## Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in hospice, palliative care and end-of-life issues — to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry.

# 25 July 2011 Edition | Issue #211



Compilation of Media Watch 2008, 2009, 2010, 2011 ©

Compiled & Annotated by Barry R. Ashpole

End of life care and health care expenditures: Scroll down to <u>U.S.A.</u> and 'Death and budgets' (p.4), published in the *New York Times*.

# Canada

#### Legal perspective

Ontario Court of Appeal considers whether consent is needed to remove patient from life support

NORTON ROSE GLOBAL | Online article – Accessed 22 July 2011 – End-of-life decisions are not only emotionally overwhelming for the family members involved, but also raise a host of complicated legal issues. This complexity is illustrated by the recent Court of Appeal decision in *Rasouli v Sunnybrook Health Sciences Centre*, which addresses whether a physician must obtain the consent of a substitute decision-maker to withdraw life-sustaining measures from a patient where there is no chance of medical recovery. There are several issues raised by the decision that warrant further discussion. [For example], the Court of Appeal's "treatment package" approach – that is, consent is required whenever the termination of existing life support measures is to be immediately followed by palliative care – does not address the doctors' concern about the physician-patient relationship. Palliative care is frequently the logical next step after removing life support. <a href="http://www.nortonrose.com/knowledge/publications/54094/ontario-court-of-appeal-considers-whether-consent-is-needed-to-remove-patient-from-life-support">http://www.nortonrose.com/knowledge/publications/54094/ontario-court-of-appeal-considers-whether-consent-is-needed-to-remove-patient-from-life-support</a>

**N.B.** Norton Rose is a leading international legal practice.

From Media Watch dated 4 July 2011:

ONTARIO | Globe & Mail – 29 June 2011 – 'Doctors can't make life-support decisions on their own: Court.' Ontario's top court has ruled doctors must get approval from a provincial medical board when their decision to withdraw life-support treatment goes against the wishes of a patient's family. <a href="http://www.theglobeandmail.com/news/national/doctors-cant-make-life-support-decisions-on-their-own-court/article2080320/">http://www.theglobeandmail.com/news/national/doctors-cant-make-life-support-decisions-on-their-own-court/article2080320/</a>

## U.S.A.

#### Caring for the dead at home

CALIFORNIA | Sacramento Bee – 24 July 2011 – Every time Heidi Boucher goes to her corner store in ... the checkout person will ask what she plans to do with the big blocks of dry ice she buys. Boucher used to make up little white lies, but now she tells the truth: She uses the ice to care for the dead. In her spare time, but more and more with each passing month, Boucher works as a kind of midwife for the recently deceased. She is a home death care worker, a natural death care provider. People use her in lieu of a funeral home. Day or night, she will drive to clients' homes to care for the body of a loved one. <a href="http://www.sacbee.com/2011/07/24/3790359/marcosbreton-caring-for-the-dead.html">http://www.sacbee.com/2011/07/24/3790359/marcosbreton-caring-for-the-dead.html</a>

## Preparing Americans for death lets for-profit hospices neglect end of life

CALIFORNIA | San Francisco Chronicle -22 July 2011 – As hospice care has evolved from its charitable roots into a \$14 billion business run mostly for profit, patients ... and their families have paid a steep price. according to lawsuits and federal [government] investigations. Providers have been accused of boosting their revenues with patients who aren't near death and not eligible for hospice – people healthy enough to live a long time with traditional medical care. In hospices, patients give up their rights to "curative" measures because they are presumed to be futile. More than four in 10 Americans now meet their end in hospice care, drawn by its promise of palliation and pain alleviation instead of extreme measures in their waning days. Medicare's hospice rolls doubled to 1.1 million patients from 2000 to 2009, the last year of available data. http://www.sfgate.com/cgibin/article.cgi?f=/g/a/2011/07/22/bloomberg1 376-LOPPSE1A74E901-3G83F78B9VT0I642MF1U1GBMDE.DTL

From Media Watch dated 4 July 2011:

 NEW YORK TIMES | Online article – 27 June 2011 – 'Concerns about costs rise with hospices' use.' Medicare's bill for hospice care rose to more than \$12 billion in 2009 from \$2.9 billion in 2000. Although the benefit is intended for patients who have no more than six months to live, 19% now receive hospice services for longer, according to the Medicare Payment Advisory Commission.http://www.nytimes.com/2011/06/28/health/28hospice.html? r=1&ref=hospicecare

