# Media Watch...

is intended as an advocacy and research tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in hospice and palliative care, and in the quality of end-oflife care in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

Experiencing loss and separation: Scroll down to <u>Specialist Publications</u> and 'Summer's end and sad goodbyes: Children's picturebooks about death and dying' (p.8), in *Children's Literature in Education.* 

# <u>Canada</u>

# Assisted (or facilitated) death

Representative sample of recent news media coverage:

BRITISH COLUMBIA | *The Vancouver Sun* – 8 February 2013 – 'Only 20% doctors would perform euthanasia if legal, poll of MDs finds.' Only one in five doctors in Canada would be willing to perform euthanasia if physician-assisted dying were legalized in this country, a survey by the nation's largest doctors' group shows. The Canadian Medical Association poll, completed by more than 2,000 doctors, found that only 20% of MDs surveyed said they would be willing to perform euthanasia, while twice as many ... would refuse to do so. Twenty-three per cent of doctors surveyed said they were not sure how they would respond to a request for euthanasia; 15% didn't answer.http://www.vancouversun.com/health/Only+cent+doctors+would+perform+euthanasia+legal+p oll+finds/7939308/story.html

# <u>U.S.A.</u>

# Advance health care directives

# West Virginia Center End-of-Life Care gets record requests for help

WEST VIRGINIA | *The Herald-Dispatch* (Huntington) – 8 February 2013 – Nearly 89,000 people requested forms for advance health care directives last year, setting a record for the West Virginia Center for End-of-Life Care. The center at West Virginia University was launched in 2002 to help people with medical powers of attorney, living wills, and medical orders such as do-not-resuscitate cards. It also offers POST forms, short for Physician Orders for Scope of Treatment. A total of 88,704 advance directives and medical orders were requested last year. More than half were POST forms converting a patient's wishes into medical orders. That ensures doctors do only what their patients want. <a href="http://www.herald-dispatch.com/news/briefs/x2130796034/WVU-End-of-Life-Care-gets-record-requests-for-help">http://www.herald-dispatch.com/news/briefs/x2130796034/WVU-End-of-Life-Care-gets-record-requests-for-help</a>

# Louisiana's hospice reprieve temporary

LOUISIANA | United Press International (UPI) – 7 February 2013 – The last-minute reprieve of Louisiana's hospice care for the state's poor who are dying will only last a few months, a state senator said. State Senator Fred Mills Jr., a Republican, told UPI the restored funding of \$1.1 million to provide end-of-life care for those in a hospice facility or provided hospice care in the home, allowed the state five months to work for alternative solutions because the same budget cut is scheduled for the next fiscal year. <a href="http://www.upi.com/Health\_News/2013/02/07/Louisianas-hospice-reprieve-temporary/UPI-25221360287702/">http://www.upi.com/Health\_News/2013/02/07/Louisianas-hospice-reprieve-temporary/UPI-25221360287702/</a>

Noted in Media Watch, 28 January 2013:

 LOUISIANA | The Advertiser – 22 January 2013 – 'Louisiana will continue Medicaid hospice...' <u>http://www.theadvertiser.com/viewart/20130123/NEWS01/130123042/Louisiana-willcontinue-Medicaid-hospice-program</u>

#### Site of death, place of care, and health care transitions

# End-of-life care often still hectic, aggressive

REUTERS | Online – 6 February 2013 – Fewer elderly Americans are dying in acute care hospitals than were a decade ago, according to a new study of where Medicare beneficiaries spend their final months of life.<sup>1</sup> However, between 2000 and 2009 there was also an increase in the proportion of people admitted to the intensive care unit in the month before they died - suggesting there hasn't been a general trend toward less aggressive end-of-life care. Researchers led by Dr. Joan Teno at Warren Alpert Medical School of Brown University in Providence. Rhode Island, reviewed Medicare claims data for more than 800.000 seniors who died in 2000, 2005 or 2009. During that span, the proportion of people who died in the hospital fell from about 33% to 25%. Use of hospice ... rose from 22% to 42% at the time of death. That finding is in line with research from the Centers for Disease Control

& Prevention, which showed an increase in the number of elderly people dying at home between 1989 and 2007. But Teno's team also saw a bump in the number of transitions between healthcare settings made in the last three months or three days of life. And the proportion of seniors with an ICU visit during their final month rose from 24% to 29%. http://www.reuters.com/article/2013/02/05/us -end-of-life-idUSBRE91418020130205

# Specialist Publications

Of related interest:

'The importance of following the money in the development and sustainability of palliative care' (p.11), in *Palliative Medicine*.

