subsidize families choosing a sea burial by 1,000 yuan and the another 1,000 yuan will go to pay service providers to cover costs such as ship tickets and insurance, Lu Chunling, director of funeral management under Shanghai Civil Affairs Bureau. http://usa.chinadaily.com.cn/epaper/2012-12/24/content_16047554.htm

Specialist Publications (e.g., in-print and online journal articles, reports, etc.)

Prediction of in-hospital mortality of patients with advanced cancer using the Chuang Prognostic Score

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Published online – 26 December 2012 – The Chuang Prognostic Score (CPS) was developed to predict survival of terminally ill patients with cancer. The CPS was assessed in 61 hospitalized adult patients with advanced cancer. Using a CPS cut off point of ≥6, in-hospital mortality was predicted with 71% positive predictive value, 91% negative predictive value, 75% sensitivity, 89% specificity, and 85% overall accuracy. http://ajh.sagepub.com/content/early/2012/12/25/1049909112467362.abstract

Media Watch Online

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://centres.sg/ (Scroll down to ‘Palliative Care Network: Media Watch’)

Australia

AUSTRALASIAN PALLIATIVE INTERNATIONAL LINK: http://www1.petermac.org/apl/links.htm (Scroll down to ‘Links,’ then to ‘Media Watch’)

Canada

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: http://www.hhnbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx (Click on ‘Current Issue’ under ‘Media Watch’)

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): http://www.hpconnection.ca/newsletter/inthenews.html

ONTARIO | Mississauga Halton Palliative Care Network: http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1

ONTARIO | Palliative Care Consultation Program (Oakville): http://www.palliativecareconsultation.ca/?q=mediawatch

Europe

HUNGARY | Hungarian Hospice Foundation: http://www.hospicehaz.hu/en/training/ (Scroll down to ‘Media Watch’)

U.K. | Omega, the National Association for End of Life Care: http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300f06522f7f7b90c

International


PALLIATIVE CARE NETWORK COMMUNITY: http://www.pcn-e.com/community/pg/file/owner/MediaWatch
Less is more

Undertreatment improves, but overtreatment does not

ARCHIVES OF INTERNAL MEDICINE | Published online – 24 December 2012 – When the authors launched the "Less Is More" series, it was with the goal of correcting what we see as a prevalent bias in American medicine: that more care (more diagnostic tests, more treatments, more procedures) is better care. As modern medicine has produced some spectacular interventions, including antibiotics for infections, antiretroviral agents for persons with human immunodeficiency virus infection, detailed imaging through computed tomography, and magnetic resonance imaging to obviate the need for diagnostic surgery, it is not surprising that physicians and our patients think that more diagnostic tests and treatments are always better.


Of related interest:

- JOURNAL OF CLINICAL ONCOLOGY | Published online – 26 December 2012 – 'Medical oncologists' perceptions of financial incentives in cancer care.' The cost of cancer care continues to increase at an unprecedented rate. Concerns have been raised about financial incentives associated with the chemotherapy concession in oncology practices and their impact on treatment recommendations. http://jco.ascopubs.org/content/early/2012/12/26/JCO.2012.43.6063.abstract

"Keeping her whole" – Bereaved families' accounts of declining a request for organ donation

CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS, 2013;22(1):55-63. Organ transplantation remains the only treatment choice for thousands of individuals with end-stage organ failure. Currently in the U.K. 10,000 individuals could benefit from an organ transplant, but the shortage of available organs means that 1,000 people die each year while waiting. Relatives of potential organ donors are the most critical link in maintaining organ availability for transplantation, as they must give their explicit consent before organ donation can take place. U.K. refusal rates of 40%, which rise to 70% in non-white groups, are therefore of concern. Sque and colleagues... challenged the notion that the most important reason that relatives agreed or declined donation was knowledge of the deceased person's wishes, as most families reported a need to protect the integrity of the deceased person's body, even if it meant the deceased's wish to be an organ donor was not fulfilled. This decision made by participants to decline organ or tissue donation appeared to be made in the context of deeply distressing concerns related to the "cutting up" of the body.

http://journals.cambridge.org/action/displayFulltext?type=1&fid=8771561&jid=CQH&volum eid=22&issueId=01&aid=8771559&bodyId=&membershipNumber=&societyETOCSession=


The (half) truth about grief

ILLNESS, CRISIS & LOSS, 2012;20(4):389-395. The recent critique of the bereavement field offered by author Ruth Davis Konigsberg takes grief theorists and researchers to task for perpetuating self-serving stage-based models of mourning that ignore the resilience of most bereaved people, while promulgating a form of grief counseling that is neither necessary nor effective. [The author of this commentary underscores] the truth embedded in her analysis, but also the half-truths that result from its simplification and neglect of broader considerations. http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,7,12;journal,1,72;linkingpublicationresults,1:103734,1

Cont.
Noted in Media Watch, 9 July 2012:


**Exploring children's understanding of death: Through drawings and the Death Concept Questionnaire**

*DEATH STUDIES, 2013;37(1):47-60.* To investigate whether children's understanding of the concept of death varies as a function of death experience and age, 52 children aged 7, 9, and 11 years (26 had a personal death experience), drew a picture reflecting the meaning of the word death and completed the Death Concept Questionnaire for examination of Human & Animal Death. The results showed that the two methodological tools used offered complementary information and that children's understanding of death is related both to age and past experience. [http://www.tandfonline.com/doi/full/10.1080/07481187.2011.623216](http://www.tandfonline.com/doi/full/10.1080/07481187.2011.623216)


