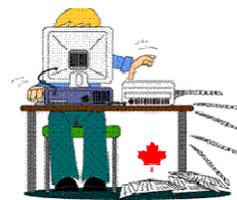


## Media Watch...

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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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013 ©

Compiled & Annotated by Barry R. Ashpole

Focusing on care coordination, communication with caregivers, and staff responsiveness: Scroll down to [Specialist Publications](#) and 'Patient experience is next measurement in value-based care' (p.6), in *American Medical News*.

## Canada

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC News | Online – 9 March 2013 – '**How 20 years has changed the debate over assisted suicide.**' The federal government will argue in front of the B.C. Court of Appeal later this month that the ban on assisted suicide should remain in place. Since 1993, when the Supreme Court of Canada ruled that Sue Rodriguez did not have the right to have a physician help her end her life, several private members bills on the issue have been defeated in the House of Commons. <http://www.cbc.ca/news/politics/story/2013/03/08/pol-the-house-physician-assisted-suicide.html>

Of related interest:

- BRITISH COLUMBIA | CTV News (Vancouver) – 4 March 2013 – '**Appeal into doctor-assisted suicide in B.C. adjourned 2 weeks.**' The appeal of a landmark B.C. Supreme Court ruling that opened the door for terminally ill people to end their lives with the help of a doctor has been adjourned. <http://www.ctvnews.ca/canada/appeal-into-doctor-assisted-suicide-in-b-c-adjourned-2-weeks-1.1180219>
- ALBERTA | *Calgary Sun* – 7 March 2013 – '**Most Albertans support assisted suicide: Study.**' A peer-reviewed study conducted by researchers at the University of Alberta found 77.4% of the 1,203 Albertans studied agreed with the right to a hastened death.<sup>1</sup> Lead researcher Donna Wilson said Albertans who had pets euthanized, or who had to take care of a dying person were more likely to be in favour of assisted suicide while Conservative, less educated and religious people were less likely to support hastened death. "We've had so many cases now where people have wanted to have assisted suicide, people (were) asking for this," she said. <http://www.calgarysun.com/2013/03/06/most-albertans-support-assisted-suicide-study>

1. 'The public's viewpoint on the right to hastened death in Alberta, Canada...', *Health & Social Care in the Community*, 6 December 2012. [Noted in Media Watch, 10 December 2012] <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12007/abstract>

## U.S.A.

### **Dead woman's family won't sue seniors' facility**

CALIFORNIA | *Los Angeles Times* – 5 March 2013 – The 87-year-old woman who died last week after a staff member at a Bakersfield senior living facility refused to perform CPR did not want life-prolonging intervention, her family said. In a statement to the Associated Press, the family of Lorraine Bayless said they do not plan to sue the facility, Glenwood Gardens. A staff member who identified herself as a nurse refused to give Bayless CPR as directed by a Bakersfield fire dispatcher, saying it was against the facility's policy for staff to do so, according to a 911 tape released by the Bakersfield Fire Department. Bayless died 26 February. Family members said they regret that "this private and personal time has been escalated by the media," according to the Associated Press. The 911 tape, in which a Bakersfield fire dispatcher pleads with the staff member to begin CPR, has garnered widespread attention.<sup>1</sup> <http://www.latimes.com/news/local/la-me-0306-bakersfield-cpr-20130306,0,5584341.story?track=rss>

1. Bakersfield Fire Department 911 tape: <http://www.kget.com/mostpopular/story/Dramatic-911-tape-reveals-dispatcher-s-fight-to/g2pqsOnJJUGDHFDTxoK04Q.csp>

### **New York takes the lead on palliative care**

NEW YORK | *Stateline* – 4 March 2013 – Practitioners are quick to point out that palliative care ... entails far more than the relieving of symptoms. Providers with specialized palliative care training help patients and their families understand complicated medical terminology and the options facing them. They also elicit from their patients what their goals are in the face of what is likely to be a grim situation. Some patients, for example, might be willing to endure any number of invasive procedures in order to extend their lives. Others might prefer to forego such treatments, focusing instead on living at home and making their last days or months meaningful without pain or extensive medical intervention. Disease specialists – oncologists, cardiologists, neurologists and others – may well be capable of conducting those conversations and alleviating discomfort. But many are trained to focus only on disease as opposed to quality of life, and are ill-equipped to carry on those conversations; others are loath to give up on "curing" the patient no matter how long the odds or how painful for the patient. "Physicians are trained to treat and cure," says Kathy