 'Change in end-of-Life care for Medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009,' *Journal of the American Medical Association*, 2013; 309(5):470-477. <u>http://jama.jamanetwork.com/article.aspx?articleid=1568250</u>

# San Diego Hospice files for bankruptcy [protection]

CALIFORNIA | *U-T San Diego* – 4 February 2013 – With its patient census shrinking after news of a Medicare audit, San Diego Hospice [SDH] filed for bankruptcy protection. Kathleen Pacurar, chief executive of San Diego Hospice, said the bankruptcy is necessary for the non-profit to reorganize. She said it should not affect the hospice's ability to care for its current and future patients. SDH's financial problems began in mid-November, when it revealed it faced the possibility of refunding millions to Medicare because its admissions policies did not follow government guidelines closely enough. <a href="http://www.utsandiego.com/news/2013/feb/04/hospice-files-for-bankruptcy/">http://www.utsandiego.com/news/2013/feb/04/hospice-files-for-bankruptcy</a>

Noted in Media Watch, 21 January 2013:

 CALIFORNIA | Kaiser Health News – 16 January 2013 – 'Slowly dying patients, an audit and a hospice's undoing.' <u>http://www.kaiserhealthnews.org/Stories/2013/January/16/sandiego-hospice.aspx</u>

Of related interest:

THE FISCAL TIMES | Online – 8 February 2013 – 'Hospice bankruptcy: Is this an alarming new trend?' Hospices nationwide are under intense scrutiny from Medicare, and facing lower growth in their reimbursement levels. "There's a bit of a squeeze going on. Hospices have to do more with less, and you can see how that could take its toll over time," said Theresa M. Forster, vice president for hospice policy and programs at the National Association for Home Care & Hospice, a trade group. <u>http://www.thefiscaltimes.com/Articles/2013/02/08/Hospice-Bankruptcy-Is-This-An-Alarming-New-Trend.aspx#page1</u>

# <u>Commentary</u>

# Letting a loved one go - pet or person

MINNESOTA | *Star Tribune* (Minneapolis) – 4 February 2013 – When asked whether it was time to put Byron "to sleep," our vet said he used the 50% rule: Were at least half of Byron's days good days? Or was it two bad days for every good? When you get to the latter, he explained, it's time. Which brings me to my second reason for pause. When not serving as faithful servant to our tiny dog, I am a geriatrician. I care for the frailest and sickest of older adults. To many people's surprise, most of my patients are as satisfied with their lives as they were when they were less debilitated. But this isn't true for everyone, and some are eager to say they've had enough. http://www.startribune.com/opinion/commentaries/189740661.html?refer=y

Noted in Media Watch, 16 April 2012:

THE NEW YORK TIMES | OpEd – 9 April 2012 – 'An ethical quandary, no matter the species.' <u>http://www.nytimes.com/roomfordebate/2012/04/09/the-ethics-of-spending-25000-on-pet-health-care/an-ethical-quandary-no-matter-the-species</u>

#### <u>Home, elder care</u>

# Hospitals try house calls to cut costs, admissions

THE WALL STREET JOURNAL | Online – 4 February 2013 – To keep patients out of the hospital, health-care providers are bringing back revamped versions of a time-honored practice: the house call. In addition to a growing number of doctors treating frail patients at home, insurers and health systems are sending teams of doctors, nurses, physician assistants and pharmacists into homes to monitor patients, administer treatments, ensure medications are being taken properly and assess risks for everything from falling in the shower to family care-giver burnout. Some are adopting programs called "Hospital at Home" to provide hospital-level care in the home, including portable lab tests, ultrasounds, X-rays and electrocardiograms. The aim is to avoid new financial penalties from the Centers for Medicare & Medicaid Services. Last October, the federal government agency started withholding certain payments to hospitals with higher-than-predicted readmission rates for patients with heart attacks, congestive heart failure and pneumonia. Nearly a fifth of its beneficiaries end up back in the hospital within 30 days ... costing \$26 billion annually. http://online.wsj.com/article/SB10001424127887324610504578278102547802848.html

Noted in Media Watch, 2 July 2012:

 MASSACHUSETTS | The Boston Globe – 1 July 2012 – 'Can house calls cut health costs?' http://bostonglobe.com/lifestyle/health-wellness/2012/07/01/can-house-calls-cut-health-carecosts-house-calls-boston-medical-center-program-testing-home-care-for-homeboundseniors/s6jidObrL7oC43lkTDK8dL/story.html

# Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE WALL STREET JOURNAL | Online 8 February 2013 'Assisted suicide on legal agenda in several states.' Bills legalizing assisted suicide are being considered in Connecticut, Vermont, New Jersey, Kansas and Hawaii and in Massachusetts ... according to the National Conference of State Legislatures, which tracks legislative trends. There are also bills related to the issue under consideration in New Hampshire, New York, Arizona and Montana. http://online.wsj.com/article/APea98f5b721344c7c8d6a10c7c2af6973.html
- NEW JERSEY | The Star-Ledger (Newark) 7 February 2013 'Assembly panel approves 'Death with Dignity Act." A bill giving terminally ill patients the legal authority to obtain a prescription that would allow them to end their lives cleared the Assembly Health Committee, over the objection of critics who pleaded with the panel to spend more time to consider the measure's moral and legal implications. The "New Jersey Death with Dignity Act" would allow adults diagnosed with a terminal disease and deemed to have only six months to live to voluntarily obtain medication "that the patient may administer" to kill themselves. The diagnosis must be made by the patient's treating doctor and affirmed by a consulting physician. Before the prescription is filled, patients must complete a form stating they are making this choice of their own free will. The form must be signed by two witnesses attesting the patient is capable of making the decision. http://www.nj.com/news/index.ssf/2013/02/post\_301.html