#### Is a family member facing hospice care?

PHILADELPHIA | Times Herald (Norristown) - 23 July 2011 – Medicare Part A will cover hospice care if the patient has received a doctor's certification that he/she is terminally ill and is expected to live less than six months. The patient must sign a statement making the choice to receive hospice care rather than routine Medicare covered benefits, which means the patient has agreed to accept palliative care to provide comfort and pain relief rather than continuing treatment and medication with the hope of finding a cure. Medicare does continue to cover health problems that are not related to the terminal illness. Hospice benefits include services provided by a doctor or nurse, social worker, counselor and homemakers. Any drugs needed to provide comfort and medical supplies are covered. In some cases, there may be a \$5 copay for some pain- or symptom-control drugs. http://timesherald.com/articles/2011/07/23/news/d oc4e2b22c1156f0142423461.txt

# Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. <a href="http://www.pcn-e.com/community/pg/file/world/world/">http://www.pcn-e.com/community/pg/file/world/</a>

#### University Hospital merger stirs end-of-life care fears

KENTUCKY | Courier-Journal (Louisville) – 21 July 2011 – A growing chorus of protest from local residents, doctors and others has erupted over the fact that Catholic doctrine could override patients' end-of-life wishes under a pending merger of three Kentucky hospitals. Under the merger proposal, University Hospital will join Jewish Hospital & St. Mary's HealthCare and St. Joseph Health System. When the merger was announced last month, officials said all the merged hospitals will follow Catholic health care directives. And while many wealthier patients could simply choose a different hospital, indigent patients have little choice but University Hospital for treatment, including end-of-life care. That has left some worried about how end-of-life decisions will be affected if living wills and decisions to remove a feeding tube, for example, will not be honored if they are "contrary to Catholic teaching." <a href="http://www.courier-journal.com/article/20110723/BUSINESS/307240044/University-Hospital-merger-stirs-end-life-care-fears?odyssey=tab%7Ctopnews%7Ctext%7CHome">http://www.courier-journal.com/article/20110723/BUSINESS/307240044/University-Hospital-merger-stirs-end-life-care-fears?odyssey=tab%7Ctopnews%7Ctext%7CHome</a>

From Media Watch dated 21 March 2011:

THE HASTINGS REPORT, 2011;41(2):28-29. 'Making sense of the Roman Catholic directive to extend life indefinitely.' In November 2009, the U.S. Conference of Catholic Bishops issued Ethical & Religious Directives for Catholic Health Care Services, requiring that all patients ... be provided with artificial hydration and nutrition if such care could extend life indefinitely. http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=5164

From Media Watch dated 28 June 2010:

NEUROLOGY TODAY, 2010;10(2):30. 'Should feeding tubes always be continued in terminal illness? Not necessarily, according to new guidance from the Catholic Church.' Ethical & Religious Directives for Catholic Health Care Services says that there is a general moral obligation to provide patients with nutrition and hydration if it would prolong their lives, but there are exceptions. <a href="http://journals.lww.com/neurotodayonline/Fulltext/2010/06170/Should\_Feeding\_Tubes\_Always\_Be\_Continued\_in.14.aspx">http://journals.lww.com/neurotodayonline/Fulltext/2010/06170/Should\_Feeding\_Tubes\_Always\_Be\_Continued\_in.14.aspx</a>

#### Prison hospice

#### Angola movie screened at prison

LOUISIANA | Associated Press – 21 July 2011 – A standing-room only crowd filled the main chapel at the Louisiana State Penitentiary to watch "Serving Life," Lisa R. Cohen's documentary on the hospice program at the prison. The movie follows four new hospice care workers and the dying inmates they care for. By the time it is finished, subtle sounds of crying filled the large auditorium. And, when the lights went up, many prisoners were still wiping their eyes. The movie, narrated by Academy Award-winning actor Forest Whittaker, will be aired on the Oprah Winfrey Network on July 28. But on Thursday, it belonged to the men at Angola, many of whom will end up in the prison's hospice program themselves. More than 90% of those incarcerated in the penitentiary will die there. <a href="http://www.seattlepi.com/news/article/Angola-movie-screened-at-prison-1530576.php">http://www.seattlepi.com/news/article/Angola-movie-screened-at-prison-1530576.php</a>

N.B. Video clip (i.e., preview) of 'Serving Life' http://www.youtube.com/watch?v=DzPzmeieXPE.