### **CPR death highlights end-of-life decision**

USA TODAY | Online – 7 March 2013 – Independent living facilities and assisted living facilities often advertise their medical/nursing care as a reason to place mom or dad into their facility. Many such facilities routinely promote the presence of 24-hour nursing availability, assistance with medication delivery, and the provision of custodial and rehabilitation services in addition to room and board. With such claims, consumers might understandably, but erroneously, believe these homes are health care facilities. <http://www.usatoday.com/story/opinion/2013/03/07/cpr-health-care/1965889/>

McMahon, head of the Hospice & Palliative Care Association of New York State. "They feel like failures if they are not able to cure the patient." Under the New York law, physicians and nurse practitioners caring for patients with advanced diseases are required to offer patients (or their proxies) information and counseling on palliative and end-of-life options. The law doesn't require those providers and institutions to provide palliative care consultation and services, but they must "facilitate access" to those services. <http://www.pewstates.org/projects/stateline/headlines/new-york-takes-the-lead-on-palliative-care-85899455781>

### **Specialist Publications**

Of related interest:

**'Hospice enrollment saves money for Medicare and improves care quality across a number of different lengths-of-stay'** (p.7), in *Health Affairs*.

## International

### End-of-life care in Taiwan

#### **Medical alliance calls on people to sign 'do not resuscitate' orders**

TAIWAN | Focus Taiwan (Taipei) – 5 March 2013 – The Taiwan Alliance for Healthcare Excellence called on people in Taiwan to obtain do-not-resuscitate [DNR], orders which it said could help ease the suffering of terminally ill patients and allow greater freedom for their family members when making decisions to end lives. Only 140,000 people in the country have signed DNR orders, which instruct medical personnel not to use invasive techniques or excessive resuscitation efforts on them if they are in critical condition. An amendment to the Hospice Palliative Care Act, which took effect this year, requires only one family member who is the terminally ill patient's next of kin and two doctors to forgo emergency resuscitation, according to the Department of Health. [http://focustaiwan.tw/ShowNews/WebNews\\_Detail.aspx?Type=aSOC&ID=201303050001](http://focustaiwan.tw/ShowNews/WebNews_Detail.aspx?Type=aSOC&ID=201303050001)

Noted in Media Watch, 4 June 2012:

- *PSYCHO-ONCOLOGY*, 2012;21(7):785-791. **'Family experience with difficult decisions in end-of-life care.'** The most difficult decisions commonly encountered in both hospice and non-hospice [hospital] wards [in Taiwan] related to truth telling, place of care, and alternative treatments. Older age, not being the main family caregiver, and less perception of burdens regarding the Hospice Natural Death Act 2000 were negatively correlated with the difficulty of decisions. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3107/abstract>

#### **Liverpool Care Pathway independent review: First meeting of the review panel**

U.K. (ENGLAND) | Department of Health – 5 March, 2013 – The panel appointed to review the use and experience of the Liverpool Care Pathway for Dying Patients (LCP), chaired by Baroness Julia Neuberger, met for the first time on 18 February 2013. At that meeting the panel acknowledged the serious nature of this review and committed to giving full consideration to all the evidence submitted to it. Members of the public and professionals are invited to share their experiences of the Liverpool Care Pathway, both good and bad, as part of an independent review. Liverpool Care Pathway independent review's public call for evidence was launched on 16 February 2013. Sessions are being held with families and carers to listen to their experiences of LCP. <http://www.dh.gov.uk/health/2013/03/lcp-review-meeting/>



#### **Barry R. Ashpole**

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

#### **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>

## End-of-life care in Australia

### **Dying let down by health system: Report**

AUSTRALIAN ASSOCIATED PRESS | Online – 4 March 2013 – Chronically ill Australians are being let down as they near the end of their life.<sup>1</sup> Chronic disease accounts for more than half of Australian deaths but scant attention is paid to the support a patient needs as their condition slowly deteriorates. Senior Adelaide University lecturer Teresa Burgess and her co-authors say the palliative care system was developed to help people dying of cancer over a relatively short period. However, chronic diseases tend to follow a much slower process and are less predictable. There is a "a progressive functional decline, poor quality of life and increasing dependency on both formal and informal caregivers as well as the health system." The authors favour a patient-centred approach based on actual needs and symptoms rather than a prognosis. They also want increased funding, better leader-

ship and the use of palliative care specialists in end-of-life education and support. <http://au.news.yahoo.com/latest/a/-/latest/16292553/dying-let-down-by-health-system-report/>

#### **Specialist Publications**

Of related interest:

**'Palliative care programs still face obstacles in mainstream cancer care'** (p.8), in *Journal of the National Cancer institute*.