# **International**

#### End-of-life care in India

# Palliative care in all wards in Thiruvananthapuram by March

INDIA (KERALA) | *The Hindu Times* – 9 February 2013 – The city Corporation's free palliative care scheme christened 'Santhwanam' will soon be launched in the 20 wards under the Vattiyur-kavu Primary Health Centre. The official launch of the programme, which has already been implemented in 80 wards since October 2012, has been scheduled for February 18. Targeting those who belong to financially weaker sections of society, the Santhwanam staff will first carry out an exhaustive survey of the bedridden, listing those in dire need of help and the specific kind of medical treatment they require. A meeting follows which will prepare a timetable, to determine the frequency with which certain patients require treatment, be it twice a week or once in two months. <a href="http://www.thehindu.com/news/cities/Thiruvananthapuram/palliative-care-in-all-wards-in-thiruvananthapuram-by-march/article4396479.ece">http://www.thehindu.com/news/cities/Thiruvananthapuram/palliative-care-in-all-wards-in-thiruvananthapuram-by-march/article4396479.ece</a>

Noted in Media Watch, 8 October 2012:

 INDIA (KERALA) | *Times of India* – 2 October 2012 – 'Now, palliative care at your doorstep.' <u>http://timesofindia.indiatimes.com/city/thiruvananthapuram/Now-palliative-care-at-your-doorstep/articleshow/16634551.cms</u>

Noted in media Watch, 26 March 2013:

 INDIA (KERALA) | IBN Live – 21 March 2012 – 'Palliative care project inaugurated.' physically and mentally to attend to their needs. The project is being implemented in five hospitals. <a href="http://ibnlive.in.com/news/palliative-care-project-inaugurated/241321-60-123.html">http://ibnlive.in.com/news/palliative-care-project-inaugurated/241321-60-123.html</a>

# 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. <u>http://www.pcn-e.com/community/pg/file/owner/MediaWatch</u>

#### Elder, home care

# Cash 'n Gran

U.K. (ENGLAND & WALES) | *The Sun* – 9 February 2013 – Ministers will unveil plans to give cash aid to anyone with assets of less than £123,000 – five times the current threshold. The move is aimed at ending the heartache of elderly people forced to sell their homes to meet the cost. Under present rules, anyone with more than £23,250 in the bank or property has to pay for residential care. At least 100,000 more pensioners will get support under the new system. Better-off people will have to pay the first £75,000 towards care before taxpayers meet the costs. That figure is double the social care cap recommended by Andrew Dilnot in his report on tackling the looming care crisis.<sup>1</sup> <u>http://www.thesun.co.uk/sol/homepage/news/politics/4787762/OAPs-neednt-sell-homes-to-afford-care-as-the-benefit-limit-soars-to-123000.html</u>

 Fairer Care Funding, Commission on Funding of Care & Support, July 2011. [Noted in Media Watch, 11 July 2011] <u>https://www.wp.dh.gov.uk/carecommission/files/2011/07/Fairer-Care-Funding-Report.pdf</u>

#### Loss of compassion and caring

# Francis report shows National Health Service is not the national treasure we thought it was

U.K. (ENGLAND & WALES) | The Guardian – 6 February 2013 – Robert Francis QC's long-awaited report has been published,<sup>1</sup> passing excoriating criticism of almost all of the main institutions that make up the management, organisation and regulation of the NHS [National Health Service], and how their collective failure prolonged the suffering of hundreds of patients attending Mid Staffordshire NHS foundation trust and their families. For those in the upper echelons of the NHS, the temptation may be to defend the service's record, point out how the diagnosis is wrong in some way and explain that all pertinent lessons have been learnt and improvements already made. This would, however, represent a profound failure to understand the core message ... namely that within parts of the NHS, dignity, care and compassion are routinely absent from the care of patients. It is arguably that fundamental security of provision that has given the NHS its iconic status, but pride in the national health care system may have bred

a complacency that goes to the core of how services are provided, managed and regulated.<u>http://www.guardian.co.uk/healthcare-</u> network/2013/feb/06/francis-report-nhsnational-treasure

# Extract from The Guardian article

This ... report sets out an even more disturbing analysis, namely that the wider NHS appears to have lost its moral compass, with the basic humanity of care sometimes playing second fiddle to central political targets, financial performance, and organisational reputation.

