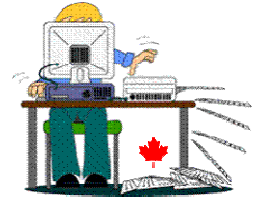


## **Media Watch...**

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-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**

**Organizational aspects of end-of-life care: Scroll down to [Specialist Publications](#) and 'Validation of quality indicators for the organization of palliative care: A modified RAND Delphi study in seven European countries (the Europall project)' (p.13), in *Palliative Medicine*.**

## **Canada**

### **Institute of Marriage & Family Canada study shows palliative care would reduce health care costs**

ONTARIO | *The B.C. Catholic* – 17 July 2013 – The Institute of Marriage & Family Canada has released a study showing that Ontario could save millions of dollars on health care costs through improving palliative care access.<sup>1</sup> The study by researcher Derek Miedema estimates improving access to palliative care, which studies have been shown is "significantly less expensive" than acute or intensive care, could save Ontario from under \$247 million to slightly over \$2.1 billion, depending on the estimate model used. "In short, good palliative care not only helps people to die comfortably, but also saves healthcare costs," Miedema writes. Ontario's savings will only increase as the Baby Boomer population ages; the first reach 80 in less than 15 years. <http://bcc.rcav.org/canadian/2929-imfc-study-shows-palliative-care-would-reduce-health-care-costs>

1. *Why Canada needs more palliative care*, Institute of Marriage & Family Canada, Ottawa, June 2013. [http://www.imfcanada.org/sites/default/files/We\\_need\\_more\\_palliative\\_care\\_June\\_2013\\_0.pdf](http://www.imfcanada.org/sites/default/files/We_need_more_palliative_care_June_2013_0.pdf)

### **Specialist Publications**

**'Aggressiveness of end-of-life care for patients with colorectal cancer in Alberta, Canada: 2006–2009'** (p.9), in *Journal of Pain & Symptom Management*.

**'Where and how people with schizophrenia die: A population-based, matched cohort study in Manitoba, Canada'** (p.9), in *Journal of Clinical Psychiatry*.

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

## New "conversation guide" helps doctors discuss end-of-life care with patients

*THE GLOBE & MAIL* | Online – 15 July 2013 – Talking about death is never easy. It's a difficult topic to approach with patients who are aging in hospitals or living with chronic illnesses. An end-of-life "conversation guide" endorsed by the Canadian Researchers at the End of Life Network and published in the *Canadian Medical Association Journal* offers steps that doctors in hospitals can follow to sensitively broach the subject with patients and their families.<sup>1</sup> "A lot of the patients I care for are seriously ill and in fragile health and my observation has been that as a health care team we don't spend the time to understand what their priorities are. I think it's an important gap that we need to close," Dr. John You, one of the authors of the guide and an associate professor at McMaster's Departments of Medicine and Clinical Epidemiology & Biostatistics, said. [http://www.theglobeandmail.com/life/the-hot-button/new-conversation-guide-helps-doctors-discuss-end-of-life-care-with-patients/article13222543/?cmpid=rss1&utm\\_source=dlvr.it&utm\\_medium=twitter](http://www.theglobeandmail.com/life/the-hot-button/new-conversation-guide-helps-doctors-discuss-end-of-life-care-with-patients/article13222543/?cmpid=rss1&utm_source=dlvr.it&utm_medium=twitter)

1. 'Just ask: Discussing goals of care with patients in hospital with serious illness,' 15 July 2013. <http://www.cmaj.ca/content/early/2013/07/15/cmaj.121274>

## End-of-life battles expose the culture clash in Canada's intensive care units

*THE NATIONAL POST* | Online – 12 July 2013 – When an Edmonton family went to court to fight a hospital's plan to withdraw life-sustaining treatment from their deathly ill patriarch, the relatives cited Islamic law, as well as judicial precedent, to bolster their case. In Winnipeg, siblings locked in a similar battle over their father's care pointed to Orthodox Jewish beliefs. A Halifax wife, meanwhile, pleaded that her husband should be prevented from dying long enough for a traditional Chinese healer to try to cure his cancer. A string of legal disputes related to the treatment of horribly sick patients has drawn increasing interest, but one compelling aspect of the quarrels has been largely overlooked. Most of the battles involve patients from ethnic and religious minorities – frequently first-generation immigrants – and point to a cultural clash in Canada's intensive-care units. Chinese, South Asian, Muslim, Middle East Christian and Orthodox Jewish families have struggled to have hospitals keep their loved ones alive – often citing an abiding belief in the sanctity of life – when physicians rooted in more pragmatic, scientific values have called further care futile. The bitter conflicts can be triggered by cultural misunderstanding, suspicion of racism or, perhaps most significantly, religious belief not yet tempered by Canada's relatively secular culture, say doctors, lawyers

and ethicists familiar with the disputes. <http://news.nationalpost.com/2012/12/07/end-of-life-battles-expose-the-culture-clash-in-canadas-intensive-care-units/>

### [Specialist Publications](#)

'Palliative care's role grows in solving end-of-life conflicts' (p.7), in *American Medical News*.

### Recent articles on decisions in end-of-life care from *The National Post*

11 July 2013 – 'Canadian doctors explain why so many of us die badly.' Often, it's not doctors who are pushing dying patients into aggressive, futile end-of-life medical treatments, but guilt-ridden relatives who can't bear the idea of "pulling the..." <http://fullcomment.nationalpost.com/2013/07/11/onathan-kay-canadian-doctors-explain-why-so-many-of-us-die-badly/>

4 July 2013 – 'Sometimes, the most humane thing for a doctor to do is let the patient die.' While Western societies obsess over health-care availability, they ignore the opposite problem: unwanted treatments inflicted on patients... <http://fullcomment.nationalpost.com/2013/07/04/onathan-kay-we-torture-people-before-they-die/>

Cont.

