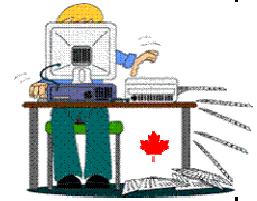


## Media Watch...

is intended as an advocacy, research and teaching 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-of-life 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

Care planning: Scroll down to [Specialist Publications](#) and ‘The remarkable staying power of “death panels”’ (p.16), in *Journal of Health Politics, Policy & Law*.

## Canada

### Why a health-care report was dead on arrival in Ottawa

*THE GLOBE & MAIL* | Online – 21 July 2015 – When the Harper government has something to brag about, we hear about it, endlessly. When the government has something to hide, the information comes out without ministerial comment on a Friday afternoon. So it was last week that the Prime Minister’s Office (PMO) buried a long, detailed report about federal innovation in health care that the government itself had commissioned.<sup>1</sup> The Advisory Panel on Healthcare Innovation [report] ... was to have been released at a news conference in Toronto 14 July. The day before the news conference, however, the PMO cancelled it and decided to release the report without notice on the Health Canada website... Just as the PMO hoped, the report received little attention. Health Minister Rona Ambrose, who was to have spoken about the report, was gagged. The posting on her department’s website was timed so that it appeared only after the [recent meeting of the] provincial premiers had finished their final news conference ... in case the report gave any or all of them ammunition to embarrass the federal government. <http://www.theglobeandmail.com/globe-debate/why-a-key-health-care-report-was-dead-on-arrival-in-ottawa/article25608277/>

#### Extract from the report of the Advisory Panel on Healthcare Innovation

End-of-life care exemplifies some of these challenges. The Supreme Court of Canada decision in *Carter v. Canada* has been widely interpreted as decriminalizing physician assistance in dying. In responding, governments will need to balance the needs of the patients with protection of the vulnerable. As seems to be the rule in Canada, there are also jurisdictional complexities. Regulation of medical services falls within the constitutional jurisdiction of provinces and territories. Absent federal revisions to the Criminal Code, some provinces and territories will move ahead with regulations while others take a “wait and see” approach – a situation that puts terminally ill Canadians on an uneven playing field.

**N.B.** End-of-life care is mentioned on p.54 and referenced in Figure 6.2 (p.63).

1. ‘Unleashing Innovation: Excellent Healthcare for Canada,’ Report of the Advisory Panel on Healthcare Innovation, 2015. <http://www.healthycanadians.gc.ca/publications/health-system-systeme-sante/report-healthcare-innovation-rapport-soins/alt/report-healthcare-innovation-rapport-soins-eng.pdf>

## Ajax-Pickering hospital to improve end-of-life care

ONTARIO | Durhamregion.com – 20 July 2015 – A new report has been released on how to improve the care and supports provided to people as they approach the end of their lives at the Ajax-Pickering Hospital.<sup>1</sup> Released by the Rouge Valley Health System's board of directors, the advice was gathered from community members, staff, physicians and hospital volunteers and is largely based on input gathered through nine focus groups led by the hospital's volunteer Community Advisory Group. It focused on how families have experienced end-of-life care in their communities and at the [regional] hospital... <http://www.durhamregion.com/news-story/5734936-ajax-pickering-hospital-to-improve-end-of-life-care/>

### Specialist Publications

**'Family physicians enhance end-of-life care: Evaluation of a new continuing medical education learning module in British Columbia'** (p.12), in *BMC Medical Education*.

1. 'Report on End-of-Life Care Patient/Family Experience,' Rouge Valley Health System, 2015. <http://www.rougevalley.ca/images/PDFs/publications/2015/RVHS-End-of-Life-Care-Report-JULY2015.pdf>

**N.B.** See '2014 Report of the Office of the Auditor General of Ontario' (Chapter 3: Ministry of Health & Long Term Care – Palliative Care, pp.258-288). [Noted in Media Watch, 15 December 2014, #388 (p.2)] [http://www.auditor.on.ca/en/reports\\_2014\\_en.htm](http://www.auditor.on.ca/en/reports_2014_en.htm)

## New pain treatments are a boon to palliative care patients

BRITISH COLUMBIA | *The Vancouver Sun* – 18 July 2015 – Using a guided X-ray or CT scan and one or two tiny incisions, Dr. Peter Munk ... can perform procedures that bring great pain relief. "You can stick a probe into a tumour that is gnawing away at a piece of bone and burn it or freeze it, or stick bone cement into it, particularly if the bone is crumbling. If you support the bone and destroy some of the tumour then their quality of life can suddenly improve," says Munk. What's not possible is to meet the needs of all the patients in the province who could benefit, leaving some to suffer in intractable pain or live out their final days in a drug-induced haze. The minimally invasive palliative procedures (MIPP) being developed and performed by Munk, head of bone and joint radiology at Vancouver General Hospital, are a relatively new treatment option for palliative care cancer patients. They are easy to perform and cost effective, reducing hospital bed stays and freeing up resources. But without dedicated funding, the physicians skilled enough to perform these procedures are squeezing patients in around other responsibilities... <http://www.vancouversun.com/health/Funding+shortfall+threatens+promising+procedure+cancer+patients+with+video/11223903/story.html>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE TORONTO STAR* | Online – 23 July 2015 – '**Peter MacKay says assisted-death panel won't determine government's response.**' Panellists tasked with consulting Canadians on the highly controversial issue of doctor-assisted death won't dictate the government's response to the Supreme Court's ruling on the matter, Justice Minister Peter MacKay says. The government has been accused of creating a biased panel since two of its three members are outspoken opponents of allowing Canadians to seek medical help to end their lives. But MacKay, who is not seeking re-election, said Wednesday it's important to remember who holds the decision-making power. "Ultimately, it is the executive branch of the country that will make these important decisions on legislation that I believe, and this is my view, are necessary to fill what is quite a gap now in our Criminal Code as a result of the Carter decision," MacKay said in Halifax. <http://www.thestar.com/news/canada/2015/07/23/peter-mackay-says-assisted-death-panel-wont-determine-governments-response.html>

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- *THE GLOBE & MAIL* | Online – 20 July 2015 – ‘**Canadians deserve stronger response on assisted death.**’ If it were being honest, the government of Prime Minister Stephen Harper would have simply said, “We don’t want to deal with legislation on assisted death until after the election,” or, better yet, taken a firm position and been willing to debate and defend it during the coming federal election campaign. Instead, it opted for cowardly dithering, appointing a panel “to consult with Canadians on options to respond to the Supreme Court of Canada’s decision” and giving the panel a late-fall deadline – conveniently after the 19 October vote – to report back on legislative options. Worse yet, the government stacked the panel with opponents of assisted death, showing contempt not only for the landmark ruling, but for the process of law-making more generally. On 6 February [2015], the Supreme Court struck down two sections of the Criminal Code, Sections 14 and 241(b), as unconstitutional, essentially removing the barriers to assisted death for competent adults. The court also gave the federal government 12 months to come up with new legislation – or not. The Conservative government did not like the decision. But that is no excuse for inaction. It should have got down to work the day after the ruling, not waited five months to appoint a committee of dubious value. Regardless of the ruling party’s views, Parliament has an obligation to draft legislation that is constitutional or to state clearly that there will be no law. <http://www.theglobeandmail.com/globe-debate/we-dont-need-an-outside-panel-to-assess-right-to-die-law/article25594885/>

## [U.S.A.](#)

### **The business of dying has never been more lucrative**

*THE HUFFINGTON POST* | Online – 24 July 2015 – For-profit hospices saw profit margins exceed 15% in 2012, according to a new report from the Medicare Payment Advisory Commission, which advises Congress on health policy.<sup>1</sup> No other Medicare-financed health service was as profitable. The new data is likely to give new ammunition to critics of the current payment system... [http://www.huffingtonpost.com/entry/hospice-report\\_55b1307ee4b0a9b94853fc7a](http://www.huffingtonpost.com/entry/hospice-report_55b1307ee4b0a9b94853fc7a)

1. ‘Health Care Spending and the Medicare Program,’ Medicare Payment Advisory Commission, June 2015. <http://medpac.gov/documents/data-book/june-2015-databook-health-care-spending-and-the-medicare-program.pdf?sfvrsn=0>

**N.B.** Selected articles on for-profit hospice noted in past issues of Media Watch are listed in the weekly report of 8 June 2015, #413 (pp.4-5).