# Worth Repeating

**"'Tu souffres, cela suffit": The compassionate hospital'** (p.14), in *Journal of Palliative Medicine.* 

1. 'Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry,' February 2013. http://www.midstaffspublicinquiry.com/report

Of related interest:

 U.K. (ENGLAND & WALES) | The Daily Telegraph – 6 February 2013 – '3,000 more patients have died needlessly in hospital.' More than 3,000 people may have died unnecessarily at five NHS trusts in a crisis that could dwarf the horrors at Mid Staffordshire, which were detailed in a devastating report. <u>http://www.telegraph.co.uk/health/healthnews/9854030/3000-morepatients-have-died-needlessly-in-hospital.html</u>

#### End-of-life care in the prison environment

#### Prisons ombudsman: Dying inmates 'inappropriately' handcuffed or chained

U.K. (ENGLAND & WALES) | The Guardian – 5 February 2013 – More than 50 dying prisoners have been wrongly chained or handcuffed during their final days in hospital in the past five years, the prisons ombudsman has revealed. In one case a terminal cancer patient died in hospital while he was handcuffed to a prison officer and in another a prisoner remained chained while he was in a medically induced coma for four days. Nigel Newcomen, the prisons and probation ombudsman, said restraints such as escort chains and handcuffs were used on the majority of dying prisoners who were admitted to a hospital or hospice in the last months of their lives since 2007. "The majority had been restrained while in hospital and it was identified in 51 investigations that the level of restraints used had been inappropriate," he said, citing examples when frail, immobile and even unconscious prisoners had remained restrained. The ombudsman added that reports on 23 of the 51 cases in which restraints had been used "inappropriately" were published January and October 2012. http://www.guardian.co.uk/society/2013/feb/ 05/prisons-ombudsman-dying-inmatesrestrained

# **Specialist Publications**

Of related interest:

**'Limited options for redress'** (p.7), in *Canadian Medical Association Journal.* 

'The Prague Charter: Urging governments to relieve suffering and ensure the right to palliative care' (p.10), in *Palliative Medicine*.

**N.B.** Articles and reports focused on the provision and delivery of end of life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at the foot of p.14.

# Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (SCOTLAND) | *The Scotsman* (Edinburgh) 9 February 2013 'Assisted suicide debated ahead of bill revamp.' Ministers are debating the implications of assisted suicide in light of revamped proposals to legalise the practice. <u>http://www.scotsman.com/news/politics/top-</u> stories/assisted-suicide-debated-ahead-of-bill-revamp-1-2783053
- FRANCE | Spero News 6 February 2013 'Report concludes that public is accepting euthanasia.' Nicole Delepine, of the paediatric oncology unit of Raymond university hospital, has published a report on "euthanasia, or the radical reduction of spending on health."<sup>1</sup> Denouncing what she says are too many cases of euthanasia in France, she explains the drift of the country towards euthanasia and why it should not be legalised because the motivation behind the project is more economic that compassionate. <a href="http://www.speroforum.com/a/FHLIDIETQC23/73609-France-Report-concludes-that-public-is-accepting-euthanasia">http://www.speroforum.com/a/FHLIDIETQC23/73609-France-Report-concludes-that-public-is-accepting-euthanasia</a>
  - 1. 'L'euthanasie, ou la réduction radicale des dépenses de santé,' *Economie matin*, 29 January 2013. <u>http://www.economiematin.fr/les-experts/item/3391-debat-euthanasie-economies-securite-sociale</u>
- AUSTRALIA (TASMANIA) | ABC News 5 February 2013 'Euthanasia debate continues in Tasmania – a personal perspective.' The state government is again giving Tasmanians an opportunity to have their say on assisted dying. Premier Lara Giddings and Greens minister Nick McKIm have issued a consultation paper for people to have input on whether people suffering terminal illness can choose to die with dignity.<sup>1</sup> <u>http://blogs.abc.net.au/tasmania/2013/02/euthanasia-debate-</u> continues-in-tasmania-a-personal-perspective.html
  - 1. Consultation Paper on Voluntary Assisted Dying, Office of the Premier of Tasmania, February 2013. <u>http://www.premier.tas.gov.au/featured\_releases/voluntary\_assisted\_dying</u>

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

#### Liverpool Care Pathway

# End of life protocols: Helping to die well or helping to die?

BIOETHICS MATTERS, 2013;11(1):1-4. Should use of The Liverpool Care Pathway be banned? It would seem that used in the right hands, for the right people, with full transparency and consent that it is not wrong in itself. But when used to hasten death, or, shockingly, to meet some type of arbitrary target, it is completely abhorrent and clearly wrong. We must make that crucial distinction, and it is to be hoped that the results of the enquiry will insist that doctors do the right thing: protect vulnerable patients and help them to live out their last days in dignity. <a href="http://www.ccbi-utoronto.ca/wp-content/uploads/2012/03/Bioethics-Matters\_Vol11No1\_End-of-Life-Protocols\_MMcQueen.pdf">http://www.ccbi-Protocols\_MMcQueen.pdf</a>

# Is educating community nurses about end-of-life care a waste of resources?

BRITISH JOURNAL OF COMMUNITY NURSING, 2013;18(2):77. The health system – and palliative care in particular – are facing difficult financial times due to spending cuts. It seems that when times are this hard one of the first things to go is staff education, which is disturbing considering that it takes years to train community palliative care nurses to function at specialist level. http://www.bjcn.co.uk/cgi-bin/go.pl/library/article.html?uid=96598;article=BJCN 18 2 77