Noted in Media Watch, 27 May 2013, #307 (p.1):

- ONTARIO | *Metro News* (Toronto) – 23 May 2013 – **'Family battles Sunnybrook hospital over comatose man's right to live.'** An ongoing [*Toronto Star* investigation into end-of-life care in Canada has documented five ... disputes at Sunnybrook [Health Sciences Centre]<sup>1</sup> ... placing the hospital at the centre of a growing debate that has confounded the medical and legal communities, patients and their families. <http://metronews.ca/news/toronto/682191/family-battles-sunnybrook-hospital-over-comatose-mans-right-to-live/>
  1. Listing of *The Toronto Star* articles: <http://www.thestar.com/search.html?q=Hassan+Rasouli>  
Alternatively: <http://www.thestar.com/search.html?q=Consent+and+Capacity+Board%27>

Noted in Media Watch, 17 December 2012, #284 (p.10):

- *JOURNAL OF CRITICAL CARE*, 2013;28(1):22-27. **'Best interests at end of life: An updated review of decisions made by the Consent & Capacity Board of Ontario.'** There was a significant increase (235%) in decisions from this tribunal between 2009 and 2011. Substitute decision makers rely on an appeal to their own values or religion in their interpretation of best interests; physicians rely on clinical conditions; board emphasizes alignment with Health Care Consent Act. <http://www.sciencedirect.com/science/article/pii/S0883944112003152>

**N.B.** Canadian news media coverage and commentaries in specialist publications in the fields of bioethics and medicine on the issue of withdrawal or withholding of life-sustaining treatment have been noted on a regular basis in Media Watch.

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 17 July 2013 – **""That terrifies us"": Canadian doctors get virtually no training on handling a patient's desire to die.'** As Canadians debate assisted suicide as a largely academic issue, doctors and nurses are routinely asked by dying patients for a medical push over the edge, specialists say. And yet, they get little preparation for arguably the most difficult conversation they will ever have with a patient. Most doctors finish their degrees and five years of specialty training with virtually no instruction on how to deal with death generally, let alone patients who ask for help with suicide, said Dr. Mike Harlos, medical director of palliative care for the Winnipeg Regional Health Authority. The most frightening interface with the health care system is the dying bit. <http://news.nationalpost.com/2013/07/16/that-terrifies-us-canadian-doctors-get-virtually-no-training-on-handling-a-patients-desire-to-die/>

#### Specialist Publications

**'Physician assisted suicide: The great Canadian euthanasia debate'** (p.14), in *International Journal of Law & Psychiatry*.

From the archives:

- *PALLIATIVE MEDICINE*, 2006;20(7):703-710. **'Responding to desire to die statements from patients with advanced disease: Recommendations for health professionals.'** Health professionals may struggle to determine whether a "desire to die" statement (DTDS) is about a request for hastened death, a sign of psychosocial distress, or merely a passing comment that is not intended to be heard literally as a death wish. Given the lack of guidelines to assist health professionals with this issue, the authors have prepared multidisciplinary recommendations for responding to a DTDS, underpinned by key principles of therapeutic communication and a systematic review of empirical literature. <http://pmj.sagepub.com/cgi/content/abstract/20/7/703>

## U.S.A.

### Incentives may encourage end-of-life discussions

REUTERS | Online – 19 July 2013 – Offering medical trainees a financial incentive to write hospital patients' end-of-life wishes in their medical records led to a spike in the proportion of records with such notations, a new study found.<sup>1</sup> Past studies have suggested that although many elderly people prefer to die at home instead of in the hospital receiving aggressive treatment, some never have a discussion about end-of-life care with their doctors or have such wishes recorded. "The conversation is the most important part of this process," said Dr. Joshua Lakin, who led the study while at the University of California, San Francisco [UCSF]. "Everyone feels that that conversation piece leads to more likelihood of having health care delivered that's in line with (the patient's) wishes." As part of the study, internal medicine residents at UCSF each received

\$400 if, as a group, they recorded discussing end-of-life issues, including designation of a surrogate decision-maker, with at least three quarters of hospital inpatients. Residents received reminder emails about the program, followed by feedback on a team and individual level as the year went on. <http://www.chicagotribune.com/health/sns-rt-us-incentives-discussions-20130719,0,1988110.story>

#### Specialist Publications

**'Implementing Physician Orders for Life-Sustaining Treatment [POLST] in California hospitals: Factors associated with adoption'** (p.8), in *Journal of the American Geriatric Society*.

1. 'Incentivizing residents to document inpatient advance care planning,' *JAMA Internal Medicine*, 15 July 2013. Because most end-of-life discussions occur in hospitals, the authors implemented a quality improvement program incentivizing resident physicians to consistently document key information about inpatient advance care planning discussions in a timely manner in an accessible location. <http://archinte.jamanetwork.com/article.aspx?articleid=1713506>

Of related interest:

- MASSACHUSETTS | Sun Life Financial – 15 July 2013 – **'Many fear the financial impact of a critical illness more than dying from one.'** [A white paper] 'Well-Placed Fears: Workers' Perceptions of Critical Illness' found that many workers feared the financial impact of a critical illness even more than dying from one. [http://contentz.mkt5013.com/lp/42828/263718/Critical-Illness-Research-Whitepaper\\_13.pdf](http://contentz.mkt5013.com/lp/42828/263718/Critical-Illness-Research-Whitepaper_13.pdf)