### **South Asians in U.S. reluctant to report pain: Study**

INDO-ASIAN NEWS SERVICE | Online – 24 July 2015 – South Asians living in the U.S. are more reluctant than other ethnicities to report pain as well as seek medication to treat the pain they experience near the end of their lives, says a new study...<sup>1</sup> The study noted that this typical behaviour common among people from South Asia could be attributed to their culture. "In South Asian culture, it is common for patients not to report their pain to avoid burdening others or being seen as weak," said lead study author Nidhi Khosla, assistant professor at the University of Missouri... The researchers said this finding ... provides an opportunity for health care professionals to deliver better culturally responsive care to South Asian patients and their families. South Asians are a culturally similar group with origins in India, Pakistan, Bangladesh, Nepal, Sri Lanka, Bhutan and Maldives. In 2010, the U.S. Census reported 3.8 million South Asians were living in the U.S., an increase of more than 80% since 2000. <http://www.ndtv.com/diaspora/south-asians-in-us-reluctant-to-report-pain-study-1200161>

1. ‘Perspectives of health care providers on U.S. South Asians’ attitudes toward pain...,’ *American Journal of Hospice & Palliative Medicine*, 29 June 2015. [Noted in Media Watch, 6 July 2015, #416 (p.7)] <http://ajh.sagepub.com/content/early/2015/06/25/1049909115593063.abstract>

## Benefit of end-stage chemotherapy is questioned

*THE NEW YORK TIMES* | Online – 23 July 2015 – It is an excruciating question for cancer patients with a prognosis of only months to live. Should they try another round of chemotherapy? Guidelines for oncologists say no for very sick patients, those who are often bedridden and cannot handle most daily needs themselves. But for patients who are more self-sufficient, chemotherapy is considered a reasonable option. Despite its well-known toxic side effects, many end-stage patients and their doctors have considered chemotherapy worth trying, believing it may ease discomfort or buy time. Now, a [multi-national, longitudinal] study suggests that even those stronger patients may not benefit from end-of-life chemotherapy<sup>1</sup> – and that for many their quality of life may worsen in their final weeks compared with patients who forego last-ditch treatment. [http://www.nytimes.com/2015/07/24/health/chemotherapy-may-worsen-end-of-life-quality-study-finds.html?\\_r=0](http://www.nytimes.com/2015/07/24/health/chemotherapy-may-worsen-end-of-life-quality-study-finds.html?_r=0)

1. 'Chemotherapy use, performance status, and quality of life at the end of life,' *JAMA Oncology*, 23 July 2015. <http://oncology.jamanetwork.com/article.aspx?articleid=2398177>

Noted in Media Watch, 23 February 2015, #398 (p.10):

- *CANCER* | Online – 11 February 2015 – '**Patient beliefs that chemotherapy may be curative and care received at the end of life among patients with metastatic lung and colorectal cancer.**' A third of the patients [i.e., study participants] recognized chemotherapy was "not at all" likely to cure their cancer. Such patients were no less likely than other patients to receive end-of-life chemotherapy; they were more likely than other patients to enroll in hospice. <http://onlinelibrary.wiley.com/doi/10.1002/cncr.29250/abstract;jsessionid=E2816D4B492DD0AE0210D55FDC22D0E0.f04t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Noted in Media Watch, 10 March 2014, #348 (p.10):

- *BRITISH MEDICAL JOURNAL* | Online – 5 March 2014 – '**Chemotherapy near the end of life.**' Even as cancer treatments become more effective, we can still wonder about the symbolic meaning behind decisions to pursue chemotherapy near the end of life. Although most patients with metastatic cancer choose to receive palliative chemotherapy, evidence [from a 2012 study] suggests most do not clearly understand its intent. <http://www.bmj.com/content/348/bmj.g1529>
  1. 'Patients' expectations about effects of chemotherapy for advanced cancer,' *New England Journal of Medicine*, 2012;367(17):1616-1625. [Noted in Media Watch, 29 October 2012, #277 (p.2)] <http://www.nejm.org/doi/full/10.1056/NEJMoa1204410>

## Medicare to try a blend of hospice care and treatment

*THE NEW YORK TIMES* | Online – 22 July 2015 – Most older Americans close to death have to make a difficult choice: continue with traditional medical treatment or switch to hospice care, which focuses not on a cure but on easing their remaining days. Now, Medicare is testing a third alternative: both. The new pilot program, designed to affect the care of about 150,000 Medicare patients over the next four years, will allow patients with terminal diseases to receive hospice care to manage suffering and counseling to plan for the end of life – but still see doctors and get medical treatments, like chemotherapy or hospitalization, intended to fight their illnesses. The test program is based on research that shows that patients with access to both so-called palliative care and traditional medicine often end up with a better quality of life and less expensive, intense medical treatment. The approach may even offer the patients a longer life span than those treated with traditional medicine alone. That surprising result came from a type of study that is unusual in evaluating services for patients: a randomized controlled trial. Such trials, which randomly assign patients to get different sorts of care, are common for studying new drugs, but rare

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when it comes to health care policy. But they are becoming more popular, as The Upshot reported last year,<sup>1</sup> because randomized trials can provide definitive, and counterintuitive, results. The question of how to mix palliative care, intended to manage patients' symptoms, and curative care to fight disease has been studied in three randomized trials of cancer patients.<sup>2,3,4</sup> All showed benefits to the approach. [http://www.nytimes.com/2015/07/22/upshot/medicare-to-try-a-blend-of-hospice-care-and-treatment.html?\\_r=0&abt=0002&abg=1](http://www.nytimes.com/2015/07/22/upshot/medicare-to-try-a-blend-of-hospice-care-and-treatment.html?_r=0&abt=0002&abg=1)

1. 'How to arrive at the best health policies,' *The New York Times* (Upshot), 21 November 2014. <http://www.nytimes.com/2014/11/23/upshot/how-to-arrive-at-the-best-health-policies.html?abt=0002&abg=1>
2. 'Early palliative care for patients with advanced cancer: A cluster-randomised controlled trial,' *The Lancet*, 2014;383(9930):1721-1730. [Noted in Media Watch, 22 December 2014, #389 (p.15)] [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(13\)62416-2/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)62416-2/abstract)
3. 'Early palliative care for patients with metastatic non-small-cell lung cancer,' *New England Journal of Medicine*, 2010;363(8):733-742. [Noted in Media Watch, 23 August 2010, #163 (p.8)] <http://www.nejm.org/doi/pdf/10.1056/NEJMoa1000678>
4. 'Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer...' *Journal of the American Medical Association*, 2009;302(7):741-749. [Noted in Media Watch, 24 August 2009, #111 (p.6)] <http://jama.jamanetwork.com/article.aspx?articleid=184422>

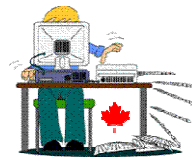
Of related interest:

- CALIFORNIA | *California Healthline* – 21 July 2015 – **“Visionary” pilot targets palliative care.** A Medi-Cal managed care pilot program ... in Humboldt County will try a team-based, telemedicine-enabled approach to palliative care for patients with serious illnesses. The nine-month pilot is due to be launched 1 September. <http://www.californiahealthline.org/capitol-desk/2015/7/visionary-pilot-targets-palliative-care>
- MASSACHUSETTS | *The Boston Globe* – 20 July 2015 – **‘Making the end of life part of health care.’** The news ... that Medicare plans to reimburse doctors for conversations with patients about medical treatment at the end of life represents an important step forward for public policy in health care. It also signals a welcome shift to a more open attitude toward a subject most people would rather avoid. In short, the agency is proposing to support open discussions with medical professionals about the way we want to die. Decisions by Medicare, which insures 55 million older Americans, often set the standard followed by private insurers as well. <https://www.bostonglobe.com/opinion/editorials/2015/07/19/making-end-life-part-health-care/1USjMcW8H2aFsh11BZWQ8K/story.html>
- NEW JERSEY | NJ Spotlight (Montclair) – 20 July 2015 – **‘Growth of hospice care transforming home-health agencies across New Jersey.’** Hospice care has grown so rapidly in recent years, climbing from 870,000 Medicare patients nationally in 2005 to 1.27 million in 2012, that it has reshaped the healthcare industry in New Jersey. One area where this change can be seen most dramatically is home care. Hospice ... was once delivered in a separate facility. <http://www.njspotlight.com/stories/15/07/19/ospice-transforming-home-health-agencies-across-new-jersey/>

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### [Barry R. Ashpole](#)

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a 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 college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>



## Don't get cancer if you're in prison

NEWSWEEK | Online – 22 July 2015 – There is little hard data on the quality of medical treatment behind bars, says Dr. Marc Stern, a correctional health care consultant and former health services director for the Washington State Department of Corrections. Nor is there much regulation of correctional facility health care. No one disputes that prison care saves lives and often treats people who might not otherwise be treated. Many who end up imprisoned are too poor to get adequate health care on the outside. The problems tend to stem from underlying financial issues: There is little public investment in correctional health care systems... <http://www.newsweek.com/2015/07/31/dont-get-cancer-if-youre-prison-356010.html>

### [Prison Hospice Backgrounder](#)

The provision – or lack – of quality end-of-life care in the prison system has been highlighted on a fairly regular basis in Media Watch. A compilation of the articles, reports, etc., noted in the weekly report is available on the Palliative Care Community Network website at: <http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons>



## Different stories in states' home care rankings

GEORGIA | *The Ledger-Enquirer* (Columbus) – 21 July 2015 – Home health service, when and where it's possible, is a preferred option for millions of Medicare beneficiaries, for reasons that should be self-evident. It's more convenient and certainly more comfortable for most people than being treated in a clinic, nursing home or hospital, not to mention saving patients the trouble and expense of getting there. And for the most part, the care is just as effective and of just as high quality as on-site services. But a new Medicare ranking system compiled by *Kaiser Health News* offers a decidedly mixed assessment of the state of home health care in this area.<sup>1</sup> That system ranks Georgia fourth-worst in the country in the percentage of home health agencies that earned superior (4- or 5-star) ratings. The evaluation is based on a combination of measures such as timely care; patient education about medications and drug interaction; reasonable improvement in patient mobility; pain management; patient hygiene, and hospital admission rates. Interestingly, neither the low- nor the high-ranking states in this evaluation were necessarily among the "usual suspects" in either category: The four states ranked worse than Georgia, which had just 12% of its home health agencies with superior ratings, were Oregon, at 9%, Wyoming (4), Washington (3) and Alaska, with a flat zero. By contrast, Alabama was among the states in which a third or more of its home health organizations received superior ratings, along with California, Florida, Maryland, New Jersey, Pennsylvania, Rhode Island, South Dakota and Utah. <http://www.ledger-enquirer.com/2015/07/21/3823561-different-stories-in-states-home.html?rh=1>

1. 'Home health agencies get Medicare's star treatment,' *Kaiser Health News*, 16 July 2015. <http://khn.org/news/home-health-agencies-get-medicares-star-treatment/>

### [Media Watch: Online](#)

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.19.

Johns Hopkins School of Medicine study

**Despite gains in advance directives, study finds more intensive end-of-life cancer care**

KAISER HEALTH NEWS | Online – 21 July 2015 – Conversations about end-of-life care are difficult. But even though most people now take some steps to communicate their wishes, many may still receive more intensive care than they would have wished, a study this month found.<sup>1</sup> Researchers analyzed the responses from the next of kin, usually a spouse or child, of 1,985 participants with cancer who died between 2000 and 2012. The patients' family members responded to questions about how frequently patients had signed durable power of attorney documents or living wills or participated in conversations about their end-of-

life preferences. Researchers examined the association between those advance care planning activities and the medical care the cancer patients received at the end of life. <http://khn.org/news/despite-gains-in-advance-directives-study-finds-more-intensive-end-of-life-cancer-care/>

**Specialist Publications**

**'The remarkable staying power of "death panels,"'** (p.16), in *Journal of Health Politics, Policy & Law*.

1. 'Trends in advance care planning in patients with cancer: Results from a national longitudinal survey,' *JAMA Oncology*, 9 July 2015. [Noted in Media Watch, 13 July 2015, #418 (p.11)] <http://oncology.jamanetwork.com/article.aspx?articleid=2383145>

**Making caregiving across state lines easier**

AMERICAN ASSOCIATION FOR RETIRED PERSONS NEWS | Online – 20 July 2015 – Imagine you're a caregiver for your mom, who lives in Oregon. You, however, live in North Carolina. As your mother's health declines, you become her legal guardian in Oregon, making decisions about her property, medical care and living arrangements. The process of becoming your mom's legal guardian was not only time consuming but costly. Now your mother wants to move to North Carolina to be closer to you. North Carolina won't recognize a guardianship order from Oregon, so you will now have to repeat the extensive and often costly process again in North Carolina. While hypothetical, this scenario can be very real for many family caregivers. The fact is: Every caregiving situation is different, and people move and care for their loved ones from different states every day. <http://blog.aarp.org/2015/07/20/making-caregiving-across-state-lines-easier/>

Noted in Media Watch, 13 October 2014, #379 (p.2):

- NATIONAL PUBLIC RADIO | Online – 9 October 2014 – **'How to care for your aging parents from a distance.'** Worrisome signs of your parent's frailty, progressive memory loss or the decline in health require more and more of your help and attention. But what if you live a good distance away? <http://www.pbs.org/newshour/updates/long-distance-caregiving-parents/>

Noted in Media Watch, 10 September 2013, #270 (p.2):

- *THE WASHINGTON TIMES* | Online – 3 September 2012 – **'A world apart, the challenges of long-distance caregiving.'** In today's mobile society, many families are geographically spread apart, and that can create a constant sense of concern and generate tremendous guilt. <http://communities.washingtontimes.com/neighborhood/lifecycles/2012/sep/3/world-apart-challenges-long-distance-caregiving/>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | Southern California Public Radio – 24 July 2015 – ‘**Judge dismisses suit seeking to legalize doctor-assisted suicide.**’ A San Diego Superior Court judge dismissed a lawsuit that sought to legalize physician-assisted suicide for terminally ill Californians. The judge, Gregory Pollack, rejected the plaintiffs’ argument that the state law prohibiting doctors from prescribing life-ending medication violates California’s constitution. He said the debate over the issue is best left to the legislature and the voters, according to journalists and activists who were in the courtroom. <http://www.scp.org/news/2015/07/24/53345/judge-dismisses-suit-seeking-to-legalize-doctor-as/>

## International

### End-of-life care in New Zealand

#### **Survey shows doctors and nurses more involved in “end-of-life” decisions**

NEW ZEALAND | *The Nelson Mail* – 24 July 2015 – A University of Auckland study anonymously surveyed 650 GPs, with 16 reporting prescribing, supplying or administering a drug with the explicit intention of bringing death about more quickly.<sup>1</sup> But in 15 of those cases, it was nurses who administered the drugs. Researchers acknowledged the actions of the GPs would generally be understood as euthanasia, but the survey did not use that term. In the survey, led by Auckland University senior lecturer Dr. Phillipa Malpas, GPs were asked about the last death at which they were the attending doctor. Of the 650 to respond, 359 (65.6%) reported that they had made decisions, such as withdrawing treatment or alleviating pain, taking into account the probability that they may hasten death. Some

made explicit decisions about hastening death. Of the 359, 16.2% withheld treatments with the “explicit purpose of not prolonging life or hastening the end of life.” <http://www.stuff.co.nz/nelson-mail/news/70505221/survey-shows-doctors-and-nurses-more-involved-in-endoflife-decisions>

#### **Specialist Publications**

‘Place of death in the population dying from diseases indicative of palliative care need: A cross-national population-level study in 14 countries’ (pp.15-16), in *Journal of Epidemiology & Community Health*.