#### The growing contributions and costs of family caregiving

AMERICAN ASSOCIATION OF RETIRED PERSONS | Online report – 18 July 2011 – In 2009, about 42.1 million family caregivers in the U.S. provided care to an adult with limitations in daily activities at any given point in time, and about 61.6 million provided care at some time during the year. The estimated economic value of their unpaid contributions was approximately \$450 billion in 2009, up from an estimated \$375 billion in 2007. <a href="http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf">http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf</a>

### Hospice care debate has caregivers concerned

CONNECTICUT | Newtown Patch – 18 July 2011 – Controversial new regulations in hospice care are expected to come before the legislature this fall. Some officials believe the new regulations will expand the opportunities for hospice care in this part of the state, while others believe the change could water down the requirements in place now and potentially affect the quality of service patients and their families receive. <a href="http://newtown.patch.com/articles/hospice-care-debate-has-caregivers-concerned">http://newtown.patch.com/articles/hospice-care-debate-has-caregivers-concerned</a>

### Death and budgets

NEW YORK TIMES | Online OpEd – 14 July 2011 – I hope you had the chance to read ... Dudley Clendinen's ... 'The Good Short Life.¹ Clendinen is dying of amyotrophic lateral sclerosis... If he uses all the available medical technology, it will leave him, in a few years' time, "a conscious but motionless, mute, withered, incontinent mummy of my former self." Instead of choosing that long, dehumanizing, expensive course, Clendinen has decided to face death as one of life's "most absorbing thrills and challenges." He concludes: "When the music stops – when I can't tie my bow tie, tell a funny story, walk my dog, talk with Whitney, kiss someone special, or tap out lines like this – I'll know that Life is over. It's time to be gone." Clendinen's article is worth reading for the way he defines what life is. http://www.nytimes.com/2011/07/15/opinion/15brooks.html

1. 'The Good Short Life,' *New York Times* (Sunday Review), 9 July 2011. http://www.nytimes.com/2011/07/10/opinion/sunday/10als.html

# International

#### Treatment withdrawal case begins

U.K. | *Mirror* (London) – 19 July 2011 – A High Court judge being asked whether lifesustaining treatment should be withdrawn from a brain-damaged woman described as being in a "minimally conscious state" has started hearing evidence. The application for withdrawal of artificial nutrition and hydration has been made by relatives of the woman. Mr. Justice Baker, who is hearing the action at the Court of Protection in London, has previously described it as a "unique" case which raises "very important issues of principle." http://www.mirror.co.uk/news/latest/2011/07/19/treatment-withdrawal-case-begins-115875-23281844/

### **Specialist Publications**

Of particular interest:

'Negotiated dying: A grounded theory of how nurses shape withdrawal of treatment in hospital critical care units,' (p.8), published in the *International Journal of Nursing Studies*.



### 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: <a href="http://www.ipcrc.net/barry-r-ashpole.php">http://www.ipcrc.net/barry-r-ashpole.php</a>

#### Media plays role in palliative care awareness

AFRICA (NAMIBIA) | *New Era* (Windhoek) – 18 July 2011 – Media is strategically placed to advocate for and promote wider awareness of issues surrounding hospices and palliative care. Speaking at a meeting convened by the African Palliative Care Association and the Hospice & Palliative Care Association of Zimbabwe, clinical and technical advisor Eunice Garangana, urged authorities to seek media support in disseminating information and creating awareness among the public on issues that can improve the lives of people living with life-threatening illnesses. <a href="http://www.newera.com.na/article.php?articleid=39696&title=Media%20plays%20role%20in%20palliative%20care%20awareness">http://www.newera.com.na/article.php?articleid=39696&title=Media%20plays%20role%20in%20palliative%20care%20awareness</a>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