#### End-of-life care in the prison environment

# Limited options for redress

*CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online – 7 February 2013 – When Douglas Fraser's back pain became acute in April 2011, he asked to see a doctor at the Bath Institution, a medium-security federal prison in southern Ontario where he'd been incarcerated for four years. But it was two months before the 58-year-old got his wish, and another four months of searing pain and weight loss, as well as constant demands from family and friends that prison officials escalate his health services, before Fraser was finally taken to Kingston General Hospital for assessment. He was soon diagnosed with pancreatic cancer. In the remaining three months of his life, Fraser contended the delay in providing him access to external care, constituted a death warrant. Fraser's mother, Muriel, a softspoken native of Tillsonburg, Ontario, is convinced the Correctional Service of Canada (CSC) issued just such a decree. "My son was clearly denied his right to health care equal to what non-prisoners expect." Dr. Ivan Stewart, the palliative care physician who treated Fraser in the final months of his life, doesn't go quite that far. But Stewart does believe CSC failed to provide equitable health care by providing Fraser inadequate palliative care in the Kingston Penitentiary, which is "a totally inadequate facility for a patient to be sent to die in." http://www.cmaj.ca/site/earlyreleases/7feb13 limited options for redress.xhtml

Cont on next page



# 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>

Of related interest:

 CANADIAN MEDICAL ASSOCIATION JOURNAL | Online – 5 February 2013 – 'Providing principled health care in prison.' Ethical considerations are often lost in the heated rhetoric that typically emerges in debates about the treatment of the incarcerated. But, having deprived prisoners of their freedom and the ability to access their own health care, society has an... http://www.cmaj.ca/site/earlyreleases/5feb13\_providing\_principled\_health\_care\_in\_prison.xht ml

# Summer's end and sad goodbyes: Children's picturebooks about death and dying

CHILDREN'S LITERATURE IN EDUCATION, 2013;44(1):1-14. This article explores children's picturebooks about death and grieving by considering both psychological and literary aspects. Two questions frame this analysis: How can picturebooks, particularly written for young children, support children's grief when someone dies? How do the illustrations and text of picture books express and convey the aesthetic and emotional experience of loss? Using both psychological research on children's grief reactions and literary analysis of picturebooks, this paper reviews picturebooks that have been published on the topic of death from 2001 to 2011 and then closely analyzes three books that span a range of topics and approaches to death. Findings indicate that children's picturebooks convey important psychological and cultural issues through text and illustrations. Furthermore, understanding some of the psychological and literary features of children's picturebooks that address death and grieving can help educators to provide support and understanding for children when they experience loss. <a href="http://link.springer.com/article/10.1007/s10583-012-9174-3">http://link.springer.com/article/10.1007/s10583-012-9174-3</a>

Noted in Media Watch, 12 November 2012:

 MEDICAL HUMANITIES | Online – 8 November 2012 – 'Good grief: Bereavement literature for young adults...' <u>http://mh.bmj.com/content/early/2012/11/07/medhum-2012-010260.abstract</u>

# 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.

#### Initiating difficult conversations

# The hardest words

*FAMILY MEDICINE*, 2013;45(2):130-131. In medical school it's easy to convince yourself that you won't fall into the seeming laziness of neglecting end-of-life issues. With a student's *naïveté*, I once assured myself that I would always address end of life in my outpatient pulmonary clinic, never considering the constant pressure to keep on schedule, the endless paperwork, and phone calls awaiting me following office hours. It never occurred to me that my pager would harass me with admissions from the hospital. In practice, I began to notice the words "end of life issues next visit" appearing on my notes. When the next visit would come, the discussion would inevitably get postponed. <a href="http://www.stfm.org/fmhub/fm2013/February/Lauren130.pdf">http://www.stfm.org/fmhub/fm2013/February/Lauren130.pdf</a>

# Default options in advance directives influence how patients set goals for end-of-life care

HEALTH AFFAIRS, 2013;32(2):408-417. Although decisions regarding end-of-life care are personal and important, they may be influenced by the ways in which options are presented. The authors randomly assigned 132 seriously ill patients to complete one of three types of advance directives. Two types had end-of-life care options already checked – a default choice – but one of these favored comfort-oriented care, and the other, life-extending care. The third type was a standard advance directive with no options checked. Most patients preferred comfort-oriented care, but the defaults influenced those choices: 77% of patients in the comfort-oriented group retained that choice, while 43% of those in the life-extending aroup rejected the default choice and selected comfort-oriented care instead. Among the standard advance directive group, 6% of patients selected comfort-oriented care. The findings suggest patients may not hold deep seated preferences regarding end-of-life care.http://content.healthaffairs.org/content/ 32/2/408.abstract?sid=3c954630-9d13-4c5f-8f34-7a69a357ea96

The discursive construction of the good death and the dying person: A discourse-theoretical analysis of Belgian newspaper articles on medical end-of-life decision making

JOURNAL OF LANGUAGE & POLITICS, 2012; 11(4):479-499. The concept of a good death is central to contemporary discourses on death and dying; it is also frequently used in contexts of end-of-life decision-making. The authors argue that in and through the medical-revivalist discourse, which challenges the idea that curative treatment is necessary beneficial and constructs death as something familiar, a good death is discursively organised around two nodal clusters: control, autonomy and dignity, and awareness and heroism. Moreover, they also argue that ... political contestation exists over the articulation of these nodal points. Especially two social movements, the right to die movement and the palliative care movement, have been at the forefront of the political struggle over the good death. http://benjamins.com/#catalog/journals/jlp.11.4.01 van/details