1. ‘End-of-life medical decision making in general practice in New Zealand,’ *New Zealand Medical Journal*, 2015;128(1418). (Subscription required) <https://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2015/vo-128-no-1418-24-july-2015/6593>

#### **Nurses afraid of giving medication to patients about to die, senior doctor says**

AUSTRALIA (Victoria) | *The Age* – 23 July 2015 – Some nurses are afraid of repercussions when giving medication to patients who are close to death, a senior Alfred Hospital doctor says. The hospital’s director of palliative care Michelle Gold told a Victorian parliamentary inquiry into end-of-life choices she was concerned sometimes pain relief was withheld or given in lower doses because hospital staff were scared. “It’s not uncommon for us to have a scenario on the ward where the nursing staff are very fearful that if they give that injection and the patient dies at x point in time ... there will be a repercussion for them,” she said. She said change in palliative care moved at a “glacial pace” in Australia. <http://www.theage.com.au/victoria/nurses-afraid-of-giving-medication-to-patients-about-to-die-senior-doctor-says-20150723-gjj675.html>

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**N.B.** Submissions to the inquiry into end-of-life choices, Legal & Social Issues Committee, Legislative Council, Victoria: <http://www.parliament.vic.gov.au/lsc/article/2609>

Noted in Media Watch, 6 October 2014, #378 (p.7):

- AUSTRALIA (Victoria) | Grattan Institute (Melbourne) – September 2014 – ‘**Dying well.**’ Despite widespread assumptions about the cost of end-of-life care, only about \$5-billion a year is spent on the last year of life for older people in a health budget of \$100-billion. But only about \$100-million is spent on helping people to die at home. A change in focus will not save much, but will help more people to die well. <http://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf>

#### **End-of-life care in England**

#### ***Time for action: Why end-of-life care needs to improve and what we need to do next***

U.K. (England) | National Council for Palliative Care (NCPC) – 23 July 2015 – The NCPC has today called for a review into how dying, death and bereavement are dealt with across government departments and public bodies. The calls are included in NCPC’s new report ... which sets out the case for strong national leadership from Government on end-of-life issues in the wake of a series of hard-hitting reports. Although much has been achieved since the first national End-of-Care Strategy in 2008, the report argues that the scale and rate of change needs to be stepped up, not least to meet new demographic challenges. As part of this NCPC would like the Government to consider following the example of the Irish Taoiseach,<sup>1</sup> who recently announced the establishment of an independent review of the way in which government departments and public bodies deal with end-of-life issues. It is envisaged that a review in England would focus not only on how to ensure continued improvements to end-of-life care in the NHS but also on issues including how the benefits system supports people who are terminally ill, are carers or who have been bereaved; bereavement support in the workplace; coroner rules relating to home deaths; how children are supported on issues around dying, death and bereavement in schools; and public awareness of ways in which they can plan ahead, including through Lasting Power of Attorney and Wills. <http://www.ncpc.org.uk/sites/default/files/Time%20for%20Action%20FINAL.pdf>

1. ‘Report on End of Life and Palliative Care in Ireland,’ Houses of Oireachtas’ Joint Committee on Health & Children, 2014. [Noted in Media Watch, 21 July 2014, #367 (p.4)] [http://www.oireachtas.ie/parliament/oireachtasbusiness/committees\\_list/health-and-children/reports/](http://www.oireachtas.ie/parliament/oireachtasbusiness/committees_list/health-and-children/reports/)

**N.B.** See: ‘Actions for End-of-Life Care: 2014-2016,’ National Health Service England, November 2014. <http://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf>; ‘One Chance to Get it Right: Improving people’s experience of care in the last few days and hours of life,’ Leadership Alliance for the Care of Dying People, June 2014. [Noted in Media Watch, 30 June 2014, #364 (p.7)] <https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations>

Of related interest:

- U.K. (England) | *The Guardian* – 21 July 2015 – ‘**Hospitals show “shocking” lack of care discharging vulnerable patients.**’ “Shocking” lack of care for vulnerable people discharged unsafely from hospital has been condemned by a state-funded “consumer champion.”<sup>1</sup> Whether it is about properly helping new mums at risk with depression, or making sure the patients receiving end-of-life care are given the support they need to spend their final days at home with their loved ones rather than in hospital, everyone should experience a safe, dignified and well-planned transfer of care. <http://www.theguardian.com/society/2015/jul/21/healthwatch-hospitals-discharging-vulnerable-patients-lack-of-care->

1. ‘Safely Home: What happens when people leave hospital and care settings?’ The findings of a special inquiry by the charity, Healthwatch England: 21 July 2015. [http://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/170715\\_healthwatch\\_special\\_inquiry\\_2015\\_1.pdf](http://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/170715_healthwatch_special_inquiry_2015_1.pdf)

## Elder care in Ireland

### **Nursing home residents “not declaring” full assets – report**

IRELAND | *The Irish Times* (Dublin) – 21 July 2015 – A tough clampdown is being urged on nursing home residents who are failing to declare lucrative personal assets and income, including houses and pensions from abroad. A review of the Fair Deal nursing home scheme, which heavily subsidises fees and will cost €1.5 billion this year, has found major weaknesses in the means-testing of residents who apply for the financial support. <http://www.independent.ie/irish-news/health/nursing-home-residents-not-declaring-full-assets-report-31391414.html>

## Children’s hospices in England

### **Hospices rely on fundraising as effects of cutbacks hit hard**

U.K. (England) | *The Oxford Mail* – 18 July 2015 – Hospices caring for terminally ill people in the county are being forced to up their fundraising efforts to balance the books in the wake of authority cuts. Helen & Douglas House (HDH) in East Oxford [the world’s first children’s hospice] needs to raise more than £5 million each year to keep caring for terminally ill children and young adults. The hospice said that last year it got just over 10% of that through National Health Service England statutory funding and had to rely on the public, grants and other donations for the rest. While HDH got £1.1 million of statutory funding in 2013-2014, it got just £615,000 in 2014-2015. The hospice said it was too early to say whether this would rise or fall over the next year. Helen & Douglas House said it got no cash from either Oxfordshire Clinical Commissioning Group or Oxfordshire County Council. The reported challenges of “fragile, unfair and unsustainable” contributions from statutory commissioners are a recognised reality for Helen & Douglas House,<sup>1</sup> which needs to generate nearly 90% of its costs of care through voluntary donations each year. [http://www.oxfordmail.co.uk/news/13462880.Hospices\\_rely\\_on\\_fundraising\\_as\\_effects\\_of\\_cutbacks\\_hit\\_hard/](http://www.oxfordmail.co.uk/news/13462880.Hospices_rely_on_fundraising_as_effects_of_cutbacks_hit_hard/)



1. 'Commissioning and statutory funding arrangements for hospices in England: Survey 2015,' Hospice UK and Together for Short Lives. [Noted in Media Watch, 20 July 2015, #419 (p.6). [http://www.togetherforshortlives.org.uk/assets/0001/1502/Hospice\\_commissioning\\_and\\_funding\\_survey\\_results\\_2015.pdf](http://www.togetherforshortlives.org.uk/assets/0001/1502/Hospice_commissioning_and_funding_survey_results_2015.pdf)