### In a culture of disrespect, patients lose out

*THE NEW YORK TIMES* | OpEd – 18 July 2013 – I've always thought about respect as common decency, something we should do because it's simply the right thing to do. In the medical world, we certainly need to strive for respectful behavior, especially given our historically rigid pecking order, our ingrained traditions of hierarchical bullying and, of course, a primary constituency – patients who are often on uniquely vulnerable footing. But then I stumbled across two [journal] articles ...that talked about respect as an issue of patient safety.<sup>1,2</sup> The authors, a group of doctors and researchers at Harvard medical School, outlined the myriad acts of disrespect that we've come to accept as a way of life in medicine, and showed how these lead to a final pathway of harm to our patients. This shift in perspective was a shock to the system. When we tolerate a culture of disrespect, we aren't just being insensitive, or obtuse, or lazy, or enabling. We're in fact violating the first commandment of medicine. How can we stand idly by when our casual acceptance of disrespect is causing the same harm to our patients as medication errors, surgical mistakes, handoff lapses and miss lab results? <http://well.blogs.nytimes.com/2013/07/18/in-a-culture-of-disrespect-patients-lose-out/?ref=health>

Cont.

1. 'Perspective: A culture of respect, Part 1: The nature and causes of disrespectful behavior by physicians,' *Academic Medicine*, 2013;87(7):845-582.  
[http://journals.lww.com/academicmedicine/Fulltext/2012/07000/Perspective\\_A\\_Culture\\_of\\_Respect,\\_Part\\_1\\_The.10.aspx](http://journals.lww.com/academicmedicine/Fulltext/2012/07000/Perspective_A_Culture_of_Respect,_Part_1_The.10.aspx)
2. 'Perspective: A culture of respect, Part 2: Creating a culture of respect,' *Academic Medicine*, 2013;87(7):583-585.  
[http://journals.lww.com/academicmedicine/Fulltext/2012/07000/Perspective\\_A\\_Culture\\_of\\_Respect,\\_Part\\_2\\_11.aspx](http://journals.lww.com/academicmedicine/Fulltext/2012/07000/Perspective_A_Culture_of_Respect,_Part_2_11.aspx)

### **Nelson Mandela's illness puts spotlight on palliative care**

ABC NEWS | Online – 15 July 2013 – Ailing human rights icon Nelson Mandela's ill health and repeated hospital stays have put the spotlight on palliative care, a growing branch of medicine that provides seriously ill patients with relief from the symptoms, pain and the stress of sickness. "Mandela is clearly an important public figure and his high-profile case helps raise awareness of palliative care," said Dr. Sean Morrison, director of palliative care at Mount Sinai Medical Center in New York City. Palliative care specialists, including doctors, nurses, social workers and other health care providers, work together to improve quality of life for patients and their families, Morrison said. Most palliative care physicians are internists or practice family medicine with an additional subspecialty and board certification in palliative medicine. With approximately 90 million Americans living with a serious and life-threatening illness, according to the Center to Advance Palliative Care in New York City, medical experts say there is a pressing need for palliative services and programs. <http://abcnews.go.com/Health/nelson-mandelas-illness-highlights-palliative-care/story?id=19672326#.UeUzjtJwomY>

Of related interest:

- CABLE NEWS NETWORK | Online – 18 July 2013 – **'Do we want to die tethered to a machine?'** The predicament facing Nelson Mandela, who has been critically ill for the past five weeks and turns 95 on Thursday, brings into sharp focus an important question that eventually affects all of us. How do we want to die? <http://www.cnn.com/2013/07/18/opinion/mayer-end-of-life-care/index.html>

Noted in Media Watch, 1 July 2013, #312 (p.5):

- THE ASSOCIATED PRESS | Online – 28 June 2013 – **'With Mandela, end-of-life care dilemmas magnified.'** The emotional pain and practical demands facing Nelson Mandela's family are universal: confronting the final days of an elderly loved one. There are no rules for how or when the end may arrive. <http://www.usatoday.com/story/news/world/2013/06/28/mandela-end-of-life-dilemmas/2473619/>

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

Representative sample of recent news media coverage:

- VERMONT | *The Burlington Free-Press* – 14 July 2013 – **'End-of-life law: The Oregon experience.'** For 15 years, Oregon has had a law allowing terminally ill patients to seek a prescription for a lethal dose of medication to hasten their own deaths. If Vermont's experience is similar, relatively few will use the law, but the number will grow each year. [http://www.burlingtonfreepress.com/apps/pbcs.dll/article?AID=2013307140013&gcheck=1&ncli ck\\_check=1](http://www.burlingtonfreepress.com/apps/pbcs.dll/article?AID=2013307140013&gcheck=1&ncli ck_check=1)

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

Media Watch (or a link to the weekly report) is posted on several websites that serve the hospice and palliative care community-at-large. See a complete listing on p.15.

## International

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

#### **Liverpool Care Pathway for dying patients to be abolished after review**

U.K. (ENGLAND) | *The Guardian* – 15 July 2013 – The Liverpool Care Pathway [LCP] is to be abolished following a government-commissioned review which heard hospital staff wrongly interpreted its guidance for care of the dying, leading to stories of patients who were drugged and deprived of fluids in their last weeks of life.<sup>1</sup> The government-commissioned review ... found it was not the pathway itself but poor training and sometimes a lack of compassion on the part of nursing staff that was to blame, while junior doctors were expected to make life-and-death decisions beyond their competence after hours and at weekends. The review says individualised end-of-life care plans must be drawn up for every patient nearing that stage. "Caring for the dying must never again be practised as a tickbox exercise and each patient must be cared for according to their individual needs and preferences, with those of their relatives or carers being considered too," said Neuberger. "Ultimately it is the way the LCP has been misused and misunderstood that had led to such great problems." She said it was too late to turn the clock back and salvage the LCP ... but in replacing it, the National Health Service must make care of the dying part of its core business. "What we have also exposed in this review is a range of far wider, fundamental problems with care for the dying – a lack of care and compassion, unavailability of suitably trained staff, no access to proper palliative care advice outside of 9-5, Monday to Friday." The government confirmed it would phase out the LCP and ... require all hospitals to review the care of dying patients. Every patient should have a named senior doctor in charge of their care. <http://www.guardian.co.uk/society/2013/jul/15/liverpool-care-pathway-independent-review>