U.K. | The Independent (London) – 20 July 2011 – 'Man pleads with court for right to end his partner's life.' This is the first time a court has been asked to rule on whether a person not in a persistent vegetative state can have life support cut. <a href="http://www.independent.co.uk/life-style/health-and-families/health-news/man-pleads-with-court-for-right-to-end-his-partners-life-2317167.html">http://www.independent.co.uk/life-style/health-and-families/health-news/man-pleads-with-court-for-right-to-end-his-partners-life-2317167.html</a>

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

# Terminal lucidity: A review and a case collection

ARCHIVES OF GERONTOLOGY & GERIATRICS | Online article - 20 July 2011 The authors review a range of terminal lucidity cases... Several of these ... suggest that during terminal lucidity, memory and cognitive abilities may function by neurologic processes different from those of the normal brain. Significant contributions to better understanding the processes involved in memory and cognition processing might be gained through in-depth studies of terminal lucidity. Increased awareness of unusual end-of-life experiences could help physicians, caregivers, and bereaved family members be prepared for encountering such experiences, and help those individuals cope with them. Increased awareness of unusual end-of-life experiences could help physicians, caregivers, and bereaved family members be prepared for encountering such experiences, and help those individuals cope with them.

http://www.sciencedirect.com/science/article/pii/S0167494311001865

#### **Media Watch Online**

The weekly report can be accessed at several websites, among them:

#### Canada

Ontario | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network:

http://www.hnhbhpc.net/Resources/UsefulLinks/Media Watch/tabid/97/Default.aspx

Ontario | HPC Consultation Services:

http://www.hpcconnection.ca/newsletter/inthenews.html

Ontario | Mississauga Halton Palliative Care Network: http://www.mhpcn.ca/Physicians/resources.htm?media watch=1

#### U.S.A.

Prison Terminal:

http://www.prisonterminal.com/news%20media%20watch.html

#### International

Global | Palliative Care Network Community: http://www.pcn-e.com/community/pg/file/world/world/

International Palliative Care Resource Center: <a href="http://www.ipcrc.net/archive-global-palliative-care-news.php">http://www.ipcrc.net/archive-global-palliative-care-news.php</a>

U.K. | Omega, the National Association for End of Life Care: http://www.omega.uk.net/news.htm

### Overcoming the challenges of bedside teaching in the palliative care setting

BMJ SUPPORTIVE & PALLIATIVE CARE | Online article – 18 July 2011 – Students and patients both appear to benefit from the experience of bedside teaching. However, bedside teaching with medical students and palliative care patients presents a number of challenges for the patient, the learner and the educator. Key considerations for bedside teaching in the palliative care context include: sensitivity to 'protection,' of palliative care patients by colleagues in relation to their involvement in bedside teaching; consideration of the patient's carer/relative as they will often be present for prolonged periods at the bedside; a maximum of one or two students (not the 'up to six' traditionally used in this type of teaching); multiple short encounters with several patients as opposed to a longer encounter with one patient; and sensitivity to the potential impact of the session on the learner as undergraduate medical students and junior doctors may find that while worthwhile and rewarding, the teaching session is also personally emotionally challenging. http://spcare.bmj.com/content/early/2011/07/18/bmjspcare-2011-000035.abstract

#### Of related interest:

- CLINICAL SIMULATION IN NURSING | Online article July 2011 'High-fidelity and gaming simulations enhance nursing education in end-of-life care.' The authors describe how an end-of-life scenario using high-fidelity simulation and an experiential gaming simulation, Seasons of Loss®, were used to enhance the curriculum on end-of-life care presented to nursing students. http://www.sciencedirect.com/science/article/pii/S1876139910001519
- JOURNAL OF PALLIATIVE MEDICINE | Online article 18 July 2011 'Effects of a ninety-minute teaching module for fourth-year medical students on a palliative care ward with student-patient encounter.' This evaluation study of an obligatory course in palliative care indicates that even a short teaching module that includes a student-patient encounter has significant effects on the medical students' self-perceived knowledge, confidence and attitudes, and their interest in palliative care. <a href="http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0025">http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0025</a>