Of related interest:

- U.K. (England) | *The Lancashire Evening Post* – 21 July 2015 – ‘**Derian House Children’s Hospice: “We can only open for 7 weeks.”**’ The Chorley hospice typically receives between five and seven per cent of its funding from the government each year. The statutory funding equates to roughly enough money to keep the doors open for around seven weeks of the year; the rest of the hospice’s income comes from fundraising, corporate and community sponsors, retail shops, and donations. Derian House cares for children in Lancashire and South Cumbria, which encompasses 15 clinical commissioning groups [CCG]. It receives financial assistance from three of those CCGs, which, together with a small grant from National Health Service England, amounts to 7% of the total income required. <http://www.lep.co.uk/news/health/local/derian-house-children-s-hospice-we-can-only-open-for-7-weeks-1-7370095>

### **[Media Watch: Back Issues](#)**

Back issues of Media Watch are available on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

## Elder care in Scotland

### **Concern as council cuts elderly care budget by £6 million**

U.K. (Scotland) | *The Edinburgh Evening News* – 18 July 2015 – Elderly care services in the Capital are facing a budget cut of £5.7 million this year – sparking warnings of “huge damage” to already stretched departments. News of the cut came as the city’s new health and social care integration joint board (IJB) met for the first time under a system which will see National Health Service Lothian pool its resources with the region’s four councils. City bosses admitted they were facing significant funding gaps but stressed they would invest £1.8 million specifically to address pressures created by Edinburgh’s ageing population. And they insisted that strategies being developed by the IJB would ensure tough savings targets are met while minimising the impact on services. But union leaders said the multi-million-pound cut would come as a body blow to front-line care workers and lead to elderly residents relying more often on hospitals and GPs. <http://www.edinburghnews.scotsman.com/news/health/concern-as-council-cuts-elderly-care-budget-by-6m-1-3834354>

Noted in Media Watch, 15 June 2015, #414 (p.6):

- U.K. (Scotland) | Care Appointments – 9 June 2015 – ‘**Report: A profile of the care at home sector in Scotland 2015.**’ Delivering care and support to people in their own homes, helping them to retain their independence and community connectedness, and preventing unnecessary admission to hospital or long-term care, are central to the Scottish Government’s strategy for reshaping care and improving outcomes for adults and older people with care needs.<sup>1</sup> <http://www.careappointments.co.uk/practice-reports/item/37400-report-a-profile-of-the-care-at-home-sector-in-scotland-2015>

1. ‘Home Delivery: A profile of the care at home sector in Scotland 2015,’ Scottish Care, June 2015. [http://scottishcare.org/docs/037\\_280\\_schomedeliveryreport2015\\_1433756203.pdf](http://scottishcare.org/docs/037_280_schomedeliveryreport2015_1433756203.pdf)

### **Assisted (or facilitated) death**

Representative sample of recent news media coverage:

- AUSTRALIA | *The Canberra Times* – 24 July 2015 – ‘**Conversation continues on end of life options...**’ The Australian Capital Territory is unlikely to be a trailblazer on the issue of voluntary euthanasia, according to ... a University of Canberra associate professor in the school of law and justice. Dr. Wendy Bonython believes the ACT will have to wait for the states to make laws on voluntary euthanasia or assisted suicide before it becomes an option to pursue locally. <http://www.canberratimes.com.au/act-news/canberra-life/conversation-continues-on-end-of-life-options-for-the-act-20150723-giixoe.html>
- THE NETHERLANDS | Expatica – 24 July 2015 – ‘**Sharp rise in euthanasia for psychiatric patients.**’ In the first six months of this year, 18 people with severe psychiatric problems have been helped to die at a special euthanasia clinic... This is more than double the total figure of 17 in 2014 as a whole... In addition, almost 100 psychiatric patients are on the waiting list for help... This is because of a shortage of psychiatrists to make the assessments and manage the requests. Last year, some 14,000 people in The Netherlands were helped to die, most of whom were suffering from cancer. [http://www.expatica.com/nl/news/country-news/DN-Dutch-Sharp-rise-in-euthanasia-for-psychiatric-patients\\_480080.html](http://www.expatica.com/nl/news/country-news/DN-Dutch-Sharp-rise-in-euthanasia-for-psychiatric-patients_480080.html)
- NEW ZEALAND | Stuff.co.nz (Wellington) – 22 July 2015 – ‘**Parliament to hold euthanasia inquiry...**’ Parliament will hold an inquiry on the introduction of euthanasia laws following the death of [a] right-to-die campaigner... The health select committee will investigate after MPs were presented with a petition signed by former Labour MP Maryan Street and 8,974 others. It demanded the committee examine public opinion on the introduction of legislation, “ which would permit medically-assisted dying in the event of a terminal illness or an irreversible condition which makes life unbearable.” <http://www.stuff.co.nz/national/politics/70457293/parliament-to-hold-euthanasia-inquiry-following-lecretia-seales-death>

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

### Literature review

#### **Advance care planning and palliative medicine in advanced dementia**

*BJPSYCH BULLETIN* | Online – Accessed 20 July 2015 – This review focuses on the organisational factors associated with advanced care planning and palliative care in dementia. However, the disconnect between the willingness of carers and health professionals to discuss these issues, and the low levels of uptake and engagement reported in the studies reviewed, call for more exploration. This would require a wider review incorporating psychosocial literature exploring personal, cultural and other influences that shape people's expectations towards death and end-of-life care. The role played by a lack of information, misperceptions about the course of the illness and the setting in which advanced care planning interventions are delivered have been cited ... as possible contributing factors. <http://pb.rcpsych.org/content/39/2/74>

Noted in Media Watch, 26 November 2012, #281 (p.7):

- *PALLIATIVE MEDICINE* | Online – 21 November 2012 – **'Professionals' experiences of advance care planning in dementia and palliative care, "a good idea in theory but ..."** While professionals agreed that advance care planning was a good idea in theory, implementation in practice presented them with significant challenges. In dementia care, the timing of when to initiate advance care planning discussions was an added challenge to them. <http://pmj.sagepub.com/content/early/2012/11/15/0269216312465651.abstract>

Of related interest:

- *BMC PALLIATIVE CARE* | Online – 25 July 2015 – **'Expert views on the factors enabling good end of life care for people with dementia: A qualitative study.'** Four key factors influencing good practice in end of life care for people with dementia were identified from the expert interviews: 1) Leadership and management of care; 2) Integrating clinical expertise; 3) Continuity of care; and, 4) Use of guidelines. The relationships between the four key factors are important. Leadership and management of care have implications for the successful implementation of guidelines, while the appropriate and timely use of clinical expertise could prevent hospitalisation and ensure continuity of care. A lack of integration across health and social care can undermine continuity of care. <http://www.biomedcentral.com/content/pdf/s12904-015-0028-9.pdf>

**N.B.** Selected articles on end-of-life care for people living with dementia noted in past issues of Media Watch are listed in the issue of the weekly report of 15 June 2015, #414 (pp.13-14).