1. *Independent Report: Review of Liverpool Care Pathway for dying patients*, Department of Health, July 2013. <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

#### Report into the quality of care and treatment

#### **Keogh's review of mortality rates in the National Health Service is a blueprint, not a red alert**

U.K. (ENGLAND) | *The Guardian* – 16 July 2013 – Talk of 14 [National Health Service] trusts with the highest mortality rates in the country and 13,000 needless deaths in the past eight years will have whetted expectations for a damning review from Sir Bruce Keogh that will show mayhem and misconduct in the National Health Service [NHS].<sup>1</sup> But once the rhetoric from political quarters has died down, the reality may look a little different. Keogh and his team have not sought to find out why the deaths occurred. There will be no public inquest and families who suspect a relative had poor care and should not have died will be disappointed. The review has not looked at how things were but at how things are – whether each hospital or group of hospitals in a trust is performing well and where the strengths and weaknesses lie. The review was a political response to ... the Francis inquiry report into failings at Mid-Staffordshire NHS Foundation Trust, which was a damning verdict on hospital care.<sup>2</sup> <http://www.guardian.co.uk/society/2013/jul/15/keogh-nhs-mortality-rates-review>

1. *Report into the quality of care and treatment provided by 14 hospital trusts in England: Overview report*, by Sir Bruce Keogh for the National Health Service July 2013. <http://www.nhs.uk/NHSEngland/bruce-keogh-review/Documents/outcomes/keogh-review-final-report.pdf>

2. *Report of the Mid Staffordshire National Health Service Foundation Trust Public Inquiry*, February 2013. [Noted in *Media Watch*, 11 February 2013, #292 (p.5)] <http://www.midstaffpublicinquiry.com/report>

#### Specialist Publications

'Guidelines published in wake of Liverpool Care Pathway phase-out announcement' (p.12), in *Nursing Times*.

Cont.



Noted in Media Watch, 15 July 2013, #314 (p.3):

- U.K. (ENGLAND) | *The Guardian* – 13 July 2013 – **'Liverpool Care Pathway for dying patients to be scrapped after review.'** The Liverpool Care Pathway for dying patients is to be scrapped, ministers are expected to announce next week after an independent review. <http://www.guardian.co.uk/politics/2013/jul/13/liverpool-care-pathway-scrapped>

Of related interest:

- NEW ZEALAND | *Stuff.co.nz* – 20 July 2013 – **'Reassurance on care for dying in New Zealand.'** The Ministry of Health is confident end-of-life care in New Zealand will not be affected by a damning review from the U.K. The Liverpool Care Pathway for dying patients is used in hospices, hospital-level residential care facilities and hospitals in more than 20 countries to improve care given to dying patients. It has been used in New Zealand since about 2004. However, it will be phased out in the U.K. after an independent review found it was failing dying patients and their families. Ministry of Health cancer services manager Ricarda Vandervorst said the way the pathway operated in the U.K. was different to how it was implemented in New Zealand. <http://www.stuff.co.nz/national/health/8944042/Reassurance-on-care-for-dying-in-NZ>
- U.K. (ENGLAND) | *The Guardian* – 16 July 2013 – **'What questions should we be asking about end-of-life preferences?'** With the focus on the Liverpool Care Pathway (LCP), there is a lot of talk about how people's end-of-life wishes are taken into account. This is a very specific example of where a tool designed to improve co-ordination between professionals has sometimes been poorly implemented to the detriment of patients and their families. But focusing on the LCP alone means we fail to see the wood for the trees. The LCP is one element of a vast end-of-life care system, which has, since 2008, been geared up to help people achieve their preferred place of death. <http://www.guardian.co.uk/healthcare-network/2013/jul/16/questions-end-of-life-liverpool-care-pathway>
- U.K. (ENGLAND) | *The Times* – 16 July 2013 – **'The failings of the Liverpool Care Pathway point to wider problems in the National Health Service.'** The hospice movement was founded to provide palliative care for the terminally ill, to ensure that in their final days patients were able to die in peace and with dignity. It is an approach that until recently was largely absent from hospitals in Britain, where care of the dying was characterised by doctors and nurses intent on prolonging life, often at the expense of the comfort of the patient and the distress of their relatives. <http://www.thetimes.co.uk/tto/opinion/leaders/article3817223.ece>

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

#### **Palliative care's role grows in solving end-of-life conflicts**

*AMERICAN MEDICAL NEWS* | Online – 15 July 2013 – A 58-year-old Russian man with advanced esophageal cancer was admitted to a U.S. comprehensive cancer center with decreased oral intake and failure to thrive. The man's family insisted on initiating parenteral nutrition, but the physician and other health professionals involved in his care saw that as medically contraindicated. The family of Russian immigrants insisted. They told of their struggles with food shortages in the old country and refused to consider what they saw as allowing their loved one to "starve to death." The clinicians eventually asked for an ethics consultation to help resolve the matter. But as is happening in a rising number of cases, it was the involvement of palliative care that helped broker an acceptable resolution. During multiple meetings, doctors explained the disproportionate burdens of parenteral nutrition – infections, blood clots, potential liver failure – given the slim benefits for the patient. And it was the palliative care team that helped address the family's concern by giving the patient intravenous glucose while starting comfort care, thus avoiding parenteral nutrition. <http://www.amednews.com/article/20130715/profession/130719981/4/>

Cont.