#### Italian law on advance directives offers no choice for patients

BRITISH MEDICAL JOURNAL | Online article – 19 July 2011 – Italy's lower house of parliament, the Chamber of Deputies, has passed a law on advance directives that explicitly excludes the option for people to refuse artificial hydration and nutrition, applies only to patients who have a neurological condition that is difficult to assess, and gives doctors the right to disregard patients' wishes. http://www.bmj.com/content/343/bmj.d4610.extract

### Surveys: Patient dissatisfaction is global

CMIO | Online report – 15 July 2011 – Twothirds of patients around the world are unhappy with their physicians, according to two recent global studies. Unclear communication is a prime reason for patients' dissatisfaction. Roughly 25% of patients globally complain that physicians don't answer questions, don't involve them in treatment decisions and use medical terms with no explanation. Forty-four percent of this trend appears to be a direct outcome of doctors not spending enough time with patients. The study was conducted an online and involving 22,600 adults in 23 countries. http://www.cmio.net/index.php?option=com articles&view=article&id=28676

# Have a problem with doctors? But what about doctors?

CANADA FREE PRESS | Online column – 16 July 2011 – Do doctors get better medical care? Today, patients frequently complain that doctors don't spend enough time with them ...[but,] doctors who are often specialists themselves don't always end up with adequate care from their colleagues.http://canadafreepress.com/index.php/articles-health/38542

# England's approach to improving end-of-life care: A strategy for honoring patients' choices

THE COMMONWEALTH FUND | Online article – 19 July 2011 – In the U.S. health care system ... the care of dying patients is generally not performed well, with pain and other distress frequently undertreated and patients' preferences not respected. England's evidence-based End of Life Care Strategy¹ could prove instructive. Both England and the U.S. struggle with similar challenges, including looking beyond the province of hospice and palliative-care specialists and initiating palliative services before the patient's final days. Aspects of the English approach that may be useful in the U.S. include strategies to help physicians recognize when patients are entering a trajectory that may end in death.

http://www.commonwealthfund.org/~/media/Files/Publications/Issue%20Brief/2011/Jul/1527\_Grave Englands approach endoflife care intl brief.pdf

1. National End-of-Life Programme: <a href="http://www.endoflifecareforadults.nhs.uk/">http://www.endoflifecareforadults.nhs.uk/</a>

## Of related interest:

NATIONAL END OF LIFE CARE INTELLIGENCE NETWORK | Online posting – 20 July 2011 –
'End of Life Care Quality Assessment (ELCQuA) tool.' This online self-assessment tool has been developed ... to help commissioners and providers of end of life care monitor the quality of services. Progress can be assessed against a set of core specifications based on the Department of Health's End of Life Care Strategy. <a href="http://www.endoflifecare-intelligence.org.uk/resources/tools/elcqua.aspx">http://www.endoflifecare-intelligence.org.uk/resources/tools/elcqua.aspx</a>

## Physicians' involvement with the New York State Health Care Proxy

EDUCATIONAL GERONTOLOGY, 2011;37(8):674-686. Physicians had positive attitudes toward the health care proxy and indicated that the most significant barriers to health care proxy completion were patient discomfort in discussing the topic, patient knowledge about the health care proxy, and timing of discussions. Physician involvement with the health care proxy included supporting patients' wishes on the health care proxy, initiating discussions with patients about the New York State health care proxy, and advocating for patients' rights about the health care proxy. http://www.tandfonline.com/doi/abs/10.1080/03601271003723388

#### From Media Watch dated 13 June 2011:

NEW YORK TIMES | Online OpEd – 6 June 2011 – 'Law on end-of-life care rankles doctors.' I shouldn't be surprised when doctors object to laws telling them how to practice medicine, as does New York State's new Palliative Care Information Act – not surprised, but in this instance, distressed. http://www.nytimes.com/2011/06/07/health/07brody.html? r=1

## From Media Watch dated 7 March 2011:

ELDER LAW ATTORNEY, 2011;21(1):32-39. 'Hospice and palliative care in New York: Changing landscape for patients, families and providers in health decision making.' In New York State, the integrated approach that has already begun to the implementation of the FHCDA [Family Health Care Decisions Act], the PCIA [Palliative Care Information Act] and the MOLST [Medical Orders for Life-Sustaining Treatment] program aligning patient goals with policy goals, systems objectives and professional training will facilitate adjustments to these changes at all levels. <a href="http://www.redlig.com/Dec10-nysba.pdf#page=32">http://www.redlig.com/Dec10-nysba.pdf#page=32</a>