#### **Family physicians enhance end-of-life care: Evaluation of a new continuing medical education learning module in British Columbia**

*BMC MEDICAL EDUCATION* | Online – 24 July 2015 –The authors present the evaluation findings from the Practice Support Program (PSP) module on enhancing end-of-life (EOL) care within primary care. Satisfaction and impact were rated very highly by over 90% of the GP respondents. Module participation increased the GPs' confidence on end of life (EOL) related communication and collaboration skills: 1) Initiating conversations about EOL care; 2) Developing an action plan for EOL care; 3) Communicating the patient's needs and wishes to other care providers; 3) Participating in collaborative care with home and community care nurses; an, 4) Accessing and referring patients to EOL specialists in the community. Increased confidence was maintained at 3-6 months following completion of training. <http://www.biomedcentral.com/content/pdf/s12909-015-0392-4.pdf>

## “From activating towards caring”

### **Shifts in care approaches at the end of life of people with intellectual disabilities: A qualitative study of the perspectives of relatives, care-staff and physicians**

*BMC PALLIATIVE CARE* | Online – 25 July 2015 – This paper describes the shifts in care approaches and attitudes that relatives and professionals perceive as the death of a person with intellectual disabilities (ID) approaches, as well as the values underlying these shifts: 1) Adapting to a new strategy of comforting care, taking over tasks and symptom relief; 2) Interweaving of emotional and professional involvement; 3) Stronger reliance on the joint interpretation of signals expressing distress and pain; 4) Magnified feeling of responsibility in medical decisions; and, 5) Intensified caring relationship between ‘two families’: relatives and care staff. Six relational values were behind these shifts: 1) “Being there” for the person with ID; 2) “Being responsive” to the person’s needs; 3) “Reflection’ on their own emotions and caring relationships; 4) “Attentiveness” to the ID person’s wishes and expressions of distress; 5) “Responsibility’ for taking joint decisions in the best interests of the person; and, 6) “Openness to cooperation and sharing” the care with others. End-of-life care for people with ID involves curtailing expectations of participation and skill acquirement, and an increase in teamwork featuring intensified comforting care, symptom management and medical decision making. Three caring relationships need to be fostered: 1) The relationship with the person with ID; 2) Relationships among professionals; and, 3) The relationship between relatives and professionals. ID care services should invest particularly in the emotional support and expertise level of care staff, and in the collaboration between relatives and professionals. <http://www.biomedcentral.com/content/pdf/s12904-015-0030-2.pdf>

**N.B.** Articles on the palliative or end-of-life care needs of individuals with intellectual and developmental disabilities have been noted in several issues of Media Watch, for example, the issues of the weekly report of 2 February 2015, #395 (pp.10-11); 29 September 2014, #377 (pp.13-14); 2 June 2014, #360 (pp.10-11); and, 10 March 2014, #348 (pp.8-9).

### **Training and supportive programs for palliative care volunteers in community settings**

*COCHRANE DATABASE SYSTEM REVIEW* | Online – 20 July 2015 – The use of volunteers in community palliative care services can extend the range of activities offered to support people who are terminally ill. The types of training and support for volunteers are likely to affect their effectiveness and influence the quality of care provided to people requiring palliative care and their families. Training and support may also be costly for palliative care organisations. The objective of this review was to assess the effects of training and support strategies for palliative care volunteers on people requiring palliative care and their families, volunteers and service quality. Despite extensive searching [i.e., after screening 2,614 citations identified through the electronic searches after duplicates were removed, and searching grey literature through websites yielded no additional titles, the authors identified 28 potentially relevant titles] the authors found no studies that they could include [in this review]. Research is needed on the impact of training and support for palliative care volunteers on patients, their families, volunteers and palliative care services. <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD009500.pub2/abstract;jsessionid=07DAA BE82265578EE2254F3DD92212ED.f03t04>

Of related interest:

- *KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE*, 2015;18(2):112-119. ‘**Occupational stress and emotional intelligence in hospice volunteers.**’ A continuous educational program is needed to ... ensure quality care for patients and their families. It should be helpful to encourage hospice volunteers to build a social network to enhance their emotional intelligence. <http://synapse.koreamed.org/search.php?where=aview&id=10.14475/kjhpc.2015.18.2.112&code=0155KJHPC&vmode=FULL>

**N.B.** Selected articles on hospice volunteers noted in past issues of Media Watch are listed in the issue of the weekly report dated 16 February 2015, #397 (pp.8-9).

**Integrating palliative care into the care of neuro-critically ill patients: A report from the Improving Palliative Care in the ICU Project Advisory Board and the Center to Advance Palliative Care**

*CRITICAL CARE MEDICINE* | Online – Accessed 20 July 2015 – The authors reviewed the existing literature on delivery of palliative care (PC) in the neuro-intensive care unit setting, focusing on challenges and strategies for establishing realistic and appropriate goals of care, symptom management, organ donation, and other considerations related to use and limitation of life-sustaining therapies for neuro-critically ill patients. Based on review of these articles and the experiences of the interdisciplinary/interprofessional expert advisory board, this report was prepared to guide critical care staff, PC specialists, and others who practice in this setting. Most neuro-critically ill patients and their families face the sudden onset of devastating cognitive and functional changes that challenge clinicians to provide patient-centered PC within a complex and often uncertain prognostic environment. Application of PC principles concerning symptom relief, goal setting, and family emotional support will provide clinicians a framework to address decision making at a time of crisis that enhances patient/family autonomy and clinician professionalism. [http://journals.lww.com/ccmjournals/Abstract/publishahead/Integrating Palliative Care Into the Care of.97209.aspx](http://journals.lww.com/ccmjournals/Abstract/publishahead/Integrating_Palliative_Care_Into_the_Care_of.97209.aspx)

**End of life or end of the road? Are rising cancer costs sustainable?  
Is it time to consider alternative incentive and funding schemes?**

*EXPERT REVIEW OF PHARMACOECONOMICS & OUTCOMES RESEARCH*, 2015;15(4):599-605. The number of cancer therapies is increasing. Treatment costs, largely reflecting increasing prices, are also increasing. The regulatory process is increasing in intensity. Countries have initiated risk sharing agreements and/or special cancer funds to accommodate this expenditure growth. Given increasing pressures elsewhere on healthcare budgets, even this response is not sustainable. With many more cancer drugs in the pipeline and the prospects of combination therapy, it is unlikely that the existing policies being applied by payers can maintain budget constraints. development costs. This perspective outlines the problems faced and suggests some solutions. <http://informahealthcare.com/doi/abs/10.1586/14737167.2015.1039518>

Of related interest:

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 20 July 2015 – ‘**Economic benefits of palliative care consultation continue to unfold.**’ benefits from palliative care intervention include the opportunity to reduce the frequency, intensity, and therefore cost of medical interventions at the end of life. <http://jco.ascopubs.org/content/early/2015/07/14/JCO.2015.62.1557.full#ref-8>
- *PALLIATIVE MEDICINE* | Online – 21 July 2015 – ‘**Estimating the cost of caring for people with cancer at the end of life: A modelling study.**’ The cost to society of providing care to people at the end of their lives is significant. Much of this cost is borne by informal care givers. The cost to formal care services of replacing this care with paid care giving would be significant and demand for care will increase as the demographic profile of the population ages. <http://pmj.sagepub.com/content/early/2015/07/21/0269216315595203.abstract>

Noted in Media Watch, 12 March 2014, #357 (p.10):

- *EXPERT REVIEW OF PHARMACOECONOMICS & OUTCOMES RESEARCH* | Online – 2 May 2014 – ‘**Strategies for the economic evaluation of end-of-life care.**’ This paper examines different theoretical perspectives from which economic evaluation of end-of-life care could be conducted, and argues for the application of a capability approach focusing on the opportunity for a good death. <http://informahealthcare.com/doi/abs/10.1586/14737167.2014.914436>

## Addressing the concerns surrounding continuous deep sedation in Singapore and Southeast Asia: A palliative care approach

*JOURNAL OF BIOETHICAL INQUIRY* | Online – 15 July 2015 – The application of continuous deep sedation in the treatment of intractable suffering at the end of life continues to be tied to a number of concerns that have negated its use in palliative care. Part of the resistance towards use of this treatment option of last resort has been the continued association of continuous deep sedation with physician-associated suicide and/or euthanasia, which is compounded by a lack of clinical guidelines and a failure to cite this treatment under the aegis of a palliative care approach. The author argues that reinstating a palliative care-inspired approach that includes a holistic review of the patient's situation and the engagement of a multidisciplinary team guided by clearly defined practice requirements that have been lacking amongst many prevailing guidelines will overcome prevailing objections to this practice and allow for the legitimization of this process. <http://link.springer.com/article/10.1007/s11673-015-9651-7>