Of related interest:

- *BRITISH JOURNAL OF HOSPITAL MEDICINE*, 2013;74(7):397-401. '**Artificial hydration in the terminally ill patient.**' This article outlines the clinical assessment of the likely net benefit of artificial hydration, and the evidence relating to its use. <http://www.bjhm.co.uk/cgi-bin/go.pl/library/abstract.html?uid=99648>

### **Family members' perceptions of end-of-life care across diverse locations of care**

*BMC PALLIATIVE CARE* | Online – 20 July 2013 – Bereaved family members [i.e., survey participants] had many unmet needs for information about the patient's changing condition, the process of dying, how symptoms would be managed and what to do at the time of death. In addition, many bereaved relatives felt the patient or resident had an unmet need for emotional support and their own emotional needs were not addressed adequately. The last place of care had the most significant effect on all of these variables, with acute care and residential care having the most unmet needs. Hospice had the fewest unmet needs, followed by the palliative and the intensive care units. The authors ... [offer] ... possible practices to address the end-of-life needs of patients and family members. <http://www.biomedcentral.com/content/pdf/1472-684X-12-25.pdf>

Of related interest:

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 18 July 2013 – '**The critical role of caregivers in achieving patient-centered care.**' Although advocacy groups such as the National Alliance for Caregivers have endorsed attention to family members and prominent organizations such as the Patient-Centered Outcomes Research Institute mention families in their research agendas, the critical role of caregivers deserves considerably more attention from clinicians. <http://jama.jamanetwork.com/article.aspx?articleid=1715921>

### **End-of-life care in the U.K.**

#### **Role modelling Gold Standards Framework principles of end-of-life care to care homes**

*END OF LIFE JOURNAL*, 2013;3(3). Care homes (especially care homes providing nursing care) have an important role in the care of dying residents and are now expected to provide good end-of-life care (EoLC). Implementing EoLC tools, such as the Gold Standards Framework (GSF) ... can provide a structure upon which to improve the quality of EoLC. However, some care homes, despite completing the GSF programme, find it difficult to implement the measures required to provide optimal EoLC. This article reflects on the author's experiences over a 2-year period of working alongside such care homes ... [focusing] ... on four aspects of EoLC to help support the staff: dignity in care; advance care planning; care of the dying resident using an integrated care plan for the last days of life; and, assessment and management of pain and depression using specified tools. <http://endoflifejournal.stchristophers.org.uk/personal-reflections/role-modelling-gsf-principles-of-end-of-life-care-to-care-homes>

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

#### **Implementing Physician Orders for Life-Sustaining Treatment [POLST] in California hospitals: Factors associated with adoption**

*JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 18 July 2013 – 65% of hospitals [surveyed] had a policy about POLST, 87% had available blank POLST forms, 84% had educated staff, and 94% reported handling POLST properly in the emergency department and on admission. Hospitals in poor areas and for-profit (vs nonprofit) hospitals were less likely to stock blank POLST forms and to have educated staff, and hospitals with community coalition interaction and in wealthier areas were more likely to handle POLST forms correctly. Although POLST is widely used in California, a significant minority of hospitals remain unprepared 3 years after implementation. Efforts to improve implementation should emphasize dissemination in poorer areas and in for-profit hospitals. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.12367/abstract>



## **Where and how people with schizophrenia die: A population-based, matched cohort study in Manitoba, Canada**

*JOURNAL OF CLINICAL PSYCHIATRY*, 2013;74(6):e551-e557. The attributable percentage of deaths was higher for respiratory illnesses (all ages) and suicide (age 10-59 years only), similar for circulatory illnesses, and lower for cancer in decedents with schizophrenia compared to matched controls. For cancer deaths, decedents with schizophrenia were equally likely to die of gastrointestinal, breast, or prostate cancer, but more likely to die of lung cancer at ages 10-59. Place of death was more likely a nursing home, less likely a hospital for decedents with schizophrenia overall and by specific cause, with the exception of suicide deaths showing no difference by place. Except for those who died in nursing homes, decedents with schizophrenia had higher general practitioner but lower specialist rates and inpatient hospital separations. Understanding where these patients die is critical for improving access to quality palliative end-of-life care. [http://article.psychiatrist.com/dao\\_1-login.asp?ID=10008307&RSID=17372494235377](http://article.psychiatrist.com/dao_1-login.asp?ID=10008307&RSID=17372494235377)

Noted in Media Watch, 5 November 2012, #278 (p.9):

- *JOURNAL OF BIOETHICAL INQUIRY* | Online – 25 October 2012 – '**The importance of patient-provider communication in end-of-life care.**' A narrative of a man with schizophrenia who wished to forgo hemodialysis – a study in the ethical importance of attention to non-verbal communication. <http://www.springerlink.com/content/x621n738448481p3/>

Noted in Media Watch, 27 August 2012, #268 (p.12):

- *SCHIZOPHRENIA RESEARCH* | Online – 20 August 2012 – '**Comparative health care use patterns of people with schizophrenia near the end of life: A population-based study in Manitoba, Canada.**' In the last six months of life, compared to their matched cohort: decedents with schizophrenia had higher rates and number of days residing in a nursing home; had higher ambulatory visit rates to general practitioners, higher rate of visits to psychiatrists and lower rates of seeing other specialists. They were less likely to have opioid analgesia or to receive palliative care. [http://www.schres-journal.com/article/S0920-9964\(12\)00422-7/abstract](http://www.schres-journal.com/article/S0920-9964(12)00422-7/abstract)