#### Of related interest:

HUFFINGTON POST | Online article – 21 July 2011 – 'Palliative Care Information Act at the bedside: Achieving truly informed consent.' The Palliative Care information Act (PCIA) says when a disease has advanced to the terminal phase and a patient is unlikely to survive six months, doctors must offer to inform them of this, and advise them of available treatments aiming to bring comfort, not vanquish disease. <a href="http://www.huffingtonpost.com/barbara-coombs-lee/palliative-care-informati">http://www.huffingtonpost.com/barbara-coombs-lee/palliative-care-informati</a> b 906237.html

# Negotiated dying: A grounded theory of how nurses shape withdrawal of treatment in hospital critical care units

INTERNATIONAL JOURNAL OF NURSING STUDIES | Online article – 19 July 2011 – The process of withdrawal of treatment in critical care environments has created ethical and moral dilemmas in relation to end of life care in the U.K. and elsewhere. Common within this discourse is the differing demands made on health professionals as they strive to provide care for the dying patient and family members. Despite reports that withdrawal of treatment is a source of tension between those nurses and doctors involved in the process, the role of the nurse in facilitating withdrawal of treatment has received relatively little attention. Differing views as to when withdrawal of treatment should commence and how it should be operationalised appeared to be underpinned by the requirements of the role that health professionals fulfil, with doctors focusing on making withdrawal of treatment decisions, and nurse's being tasked with operationalising the processes that constitute it. http://www.sciencedirect.com/science/article/pii/S0020748911002586

# Promoting excellence in end-of-life care: Lessons learned from a cohort of nursing home residents with advanced Huntington Disease

JOURNAL OF NEUROSCIENCE NURSING, 2011;43(4):186-192. Huntington disease (HD) is a genetic neurodegenerative disorder that progresses over decades and is ultimately terminal. As HD advances, patients are frequently placed in institutional care settings, including nursing homes and hospices where family, nursing staff, and interdisciplinary team members are challenged to help patients live to their highest potential and die with dignity. Over the past 8 years, the authors have cared for 53 patients and describe their experiences by presenting their demographic characteristics and the lessons they have learned in caring for them. <a href="http://journals.lww.com/jnnonline/Abstract/2011/08000/Promoting Excellence in End of Life Care Lessons.2.aspx">http://journals.lww.com/jnnonline/Abstract/2011/08000/Promoting Excellence in End of Life Care Lessons.2.aspx</a>

#### **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**

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

#### **Links to Sources**

- 1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
- 2. Links often remain active, however, for only a limited period of time.
- 3. Access to a complete article, in some cases, may require a subscription or one-time charge.
- **4.** If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
- **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.

## The palliative care model for emergency department patients with advanced illness

JOURNAL OF PALLIATIVE MEDICINE | Online article – 18 July 2011 – Palliative care services provide relief of burdensome symptoms, attention to spiritual and social concerns, goal setting, and patient–provider communication that are often not addressed in the acute care setting. While emergency providers could provide some of these services, there is a knowledge gap regarding palliative care in the emergency department setting. Emergency department-based palliative care programs are currently consultations for symptoms and/or goals of care, and have been initiated both by both the palliative care team and palliative care champions in the emergency department. Some programs have focused on the provision of hospice services through partnerships with hospice providers, which can potentially help emergency department providers with disposition. Although some data on pilot programs are available, optimal models of delivery of emergency department-based palliative care have not been rigorously studied. http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0011

From Media Watch dated 20 June 2011:

ACADEMIC EMERGENCY MEDICINE, 2011;18(6):e70-e76. 'Research priorities for palliative and end-of-life care in the emergency setting.' In a workgroup session at the 2009 Agency for Healthcare Research & Quality/American College of Emergency Physicians conference ... four key research questions arose: 1) which patients are in greatest need of palliative care services in the ED [emergency department], 2) what is the optimal role of emergency clinicians in caring for patients along a chronic trajectory of illness, 3) how does the integration and initiation of palliative care training and services in the ED setting affect health care utilization, and 4) what are the educational priorities for emergency clinical providers in the domain of palliative care? These four key questions may be answered by strengthening the evidence using six categories of inquiry: descriptive, attitudinal, screening, outcomes, resource allocation, and education of clinicians. http://onlinelibrary.wiley.com/doi/10.1111/j.1553-2712.2011.01088.x/abstract