Of related interest:

- *END OF LIFE JOURNAL* | Online – 20 July 2015 – ‘**Is sedation at the end of life compatible with the principles of palliative care?**’ This article seeks to consider whether palliative sedation is compatible with the principles of palliative care. Areas of further research are identified and recommendations for practice are made, but it is concluded that clinicians would be doing patients a disservice if this procedure were not available to patients who have a clinical need. <http://eolj.bmj.com/content/5/1/eoljnl-2015-000001.abstract>

Noted in Media Watch, 9 February 2015, #396 (‘Worth Repeating,’ p.18):

- *CORNELL JOURNAL OF LAW & PUBLIC POLICY*, 2011;20(3):469-532. ‘**Refractory pain, existential suffering, and palliative care: Releasing an unbearable lightness of being.**’ Since the beginning of the hospice movement in 1967, “total pain management” has been the declared goal of hospice care. Palliating the whole person’s physical, psycho-social, and spiritual states or conditions is central to managing the pain which induces suffering. At the end-stage of life, an inextricable component of the ethics of adjusted care requires recognition of a fundamental right to avoid cruel and unusual suffering from terminal illness. This article urges wider consideration and use of terminal sedation, or sedation until death, as an efficacious palliative treatment and as a reasonable medical procedure in order to safeguard the “right” to a dignified death. [http://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=1804326](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1804326)

Noted in Media Watch, 12 May 2014, #357 (p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 May 2014 – ‘**Palliative sedation: An analysis of international guidelines and position statements.**’ Guidelines were published by the American College of Physicians-American Society of Internal Medicine (2000), the Hospice & Palliative Nurses Association (2003), the American Academy of Hospice & Palliative Medicine (2006), the American Medical Association (2008), the Royal Dutch Medical Association (2009), the European Association for Palliative Care (2009), the National Hospice & Palliative Care Organization (2010), and the National Comprehensive Cancer Network (2012). <http://ajh.sagepub.com/content/early/2014/05/06/1049909114533002.abstract>

## Place of death in the population dying from diseases indicative of palliative care need: A cross-national population-level study in 14 countries

*JOURNAL OF EPIDEMIOLOGY & COMMUNITY HEALTH* | Online – 22 July 2015 – Studying where people die across countries can serve as an evidence base for health policy on end-of-life care. This study describes the place of death of people who died from diseases indicative of palliative care need in 14 countries [i.e., Belgium, Canada, the Czech Republic, England, France, Hungary, Italy, Mexico, the Netherlands, New Zealand, South Korea, Spain (Andalusia), the U.S.

Cont.

and Wales], the association of place of death with cause of death, socio-demographic and healthcare availability characteristics in each country and the extent to which these characteristics explain country differences in the place of death. 13% (Canada) to 53% (Mexico) of people died at home, and 25% (The Netherlands) to 85% (South Korea) died in hospital. The strength and direction of associations between home death and cause of death, socio-demographic and healthcare availability factors differed between countries. Differences between countries in home versus hospital death were only partly explained by differences in these factors. The large differences between countries in and beyond Europe in the place of death of people in potential need of palliative care are not entirely attributable to socio-demographic characteristics, cause of death or availability of healthcare resources, which suggests that countries' palliative and end-of-life care policies may influence where people die. <http://jech.bmj.com/content/early/2015/07/22/jech-2014-205365.abstract>

Of related interest:

- *SCANDINAVIAN JOURNAL OF PUBLIC HEALTH* | Online – 20 July 2015 - ‘**A population-level study of place of death and associated factors in Sweden.**’ The majority of deaths in Sweden occur in institutional settings, with comparatively larger proportions of nursing home deaths than most countries. Associations between place of death and other variables point to inequalities in availability and/or utilization of health services at the end of life. <http://sjp.sagepub.com/content/early/2015/07/18/1403494815595774.abstract>

#### End-of-life care in the U.S.

#### **The remarkable staying power of “death panels”**

*JOURNAL OF HEALTH POLITICS, POLICY & LAW* | Online – 20 July 2015 – Sarah Palin’s phrase “death panels” derailed proposed provisions of the Affordable Care Act (ACA) to pay physicians for end-of-life discussions with patients, a policy designed to make dying more humane, something all Americans desire. Even now, “death panels” has truth-value for approximately half of Americans and is used to paint ACA components as threatening to “pull the plug on Grandma.” How can this be? To some, the death panels claim is simply a lie, an improvised explosive device hurled against any ACA provision. To others, the phrase’s power stems from the public’s lack of a common vocabulary to discuss end-of-life care. “Death panels,” however, taps into many Americans’ fear of government involvement, that government’s purchasing end-of-life discussions as commodities necessitates accountability and cost control. Standardization and reduction of humanity follows, something Americans already experience routinely in their health care system. Expert jargon, compelling among experts themselves, doesn’t evoke people’s images of chats with Marcus Welby.<sup>1</sup> The jargon is unintelligible, off-putting. When that jargon enters the non-jargonized world, it mixes with common fears, extant experience of dehumanization and reduction, and awareness that someone’s plug is getting pulled all the time. “Death panels” cannot be dismissed as delusional, but neither can it help fulfill Americans’ aspirations for a humane last voyage. <http://jhppl.dukejournals.org/content/early/2015/07/02/03616878-3161212.abstract>

1. ‘Marcus Welby MD’ was a popular and ground-breaking American medical drama television series that aired from 1969 to 1976. The central character was a family practitioner with a kind bedside manner and an ability to listen attentively to his patients.

Noted in Media Watch, 13 July 2015, #418 (p.5):

- U.S. | *Forbes* – 5 July 2015 – ‘**With Palin “death panels” debunked, Congress pushes end-of-life planning.**’ Bipartisan legislation introduced in the U.S. Senate ... to help patients suffering serious illness with advanced care planning is gaining momentum. The Care Planning Act of 2015 would have Medicare reimburse doctors and other health professionals for consulting with their patients about end-of-life care. <http://www.forbes.com/sites/brucejapsen/2015/07/05/with-palin-death-panels-debunked-congress-pushes-end-of-life-planning/>

Cont.



Noted in Media Watch, 30 March 2015, #403 (p.7):

- U.S. | Reuters – 23 March 2015 – **‘Reimburse doctors for helping patients plan end-of-life care, experts say.’** Physician incentives are needed to improve end-of-life care in the U.S., health experts said at an Institute of Medicine forum convened to discuss action on the recommendations of the Institute’s seminal fall [2014] report...<sup>1</sup> When people fail to plan for end-of-life care, they may suffer through ultimately futile, invasive and often unwanted treatments. <http://www.reuters.com/article/2015/03/23/us-end-of-life-care-reimbursement-idUSKBN0MJ2E920150323>

1. ‘Dying in America: Improving Quality & Honoring Individual Preferences Near the End of Life,’ Institute of Medicine, 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] <http://www.iom.edu/-/media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf>

### **Hospice chaplains: Talking about spiritual care and avoiding the modern day “inquisition”**

*JOURNAL FOR THE STUDY OF SPIRITUALITY*, 2015;5(1):60-69. There is now a substantial body of literature on spirituality and spiritual care in healthcare. Despite the fact that many hospice chaplains are finding that they have to explain, if not justify, spiritual care, they have authored very little of that literature. The paper summarizes the history of spirituality and spiritual care in English healthcare, considers the significance of Cicely Saunders’s spirituality for her vision of hospice, and presents some of the findings from the author’s ongoing doctoral research. <http://www.maneyonline.com/doi/abs/10.1179/2044024315Z.00000000041>

Noted in Media Watch, 20 July 2015, #419 (p.11):

- *JOURNAL OF HEALTH CARE CHAPLAINCY* | Online – 13 July 2015 – **‘Recognizing success in the chaplain profession: Connecting perceptions with practice.’** The current investigation examines the communicative hallmarks [i.e., *non-verbal* vs. *verbal hallmarks*] of successful chaplaincy work as articulated by professional chaplains providing spiritual care at the end-of-life. <http://www.tandfonline.com/doi/abs/10.1080/08854726.2015.1071543#.VaqPrHIRGos>

**N.B.** Selected articles on spirituality in the context of end-of-life care noted in past issues of Media Watch are listed in the issue of the weekly report of 8 June 2015, #413 (pp.10-11).