## **Aggressiveness of end-of-life care for patients with colorectal cancer in Alberta, Canada: 2006–2009**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 18 July 2013 – A total of 2,074 patients were included [in this analysis]: 50.1% died in an acute care hospital; 3.7% received chemotherapy in the last 14 days of life; and 12.5% had multiple ER [emergency room] visits, 9.5% had multiple hospitalizations, and 2.2% had an ICU admission during the last 30 days of life. Age had the strongest association with chemotherapy use. Geographical region of residence had the strongest association with multiple ER visits and hospitalizations and dying in an acute care hospital. Tumor stage and duration of disease were associated with the ICU admission. The percentage of patients who died in an acute care hospital is higher than the 17% U.S. benchmark. Other indicators of receiving aggressive EOL care are consistent with existing care quality benchmarks. The considerable regional variation, however, indicates potential for system improvements. [http://www.jpmsjournal.com/article/S0885-3924\(13\)00312-6/abstract](http://www.jpmsjournal.com/article/S0885-3924(13)00312-6/abstract)

### **Barry R. Ashpole**



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

## End of life care in the community: The role of ambulance clinicians

*JOURNAL OF PARAMEDIC PRACTICE*, 2013;5(7):394-399. This article presents ... the issues that impact on the delivery of care to patients at the end of life, including symptom and urgent care needs in the last few days of life, preferences for care/place of care, and coordination of care. Each ... poses different challenges for ambulance clinicians. The authors outline an online education package in end of life care, which has been specifically designed for ambulance clinicians in response to an analysis of their training needs. [http://www.paramedicpractice.com/cgi-bin/go.pl/library/article.cgi?uid=99703;article=pp\\_5\\_7\\_394\\_399](http://www.paramedicpractice.com/cgi-bin/go.pl/library/article.cgi?uid=99703;article=pp_5_7_394_399)

Noted in Media Watch, 11 March 2013, #296 (p.10):

- *JOURNAL OF PARAMEDIC PRACTICE*, 2013;5(3):130-131. **'Mortality face-to-face: Death anxiety in paramedics.'** Death, to die, to have died: the irreversible cessation of cerebral, brain stem, circulatory and respiratory function, welcomed by some, unexpected by others, but inescapable by all. Death has in part to palliative care and patient empowerment movements become less of a taboo subject in healthcare, and one that is being discussed more openly within paramedic practice, literature and education. [http://www.paramedicpractice.com/cgi-bin/go.pl/library/article.cgi?uid=97251;article=pp\\_5\\_3\\_130\\_131](http://www.paramedicpractice.com/cgi-bin/go.pl/library/article.cgi?uid=97251;article=pp_5_3_130_131)

## A qualitative exploration of sensing the presence of the deceased following bereavement

*MORTALITY* | Online – 18 July 2013 – The present study sought to explore the meaning-making people engage in with regard to their experience of sensing the presence of the deceased and to focus on the experience of sensing the presence of the deceased through one of the sensory modalities. Analysis identified four super ordinate themes. "There's only one person that ever did that": Sense of presence as a unique and personally distinctive experience referred to participants' descriptions of the nature of the experiences reflecting the character of the deceased person or aspects of their relationship. "I do believe in all that, I've experienced it beforehand": Prior beliefs and understanding sense of presence consisted of the process participants used to try and make sense of their experiences. "It's not frightening anymore": The changing emotional impact of the experience explored the different emotional impacts of the experiences. "They will look at you like you're crazy": The importance of sense-of-presence experiences being validated by others referred to concerns about being stigmatised by others as a result of the experiences as well as positive self-perceptions. The themes are interpreted in the context of previous literature and novel ideas about meaning-making and positive self-perceptions are highlighted. Limitations and suggestions for future research are discussed. <http://www.tandfonline.com/doi/abs/10.1080/13576275.2013.819320>

Of related interest:

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 15 July 2013 – **'Communication and trust in the care provided to a dying parent: A nationwide study of cancer-bereaved youths.'** Compared with children who received end-of-life medical information before their loss, the risk of distrust ... was higher in those who received no information, those who only received information afterward, and those who did not know or remember if end-of-life medical information was provided. <http://jco.ascopubs.org/content/early/2013/07/12/JCO.2012.46.6102.abstract>

## Multiple hospitalizations for complications from terminal illness burdensome for older patients

*NEWS MEDICAL* | Online – 16 July 2013 – "Multiple hospitalizations for complications from a terminal illness may be burdensome for elderly patients and reflect poor quality care," writes Joan Teno of the Warren Alpert School of Medicine of Brown University [Providence, Rhode Island] and colleagues. As reported in a Research Letter,<sup>1</sup> the study population was identified using data from the national Minimum Data Set repository, which includes standardized assessments regularly completed by staff on all nursing home (NH) residents in the U.S. between January 2000 and December 2008. The researchers identified the first baseline assessment in which a resident had a Cognitive Performance Score [CPS] of 4, 5, or 6 indicating moderate to very severe cognitive impairment. Residents were followed up for 1 year from the baseline assessment date (through 2009), and residents were identified who had 2 or more hospitalizations for the same type of the following diagnoses: pneumonia, urinary tract infection (UTI), septicemia, or dehydration or malnutrition. Between 2000 and 2008, 1.3 million NH residents attained a CPS of 4, 5, or 6 and survived at least 30 days after that assessment. Compared with overall survival (476 days), the adjusted survival was significantly lower for all of the burdensome transitions: pneumonia, 95 days; UTI, 146 days; dehydration or malnutrition, 111 days; and septicemia, 89 days. "Future research is needed to understand whether these transitions are based on financial incentives, poor communication, or a lack of resources needed to diagnose and treat a NH resident," the authors write. "... the observed survival suggests that the first hospitalization with these diagnoses for NH residents with advanced cognitive impairment should result in reconsideration of the goals of care..." <http://www.news-medical.net/news/20130717/Multiple-hospitalizations-for-complications-from-terminal-illness-burdensome-for-older-patients.aspx>