No matter the species

**Palliative care and compounding for household pets**

*INTERNATIONAL JOURNAL OF PHARMACEUTICAL COMPOUNDING, 2012;16(6):452-455.* Palliative care is not a term solely used for humans when discussing health care; the term is also used when discussing veterinary patients. Pets are considered part of the family by pet owners, and they have a special relationship that only another pet owner can fully understand. This article discusses some of the healthcare problems that affect pets (and their owners), statistics on the most commonly used medications for veterinary patients, quality of life, and discussions on the veterinary pharmacist-owner-palliative pet relationship and how compounding pharmacists can prepare patient-specific medications. [http://www.ijpc.com/Abstracts/Abstract.cfm?ABS=3556](http://www.ijpc.com/Abstracts/Abstract.cfm?ABS=3556)

Noted in Media Watch, 30 April 2012:


**Premiers mois d'une maison de répit et de soins palliatifs pédiatriques**

(First months of a respite house and paediatric palliative care)

*MÉDECINE PALLIATIVE : SOINS DE SUPPORT – ACCOMPAGNEMENT – ÉTHIQUE | Published online – 21 December 2012 –* The topic of the authors’ reflection is the place that welcomes a child suffering from a life-shortening illness. Besides relieving the child's body symptoms, it appears that the familial body is an entity in its own right that must be supported on various levels – medically, psychologically and socially – and at different stages of the illness. On the frail boundary between healing and palliative care usually characterized by unforeseen risks, the multidisciplinary team of the respite house dedicate themselves to offering support and listening attentively to everyone's needs and wishes so that the child's care can also be a life plan. [http://www.sciencedirect.com/science/article/pii/S1636652212001407](http://www.sciencedirect.com/science/article/pii/S1636652212001407)

N.B. French language article.
The experience of end of life care simulation at a rural Australian University

NURSE EDUCATION TODAY | Published online – 20 December 2012 – Providing end of life care is a challenging and anxiety provoking prospect for many undergraduate nursing students and many students report a lack of preparedness in providing care. The limited availability of appropriate clinical placements limits the opportunities for nursing students to gain experience in end of life care. Advances in simulation techniques using high fidelity mannequins enable the mimicking of complex patient scenarios such as cessation of life in the provision of end of life care. A group of nursing academics at a rural Australian University designed, developed and implemented end of life care simulation to a group of 3rd year nursing students. The aim of this paper is to report on the evaluation of this educational innovation. Five major themes were identified through analysis of student evaluations: 1) Linking of theory to practice; 2) Approaching families of dying patients; 3) An encounter with death; 4) ‘Hands on’ experience in a ‘protected environment’; and, 5) Importance of post simulation discussion and debriefing. End of life care simulation has provided a valuable experience that can be difficult to obtain in clinical practice settings. However, the challenges discussed in this paper need to be taken into consideration for future use. [http://www.nurseeducationtoday.com/article/S0260-6917(12)00388-7/abstract](http://www.nurseeducationtoday.com/article/S0260-6917(12)00388-7/abstract)

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- **JOURNAL OF POLICY HISTORY.** 2013;25(1):12-41. ‘From Sander to Schiavo: Morality, partisan politics, and America’s culture war over euthanasia, 1950-2010.’ In March 1950, more than one hundred reporters, photographers, and radio broadcasters from the U.S. and around the world descended on Manchester, New Hampshire, and filed roughly 1.6 million words while covering the trial of Dr. Hermann Sander, a 41-year-old physician... Indicted on a charge of killing one of his patients, a 59-year-old woman dying of cancer, Sander was the first physician in U.S. history to stand trial for mercy killing. His trial ended in an acquittal, but from an historical perspective the significance of Sander's 1950 court appearance lay in its relevance to the country's long-standing, divisive debate over euthanasia. This debate was raging as bitterly as ever on 31 March 2005 when ... 44-year-old Terri Schiavo died after her feeding tube was removed. The Sander trial and the Terri Schiavo saga serve as book ends to a chapter in the history of euthanasia in modern America that witnessed momentous changes in the nation's moral values surrounding death and dying.

http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8783993&fulltextType=RA&fileId=S0898030612000334

Noted in Media Watch, 13 September 2010:

- **JOURNAL OF MEDICAL ETHICS.** 2010;36(9):571-573. 'How the public responded to the Schiavo controversy.' [http://jme.bmj.com/content/36/9/571.abstract](http://jme.bmj.com/content/36/9/571.abstract)


[http://www.google.com/hostednews/ap/article/ALeqM5iGq41NTRuJK_ygTwJOM94fM256XQD9EOQ7KGT](http://www.google.com/hostednews/ap/article/ALeqM5iGq41NTRuJK_ygTwJOM94fM256XQD9EOQ7KGT)

Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses, and facilitating issue specific workshops, for frontline care providers. Biosketch on the International Palliative Care Resource Center website at:

[http://www.ipcrc.net/barry-r-ashpole.php](http://www.ipcrc.net/barry-r-ashpole.php)
Worth Repeating

Moral distress: A growing problem in the health professions?

HASTINGS REPORT, 2010;40(1). In the insightful and provocative book *Final Exam*, noted author and liver transplant surgeon Pauline Chen chronicles her medical education and some of the ethical dilemmas physicians face in practice. She describes a hierarchal and often authoritative system of care, reflecting upon the frailties of care providers as well as patients. Though she does not explicitly use the term, Chen implicitly describes the impact of moral distress on health care quality, providers' ability to meet professional and ethical obligations, and subsequent provider satisfaction and retention. Moral distress, as defined by Andrew Jameton in 1984, is the inability of a moral agent to act according to his or her core values and perceived obligations due to internal and external constraints. Others have noted the psychological and physical burdens resulting from moral distress. Today, nurses and their colleagues face ethical issues that seem more complex and more frequent than when Jameton coined the term twenty-five years ago.


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Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy tool or change document.

Distribution

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1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
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3. Access to a complete article, in some cases, may require a subscription or one-time charge.
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5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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