### **The role of the Carer Support Needs Assessment Tool in palliative home care: A qualitative study of practitioners’ perspectives of its impact and mechanisms of action**

*PALLIATIVE MEDICINE* | Online – 21 July 2015 – Practitioners expressed some concerns, pre-implementation, about the negative impacts of the Carer Support Needs Assessment Tool [CSNAT] on carers and expectations raised about support available. In contrast, post-implementation, the CSNAT provided positive impacts when used as part of a carer-led assessment and support process: it made support needs visible, legitimised support for carers and opened up different conversations with carers. The mechanisms of action that enabled the CSNAT to make a difference were creating space for the separate needs of carers, providing an opportunity for carers to express support needs and responding to carers’ self-defined priorities. <http://pmj.sagepub.com/content/early/2015/07/21/0269216315596662.abstract>

Of related interest:

- *INTERNATIONAL JOURNAL OF ADOLESCENCE & YOUTH* | Online – 20 July 2015 – **‘A qualitative review of young carer services in Canada.’** In Canada, a growing number of young people provide an increasing level of unpaid care to family member(s) with a chronic illness, disability ... and/or problems related to old age. Despite young carers occupying a central role in public policy and social service programming in other countries, very little attention has been paid to these youth in Canada, with no dedicated policies acknowledging their care-work and only a handful of non-profit organisations struggling to support their needs. <http://www.tandfonline.com/doi/full/10.1080/02673843.2015.1061568#.VbOo5XIRGos>

## Experiences of continued presence: On the practical consequences of “hallucinations” in bereavement

*PSYCHOLOGY & PSYCHOTHERAPY: THEORY, RESEARCH & PRACTICE* | Online – 16 July 2015 – The authors' [17 bereaved] informants heard voices of the deceased, saw their images, felt their touch, and sometimes felt their presence unspecified in any of the senses. Analysis revealed that experiences of continued presence were meaningfully connected to the immediate environments in which they happened but also to the personal histories of the bereaved. The narratives reveal helpful and destructive potentials of these experiences. In all cases, the functions relied on the relationship with the deceased. The authors warn against oversimplification of experiences of continued presence, as significantly contrasting practical consequences commonly occurred within as well as between cases. The findings of this study support the use of talking therapies based on personal meanings to help those disturbed by their experiences of presence. <http://onlinelibrary.wiley.com/doi/10.1111/papt.12067/abstract;jsessionid=78A3675DEA524782E45F4480ED8319A5.f03t02?userIsAuthenticated=false&deniedAccessCustomisedMessage=>

Of related interest:

- *JOURNAL OF POST-ACUTE & LONG TERM CARE* | Online – 21 July 2015 – ‘**Institutional bereavement care for fictive kin: Staff grief in continuing care retirement community.**’ Emergent themes suggest long term care facilities have freedom in how to provide support for staff members, family members and other residents after the death of a loved one. However, variations in methods for notifying staff of a resident's death, inclusion of direct care staff in caring for the deceased, providing memorial services, and offering grief/bereavement support. [http://www.jamda.com/article/S1525-8610\(15\)00434-X/abstract?cc=y=](http://www.jamda.com/article/S1525-8610(15)00434-X/abstract?cc=y=)

**N.B.** Fictive kin are people who are regarded as being part of a family even though they are not related by either blood or marriage bonds. Fictive kinship may bind people together in ties of affection, concern, obligation, and responsibility.

- *MEDICALXPRESS* | Online – 22 July 2015 – ‘**New checklist helps identify children, teens with bereavement disorder.**’ With 39 straight-forward questions and an easily intelligible rating system, the ‘Persistent Complex Bereavement Disorder Checklist – Youth Version’ is the first tool of its kind. The University of California Los Angeles-University of Texas psychological test aims not only to help identify kids and teens whose grief may have taken a wrong turn but also attempts to gauge the severity of their symptoms. Authors hope educators, mental health providers, pediatricians, hospice providers and grief support communities will use the checklist. <http://medicalxpress.com/news/2015-07-checklist-children-teens-bereavement-disorder.html>

### Media Watch: Back Issues



The screenshot shows the IPCRC.NET website. At the top, there is a navigation menu with links: Home, About IPM, OIA, NCI, Partners, Contact, and Acknowledgements. Below the menu, there is a section titled 'GLOBAL PALLIATIVE CARE NEWS ARCHIVE' and 'MEDIA WATCH, CREATED AND DISTRIBUTED BY BARRY R. ASHPOLE'. A small text block says 'Please feel free to share this weekly report with your colleagues. Barry R. Ashpole, Guelph, Ontario, CANADA 519.837.8936 | baryr@ashpole@bell.net'. There is a link to 'MW 400: Palliative care in advanced lung disease: The challenge of integrating palliation into everyday care' with a PDF icon. Below that, there is a quote from CHEST: 'Online – 5 March 2015 | The tendency toward "either/or" thinking (either cure or comfort) in traditional biomedical care paradigms does little to optimize care in advancing chronic illness. Calls for improved palliation in chronic lung disease mandate a review of related care gaps and current clinical practices. read more...'. On the right side of the screenshot, there is a 'Media Watch Archives' box with a list of back issues: 2014, July - December; 2014, January - June; 2013, July - December; 2013, January - June; 2012, July - December; 2012, January - June; 2011, July - December; 2011, January - June; and Current.

#### Media Watch Archives

- 2014, July - December
- 2014, January - June
- 2013, July - December
- 2013, January - June
- 2012, July - December
- 2012, January - June
- 2011, July - December
- 2011, January - June
- Current

<http://www.ipcrc.net/archive-global-palliative-care-news.php>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *JOURNAL OF MEDICAL ETHICS*, 2015;41(8):575-576. ‘**Safeguarding choice at the end of life.**’ Across the world, in countries with permissive or restrictive existing legislation, debates about euthanasia and assisted suicide (EAS) continue to grip politicians, ethicists, physicians and the wider public. Early debates about EAS focused on whether it could ever be ethical for a physician to actively cause the death of a patient. However, most contemporary writers, including most of the contributors to this special double issue of the *Journal of Medical Ethics*<sup>1</sup> appear to accept that such actions could, in some circumstances, be ethical. Current debate is mostly focused instead on which actions are permissible, when they are permissible, and what safeguards are necessary to protect the vulnerable. <http://jme.bmj.com/content/41/8/575.full>

1. Journal contents page: <http://jme.bmj.com/content/current>

### Media Watch: Online

#### International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2015/07/media-watch/>

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

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

PALLIMED (Hospice & Palliative Medicine Blog): <http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html> [Scroll down to ‘Aggregators’ and Barry Ashpole and Media Watch]

#### Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://aphn.org/category/media-watch/>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/updates/international-palliative-care-resource-center-media-watch/>

#### Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> [Scroll down to ‘International Websites’ and [www.ipcrc.net/archive-global-palliative-care-news.php](http://www.ipcrc.net/archive-global-palliative-care-news.php) to access the weekly report]

#### Canada

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://hpcconnection.ca/general-resources/in-the-news/>

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/> [Scroll down to ‘Additional Resources’]

#### Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://www.eapcnet.eu/Themes/Organization/Links.aspx> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes>

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=b623758904ba11300ff6522fd7fb9f0c>

### 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 and research tool.

### 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.

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