1. 'Survival after multiple hospitalizations for infections and dehydration in nursing home residents with advanced cognitive impairment,' *Journal of the American Medical Association*, 2013;310(3):319-320. <http://jama.jamanetwork.com/article.aspx?articleid=1713577>

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### Media Watch: Editorial Practice

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

Noted in Media Watch, 18 March 2013, #297 (p.8):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2013;45(3):488-505. **'Delivery strategies to optimize resource utilization and performance status for patients with advanced life-limiting illness...'** A single case conference added to current specialized community-based palliative care reduced hospitalizations and better maintained performance status. Comparatively, patient/caregiver education was less effective; GP education was not effective. [http://www.jpmsjournal.com/article/S0885-3924\(12\)00274-6/abstract](http://www.jpmsjournal.com/article/S0885-3924(12)00274-6/abstract)

Noted in Media Watch, 21 November 2011, #228 (p.11):

- *PROGRESS IN PALLIATIVE CARE*, 2011;19(6):291-298. **'A narrative literature review of the evidence regarding the economic impact of avoidable hospitalizations amongst palliative care patients in the U.K.'** The evidence base ... relating to the economic impact of avoidable admissions in palliative care is limited. The feasibility of avoiding such admissions and the full economic consequences of such changes have not been clearly demonstrated. <http://www.ingentaconnect.com/content/maney/ppc/2011/00000019/00000006/art00001>

### Guidelines published in wake of Liverpool Care Pathway phase-out announcement

*NURSING TIMES* (U.K.) | Online – 19 July 2013 – National Health Service [NHS] England has published a short guideline for "doctors and nurses caring for people in the last days of life" [see sidebar right] – in the wake of the government's announcement that the LCP was to be phased out over the next six-12 months.<sup>1</sup> The guidance stated: "Where the LCP is being properly used, this must not stop abruptly. The principles of good palliative care, on which it is based, must continue to be upheld: regular assessment and management of symptom control and comfort measures, effective communication with patients and their families, and provision of psychological, social and spiritual support. These principles hold true, whether or not the LCP or any integrated care pathway or plan for the dying is used. In keeping with standard good practice, a named senior clinician should be accountable for the care of the individual patient." <http://www.nursingtimes.net/nursing-practice/clinical-zones/end-of-life-and-palliative-care/interim-guidance-on-nhs-end-of-life-care-published/5061396.article?blocktitle=News&contentID=4385>

#### The NHS England guidance notes that for patients who are currently on the LCP, nurses and doctors should:

Continue to reassess the patient regularly and frequently

Ensure a consultant review of the decision for the patient to remain on the LCP

Ensure that the patient's family is aware that the patient is on the LCP

Communicate with the patient (wherever possible) and family/carers regularly to address questions or concerns about any aspect of care, or the LCP itself

If a patient remains on the LCP, continue to implement it properly

If a patient comes off the LCP, continue to pay attention to, and address, symptom control, comfort measures, and psychological, social and spiritual care, alongside any other treatment

Reassess the patient regularly and frequently so that the care plan can be adjusted

1. 'Guidance for doctors and nurses caring for people in the last days of life,' NHS England, 2013. [http://www.ncpc.org.uk/sites/default/files/Guidance for doctors and nurses%20 Liverpool C are Pathway.pdf](http://www.ncpc.org.uk/sites/default/files/Guidance%20for%20doctors%20and%20nurses%20Liverpool%20Care%20Pathway.pdf)

## Validation of quality indicators for the organization of palliative care: A modified RAND Delphi study in seven European countries (the Europall project)

*PALLIATIVE MEDICINE* | Online – 16 July 2013 – No international set of quality indicators to measure the organizational aspects of palliative care settings exists. In total, 56 ... were rated as useful. These ... concerned the following: the definition of a palliative care service (2), accessibility to palliative care (16), specific infrastructure to deliver palliative care (8), symptom assessment tools (1), specific personnel in palliative care services (9), documentation methodology of clinical data (14), evaluation of quality and safety procedures (1), reporting of clinical activities (1), and education in palliative care (4). These quality indicators ... will be pilot tested in palliative care. <http://pmj.sagepub.com/content/early/2013/07/15/0269216313493952.abstract>

Noted in Media Watch, 8 July 2013, #313 (p.9):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(4):196-198. **'Quality assessment in palliative care – an overview.'** Quality indicators allow us to identify areas where improvement is needed within three domains: structures, processes and outcomes. [http://www.haywardpublishing.co.uk/year\\_search\\_review.aspx?pageid=58&JID=4&Year=2013&Edition=480](http://www.haywardpublishing.co.uk/year_search_review.aspx?pageid=58&JID=4&Year=2013&Edition=480)

Noted in Media Watch, 1 July 2013, #312 (p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 28 June 2013 – **'Quality indicators for palliative care: Update of a systematic review.'** Recent developments in measuring quality of palliative care using quality indicators are mainly quantitative in nature, with a substantial number of new indicators being found. However, the quality of the development process varies considerably between sets. More consistent and detailed methodological descriptions are needed for the further development of these indicators and improved quality measurement of palliative care. [http://www.jpmsjournal.com/article/S0885-3924\(13\)00143-7/abstract](http://www.jpmsjournal.com/article/S0885-3924(13)00143-7/abstract)