Of related interest:

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online 7 February 2013 'Factors associated with advance care planning discussions by area agency on aging care managers.'<u>http://ajh.sagepub.com/content/early/2013/02/07/1049909112475153.abstract</u>
- HEALTH AFFAIRS, 2013;32(2):203-206. 'Engaging patients and their loved ones in the ultimate conversation.' <u>http://content.healthaffairs.org/content/32/2/203?=right</u>
- JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online 4 February 2013 'Literacy and race as risk factors for low rates of advance directives in older adults.' <u>http://onlinelibrary.wiley.com/doi/10.1111/jgs.12134/abstract</u>

# The best interests of persistently vegetative patients: To die rather than to live?

JOURNAL OF MEDICAL ETHICS | Online – 6 February 2013 – Adults without the capacity to make their own medical decisions have their rights protected under the Mental Capacity Act (2005) in the U.K. The underlying principle of the court's decisions is the best interests test, and the evaluation of best interests is a welfare appraisal. Although the House of Lords in the well-known case of Bland held that the decision to withhold treatment for patients in a persistent vege-tative state should not be based on their best interests, judges in recent cases have still held that the best interests of persistently vegetative patients demand that the right to die with dignity prevails over society's interest to preserve life. The phrase "the right to dignity/to die with dignity" has been misused as a trump card to justify the speculation that a vegetative patient would necessarily refuse to live on machines. The authors argue that the use of the best interests test to authorise withdrawing/withholding treatment from persistently vegetative patients without an advance directive is problematic. They propose that the court could have reached the same decision by considering only the futility of treatment without working through the controversial best interests of the patient. <a href="http://jme.bmj.com/content/early/2013/02/05/medethics-2012-101117.abstract">http://jme.bmj.com/content/early/2013/02/05/medethics-2012-101117.abstract</a>

Noted in Media Watch, 21 May 2012:

 JOURNAL OF LAW & MEDICINE, 2012;19(3):430-435. 'Withdrawal of life-sustaining treatment from a patient in a minimally conscious state.' Since the seminal decision in 1993 in Airedale NHS Trust v Bland, in which the House of Lords authorised withdrawal of artificial nutrition and hydration from a patient in a persistent vegetative state, the diagnosis of a "minimally conscious state" has been recognised. <u>http://www.ncbi.nlm.nih.gov/pubmed/22558896</u>

# Deaths from cardiovascular diseases: Implications for end of life care in England

NATIONAL END-OF-LIFE CARE INTELLIGENCE NETWORK – 6 February 2013 – The number of cardiovascular disease deaths has fallen [in England] from 178,067 in 2004 to 130,192 in 2011. This report describes the patterns in mortality from cardiovascular diseases in England, highlighting variation in place and cause of death by age, sex, socio-economic deprivation and disease group. Cardiovascular diseases ...are the most common cause of death in England. Stroke is the most significant cause of disability. In 2011, 30% of all deaths were as a result of cardiovascular diseases. This report was commissioned to support the development of a new national strategy for tackling cardiovascular diseases. It will be of interest to commissioners and providers of end of life care focused on supporting and caring for patient with cardiovascular disease, as well as the patients themselves, their carers and families. <a href="http://www.endoflifecare-intelligence.org.uk/resources/publications/deaths">http://www.endoflifecare-intelligence.org.uk/resources/publications/deaths from cardiovascular diseases.aspx</a>

# The Prague Charter: Urging governments to relieve suffering and ensure the right to palliative care

PALLIATIVE MEDICINE, 2013;27(2):101-102. The European Association for Palliative Care (EAPC), International Association for Hospice & Palliative Care (IAHPC), World Palliative Care Alliance (WPCA) and Human Rights Watch have formulated 'The Prague Charter for Palliative Care as a Human Right.' The Charter urges the national governments of all developing and developed countries to implement health care and social policies that will ensure the relief of suffering through adequate access to patient-centered palliative care wherever it is needed, either in hospital, hospice, at home, or in any other place of care, in all regions of the world. The Charter is based on the 'Joint Declaration & Statement of Commitment on Palliative Care & Pain Treatment as Human Rights' (2009). <a href="http://pmj.sagepub.com/content/27/2/101.full">http://pmj.sagepub.com/content/27/2/101.full</a>

# N.B. The Prague Charter, EAPC: <u>http://www.eapcnet.eu/Themes/Policy/PragueCharter.aspx</u>

Noted in Media Watch, 4 February 2013:

- EDUCATIONAL GERONTOLOGY, 2013;39(4):241-249. 'Hospice palliative care as a human right in Canada.' http://www.tandfonline.com/doi/abs/ 10.1080/03601277.2013.750930
- JOURNAL OF PALLIATIVE MEDI-CINE | Online – 31 January 2013 – 'The Lisbon Challenge: Acknowledging palliative care as a human right.' <u>http://online.liebertpub.com/doi/abs/</u> 10.1089/jpm.2012.0394