# Bad news and first impressions: Patient and family caregiver accounts of learning the cancer diagnosis

SOCIAL SCIENCE & MEDICINE | Online article – 23 July 2011 – Studies in medical journals regarding the delivery of a cancer diagnosis typically focus on a single clinic episode where the definitive news is disclosed to the patient by the physician. Far less research characterizes the diagnosis in the way patients and their family members often describe it. This article analyzes lay accounts of learning a cancer diagnosis... The participants ... were asked to describe "the day" they learned the diagnosis. Narrative analysis revealed that in almost every case, detailed descriptions of preliminary events – such as the pace and sequence of testing; smooth or disorganized transitions between care providers; and the timeliness or delays in diagnosis – were used to contextualize the actual episode of hearing the diagnosis and reacting to the news. http://www.sciencedirect.com/science/article/pii/S0277953611004060

## European Association for Palliative Care website in Russian language

WORLD WIDE PALLIATIVE CARE ALLIANCE | Online posting – Accessed 20 July 2011 – The 'EAPC speaks Russian' website aims to bridge the information gap, caused by language barriers, by setting up and disseminating information on palliative care in the Russian language. The website will present information on core issues of palliative care useful for doctors, nurses, psychologists, allied specialists, patients and their relatives. The project was funded by the Open Society Foundation. <a href="http://www.eapcspeaksrussian.eu">http://www.eapcspeaksrussian.eu</a>.

### Assisted (or facilitated) death

Representative sample of recent articles, etc:

- PALLIATIVE MEDICINE | Online article 20 July 2011 'The first five years of euthanasia legislation in Belgium and The Netherlands: Description and comparison of cases.' In The Netherlands 10,319 cases were reported, in Belgium 1917. Gender and age distributions were similar in both countries. Most patients suffered from cancer (83-87%), but patients more often suffered from diseases of the nervous system in Belgium (8.3% vs. 3.9%). In The Netherlands, reported euthanasia more often occurred at home compared with Belgium (81% vs. 42%), where it occurred more often in hospital (52% vs. 9%). In The Netherlands, all cases were based on the oral request of a competent patient. In Belgium, 2.1% of the reported cases was based on an advance directive. The authors conclude that countries debating legislation must realise that the rules and procedures for euthanasia they would agree upon and the way they are codified or not into law may influence the practice that develops once the legislation is effected or what part of that practice is reported. http://pmj.sagepub.com/content/early/2011/07/15/0269216311413836.abstract
- JOURNAL OF LAW & MEDICINE, 2011;18(4):798-810. 'Fifty years on: Against the stigmatising myths, taboos and traditions embedded within the Suicide Act 1961 (U.K.)' Although assisted suicide carries a maximum of 14 years imprisonment in England, courts and juries have historically demonstrated a reluctance to convict, most specifically in relation to those travelling abroad to accompany a terminally ill person seeking assisted dying. The possibility of prosecution is still present, however, and there have recently been a number of challenges to the law on assisted dying. <a href="http://sites.thomsonreuters.com.au/journals/category/journal-of-law-and-medicine/">http://sites.thomsonreuters.com.au/journals/category/journal-of-law-and-medicine/</a>

# Worth Repeating

#### Going to meet death: The art of dying in the first part of the twenty-first century

HASTINGS CENTER REPORT, 2009;39(4):37-45. I have talked with many different groups about the end of life – health professionals, church and civic groups, ministers and chaplains, adult continuing education groups, American Association for Retired Persons chapters, and college students. I talk a little about the traditional fear that death will come too soon. Then I ask, "How many of you are afraid that death will come too late for you?" The result is always the same: about half the audience members raise their hands. Obviously, this fear is widespread and close to the surface. Subsequent discussion reveals that for many of them, too late is not restricted to conditions of chronic or terminal illness, but also can include situations where they are lucid and free of significant pain or illness, yet nevertheless believe they have reached a good time to die. This article is an attempt to give voice to their conviction that death may often be worth pursuing. http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=3728

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