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BIOETHICS* | Online – 11 July 2013 – **'Splitting the difference? Principled compromise and assisted dying.'** Compromise on moral matters attracts ambivalent reactions, since it seems at once laudable and deplorable. When a hotly-contested phenomenon like assisted dying is debated, all-or-nothing positions tend to be advanced, with little thought given to the desirability of, or prospects for, compromise. In this article the author argues that principled compromise can be encouraged even in relation to this phenomenon, provided that certain conditions are present. In order to qualify as appropriately principled, the ensuing negotiations require disputants to observe three constraints: they should be suitably reflective, reliable and respectful in their dealings with one another. The product that will result from such a process will also need to split the difference between the warring parties. In assisted dying, the author argues that a reduced offence of "compassionate killing" can achieve this. <http://onlineibrary.wiley.com/doi/10.1111/bioe.12041/abstract>
- *INTERNATIONAL JOURNAL OF LAW & PSYCHIATRY* | Online – 13 July 2013 – **'First do no harm: Pressing concerns regarding euthanasia in Belgium.'** Background information is provided; then major developments that have taken place since the enactment of the Belgian Act on Euthanasia are analysed. Concerns are raised about 1) the changing role of physicians and imposition on nurses to perform euthanasia; 2) the physicians' confusion and lack of understanding of the Act on Euthanasia; 3) inadequate consultation with an independent expert; 4) lack of notification of euthanasia cases; and, 5) organ transplantations of euthanized patients. Some suggestions designed to improve the situation and prevent abuse are offered. <http://www.sciencedirect.com/science/article/pii/S016025271300068X>

Cont.

- *INTERNATIONAL JOURNAL OF LAW & PSYCHIATRY* | Online – 13 July 2013 – '**Physician assisted suicide: The great Canadian euthanasia debate.**' This discussion will focus primarily on the arguments for and against decriminalizing physician assisted suicide, with special reference to the British Columbia case of *Lee Carter vs. Attorney General of Canada*. The aim is to critique the arguments and at the same time to describe the contours of the current Canadian debate. Both ethical and legal issues raised by PAS are clarified. Empirical evidence available from jurisdictions which have followed the regulatory route is presented and its relevance to the slippery slope argument is considered. The arguments presented by both sides are critically assessed. The conclusion suggested is that evidence of harms to vulnerable individuals or to society, consequent upon legalization, is insufficient to support continued denial of freedom to those competent adults who seek physician assistance in hastening their death. <http://www.sciencedirect.com/science/article/pii/S0160252713000563>
- *INTERNATIONAL JOURNAL OF LAW & PSYCHIATRY* | Online – 12 July 2013 – '**Physician-assisted suicide of patients with dementia. A medical ethical analysis with a special focus on patient autonomy.**' The authors present ethical arguments for and against PAS [physician-assisted suicide] for patients in an early stage of dementia. Their focus is on ethical questions of autonomy, conceptual and empirical findings on competence and the assessment of mental capacity to make health care decisions. They present conditions that should be met in order to ethically justify PAS for patients with dementia. From both a psychiatric and an ethical perspective, a thorough differential diagnosis and an adequate medical and psychosocial support for patients with dementia considering PAS and their relatives should be guaranteed. <http://www.sciencedirect.com/science/article/pii/S0160252713000708>
- *JOURNAL OF MEDICAL ETHICS* | Online – 18 July 2013 – '**Medical expertise, existential suffering and ending life.**' The author assesses the position voluntary euthanasia and physician-assisted suicide ought not to be accepted in the cases of persons who suffer existentially but who have no medical condition, because existential questions do not fall within the domain of physicians' professional expertise. <http://jme.bmj.com/content/early/2013/07/17/medethics-2012-100812.abstract>
- *JOURNAL OF MEDICAL ETHICS* | Online – 18 July 2013 – '**A simple solution to the puzzles of end of life? Voluntary palliated starvation.**' Should people be assisted to die or be given euthanasia when they are suffering from terminal medical conditions? Should they be assisted to die when they are suffering but do not have a 'diagnosable medical illness?' What about assisted dying for psychiatric conditions? And is there a difference morally between assisted suicide, voluntary active euthanasia and voluntary passive euthanasia? <http://jme.bmj.com/content/early/2013/07/17/medethics-2013-101379.extract>

## Worth Repeating

### **When a hospice is not a haven**

*PROGRESS IN PALLIATIVE CARE*, 2011;19(1):22-24. This case study describes statements made by a palliative care patient during a face-to-face interview while he was being treated in a hospice. His comments illustrate his unhappiness within the hospice environment to an extent that could compromise his holistic management in this setting. The authors suggest the important aspects of patient care include not just the major palliation issues of symptom control and good communications, but also attention to the rituals of daily living of individuals pertaining to the environment. The atmosphere of the hospice, as experienced by patients through their interactions with staff members within the care setting, is seen to be a significant factor for good holistic care. Hospices may need to be more aware of the impact that every member of staff, both clinical and non-clinical, can make at each patient contact. Becoming more alert to the likes and dislikes of each patient as regards the substance of these contacts may allow hospices to avoid institutionalized care practices and instead to individualize the care they offer to a greater number of their patients. <http://www.ingentaconnect.com/content/maney/ppc/2011/00000019/00000001/art00004>



## Media Watch Online

### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: [HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/](http://APHN.ORG/CATEGORY/MEDIA-WATCH/)

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

### **Australia**

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> (Scroll down to 'International Websites' to 'Palliative Care Network' to access the weekly report)

### **Canada**

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx> (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/?q=mediawatch>

ONTARIO | Toronto Central Hospice Palliative Care Network: <http://www.tcpcn.ca/?s=ashpole>

### **Europe**

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

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

### **International**

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)

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