N.B. The Lisbon Challenge, EAPC: http://www.eapcnet.eu/Themes/Policy/Li sbonchallenge.aspx

Noted in Media Watch, 26 September 2011:

 MCGILL JOURNAL OF LAW & HEALTH, 2011;5(1):106-160. 'Palliative care: An enforceable Canadian human right?' <u>http://mjlh.mcgill.ca/pdfs/vol5-</u> 1/MJLH%20Vol%20V.,%20No.%20 <u>1%20-%20Shariff.pdf</u> United Nations: Human Rights Council

Report of the *Special Rapporteur* on torture and other cruel, inhuman or degrading treatment or punishment, published February 2013

Recommendations include:

Ensure full access to palliative care and overcome current regulatory, educational and attitudinal obstacles that restrict availability to essential palliative care medications, especially oral morphine. States should devise and implement policies that promote widespread understanding about the therapeutic usefulness of controlled substances and their rational use;

Develop and integrate palliative care into the public health system by including it in all national health plans and policies, curricula and training programmes and developing the necessary standards, guidelines and clinical protocols.

Download report at: <u>http://www.ohchr.org/Documents/HRBodies/HRC</u> <u>oun-</u> <u>cil/RegularSession/Session22/A.HRC.22.53\_Engl</u> ish.pdf

#### **Editorial**

# The importance of following the money in the development and sustainability of palliative care

*PALLIATIVE MEDICINE*, 2013;27(2):103-104. Questions about cost-effectiveness and efficiency of health care are universal across developed economies, regardless of the underlying political economy of a given country or the financing of its health-care system. The articles from Klinger *et al*<sup>1</sup> regarding home-based palliative care in rural Ontario, and from Roberts and Hurst,<sup>2</sup> regarding inpatient palliative care unit staffing in England, are two cases in point. As our field continues to mature and develop, we can expect to see more of such studies taking place worldwide, because they shed much-needed light on management and sustainability issues in specialist palliative care. The study from Roberts and Hurst makes salient the point that sustainability in our field involves not only monetary inputs (resources, represented as costs) but also workforce availability. Availability is influenced by many factors across the world, including funding for specialist education and training, as well as issues of satisfaction, burnout, and turnover among specialist staff. Klinger *et al* go beyond a snapshot of current practices and attempt projections of what future, broader utilization could look like. <u>http://pmj.sagepub.com/content/27/2/103.full</u>

- 'Resource utilization and cost analyses of home-based palliative care service provision: The Niagara West End-of-Life Shared-Care Project,' pp.115-122. First published online 16 January 2012. [Noted in Media Watch, 23 January 2012] <u>http://pmj.sagepub.com/content/early/2012/01/16/0269216311433475.abstract</u>
- 'Evaluating palliative care ward staffing using bed occupancy, patient dependency, staff activity, service quality and cost data,' pp.123-130. <u>http://pmj.sagepub.com/content/27/2/123.abstract</u>

# The integration of a person-centered approach in palliative care

PALLIATIVE & SUPPORTIVE CARE | Online – 7 February 2013 – A study was conducted at a palliative care facility to document changes that occurred after the integration of a personcentered approach focusing on human freedom (which is linked to autonomy). It aimed to describe changes observed in the beliefs and practices of healthcare providers, the concept and respect of autonomy by healthcare providers, care and respect of autonomy experienced by patients' relatives, and consideration of patients' wishes through their documentation. While the analysis exposed some discrepancies with the language of the approach and differences between nurses and other healthcare providers, it revealed, above all, similarities in the changes observed between the different sources of data. The focus moved from being task-centered to being person-centered; the affirmation of the priority of respecting patients' choices, desires, and needs; a presence shifting from being available to true listening; the affirmation of following the ever-changing rhythm of the patient; and, a notion of respect of autonomy now including the other.<u>http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8832335&fulltex</u>tType=RA&fileId=S1478951512000855

#### Case study

# Last moments of life: Can telemedicine play a role?

PALLIATIVE & SUPPORTIVE CARE | Online – 7 February 2013 – During the telemedicine consultations (tele-consultation) process, Ms. C's condition deteriorated rapidly as she entered the dying phase of life. She died peacefully soon after, in the presence of the nurse, the pastoral care worker and the physician who was conducting the tele-consultation session 30 km away. The family was not present at the patient's bedside when she died. They were, however, relieved to know and were appreciative of the fact that a physician had been "present" during the patient's death.<u>http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8832347&fullte xtType=CR&fileId=S1478951512000995</u>

Noted in Media Watch, 16 July 2012:

 JOURNAL OF TELEMEDICINE & TELECARE | Online – 12 July 2012 – 'Use of home telehealth in palliative cancer care.' Family caregivers and tele-nurses felt that home tele-health enabled family caregiving, citing increased access to care, and patient and family caregiver reassurance. <u>http://jtt.rsmjournals.com/content/early/2012/07/10/jtt.2012.111201.abstract</u>

Noted in Media Watch, 2 January 2012:

 JOURNAL OF TELEMEDICINE & TELECARE | Online – 23 December 2011 – 'Organizational factors associated with the use of telehospice.' Most of the variables associated with the use of telehospice were related to characteristics of the agency director. If the director had at least a Masters degree or had a longer tenure as director of the agency, there was a higher likelihood that the agency used telehospice. If the director was a nurse ... telehospice use was ... lower. http://jtt.rsmjournals.com/content/early/2011/12/22/jtt.2011.110803.abstract

# Assisted (or facilitated) death

Representative sample of recent articles, etc:

INDIAN JOURNAL OF MEDICAL RESEARCH, 2012;136(6):899-902. 'Euthanasia: Right to life vs. right to die.' This debate cuts across complex and dynamic aspects such as, legal, ethical, human rights, health, religious, economic, spiritual, social and cultural aspects of the civilised society. Here we argue this complex issue from both the supporters and opponents' perspectives, and also attempts to present the plight of the sufferers and their caregivers. The objective is to discuss the subject of euthanasia from the medical and human rights perspective given the background of the recent Supreme Court judgement in this context. <a href="http://www.ijmr.org.in/article.asp?issn=0971-5916;year=2012;volume=136;issu=6;spage=899;epage=902;aulast=Math">http://www.ijmr.org.in/article.asp?issn=0971-5916;year=2012;volume=136;issu=6;spage=899;epage=902;aulast=Math</a>

Cont.

- INTERNATIONAL JOURNAL OF SOCIOLOGY & SOCIAL POLICY, 2012;33(3/4). 'The controversy over euthanasia in Uganda: A case of the Baganda.' Findings reveal that, almost all participants (97%) perceived euthanasia as murder. Religious and cultural convictions were major influential factors for this perception. Potential for new medical discovery, pain, guilt, physician distrust, economic need, physician role conflict, human versus divine knowledge, perception of euthanasia as license to kill, financial strain, compassion, hopelessness, and age are other themes that influenced attitudes towards euthanasia. Few studies exploring euthanasia attitudes in resource constrained nations like those of sub-Sahara Africa exist. Additionally, as the debate over euthanasia continues, especially as seen in developed nations, it is crucial to include resource constrained nations because such knowledge may help the international community's formulation of end of life policies. This study is important because it is based on current data collected in 2010. <a href="http://www.emeraldinsight.com/journals.htm?articleid=17077595&show=abstract">http://www.emeraldinsight.com/journals.htm?articleid=17077595&show=abstract</a>
- JOURNAL FOR THE STUDY OF RELIGIONS & IDEOLOGIES, 2013;12(34):19-36. 'Institutional aspects of the ethical debate on euthanasia. A communicational perspective.' Although euthanasia is seen as the problem of the individual will and as one's right to privacy, to a better quality of life or to a dignified death, it has major institutional implications. They are closely related to the juridical system, to the way of understanding state involvement in protecting the individuals and respecting their freedoms, to the institutional system of health care, to the government rules that establish social, political or professional practices. The public debate around the topics related to the human condition, like euthanasia, grants a special force to public communication, to organizational communication, to communication in professional environments, to physician-patient communication and, more generally, to interpersonal communication. The authors emphasize the importance of public debate on euthanasia... <a href="http://jsri.ro/ojs/index.php/jsri/article/view/667">http://jsri.ro/ojs/index.php/jsri/article/view/667</a>

# Media Watch Online

#### Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <u>http://centres.sq/</u> (Scroll down to 'Palliative Care Network: Media Watch")

#### Australia

AUSTRALASIAN PALLIATIVE INTERNATIONAL LINK: <u>http://www1.petermac.org/apli/links.htm</u> (Scroll down to 'Links,' then to 'Media Watch')

#### Canada

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <a href="http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx">http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx</a> (Click on 'Current Issue' under 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): http://www.hpcconnection.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/?g=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: <u>http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c</u>

#### International

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <u>http://www.ipcrc.net/archive-global-palliative-care-news.php</u>

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

# Worth Repeating

# "Tu souffres, cela suffit": The compassionate hospital

JOURNAL OF PALLIATIVE MEDICINE, 2012;15(4):457-462. The authors propose the characteristics of personal (individual) compassion may be extrapolated to the concept of corporate (organizational) compassion. Modern health care facilities attract staff members who are able to exercise varying degrees of compassion in their busy daily routines. However, little discussion has taken place on how health care organizations might best harness and integrate aspects of individual compassion to create an organization with compassion as a core value. The authors define ... a "compassionate hospital" as 1) the presence of a healing environment; 2) a sense of connection among people; and, 3) a sense of purpose and identity. They suggest how a "top down" focus on compassion as a core value by clinical leaders could maximize the compassion of health care workers, and reduce the suffering expressed and/or experienced by health care workers and patients in today's health care facilities. The ... concept is intended to act as a proposition for health policy researchers and decision-makers in health care so as to reduce the suffering of sick patients, and to restore a sense of well-being, meaning, and purpose among health care workers. http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0378?prevSearch=opera&searchHistoryKe v=

**N.B.** "Tu souffres, cela suffit" translates to "You are suffering – that is enough," the words of Louis Pasteur. Pasteur stated: "One does not ask a sick person from what country or of what religion are you. You are sick, that is enough. Put yourself in my care and I will treat you."

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