**'In search of a good ending'** (p.9), in *Medical Journal of Australia*.

**'Generalist plus specialist palliative care – creating a more sustainable model'** (p.10), in *New England Journal of Medicine*.

1. 'Meeting end-of-life care needs for people with chronic disease: Palliative care is not enough,' *Medical Journal of Australia*, 2013;198(4):186-187. What should a system that successfully combines interventional and palliative approaches look like? Using the term end-of-life care rather than palliative care could help to change health professionals' attitudes to the skills and training they require. <https://www.mja.com.au/journal/2013/198/4/meeting-end-life-care-needs-people-chronic-disease-palliative-care-not-enough>

## End-of-life care in Ireland

### **Families face geographical lottery for respite care for children with terminal illnesses**

IRELAND | *The Independent* (Dublin) – 4 March 2013 – Families in need of respite care to help look after a child with a terminal illness face a geographical lottery, a new report revealed.<sup>1</sup> Although respite services are provided in all Health Services Executive areas the level of support varies and it also depends on the kind of illness the child has. The report estimated 1,400 children are living with these illnesses. Around 350 die from the conditions annually, most of them in the first year of life. <http://www.independent.ie/lifestyle/health/families-face-geographical-lottery-for-respite-care-for-children-with-terminal-illnesses-29107673.html>

1. 'Respite Services For Children with Life-Limiting Conditions and their Families in Ireland,' Irish Hospice Foundation and the Children's Sunshine Home, March 2013. [Noted in Media Watch, 4 March 2013] <http://hospicefoundation.ie/wp-content/uploads/2012/05/Respite-Services-for-children-with-life-limiting-conditions-and-their-families.pdf>

#### **Quotable Quotes**

*As we journey through life, discarding baggage along the way, we should keep an iron grip, to the very end, on the capacity for silliness. It preserves the soul from desiccation.*  
Humphrey Lyttelton, British broadcaster and jazz musician (1921-2008).

## Appeal of Court of Protection decision

### Judges rule that doctors are not obliged to prolong life 'at all costs'

U.K. | *The Daily Telegraph* – 1 March 2013 – The "deeply unhappy case" resulted in the death of David James, 68, a retired musician, on New Year's Eve, seven months after he was admitted to hospital. His wife May, 67, and daughter Julie, 48, took on a National Health Service trust in a legal bid to keep him alive but ultimately failed to convince the court that he should continue to be given life saving treatment. Sir Alan Ward said that in reaching his decision, he had to take into account the "virtual certainty" that Mr. James would never have left intensive care, that he would always have been reliant on a ventilator and that he would continue to fall victim to recurring infections. "The harsh reality, so harsh that it was understandably impossible for the family to accept it, was that his position was hopeless," he said. The judge accepted medical evidence that Mr. James's life would have become "quite intolerable" were he to survive a further setback. <http://www.telegraph.co.uk/news/uknews/9903693/Judges-rule-that-doctors-are-not-obliged-to-prolong-life-at-all-costs.html>

Noted in Media Watch, 17 December 2013:

- *BRITISH MEDICAL JOURNAL* | Online – 10 December 2012 – '**Hospital is refused permission to withhold "futile" treatment if patient's condition deteriorates.**' A High Court judge has refused to give a hospital trust caring for a man deemed minimally conscious by clinicians a declaration that it need not offer him "futile and burdensome" treatment if his condition deteriorated. The unnamed trust wanted a declaration that it need not give David James ... cardio-pulmonary resuscitation, renal replacement treatment, or invasive support for chronic low blood pressure in an attempt to keep him alive. But at the Court of Protection Mr. Justice Peter Jackson refused the declaration, which was strongly opposed by James's family. <http://www.bmj.com/content/345/bmj.e8404>

### 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.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (ENGLAND) | *Nottingham Post* – 6 March 2013 – **'Post readers say assisted suicide should be legalised.'** Eighty-eight per cent of 317 people who answered the question believed it should be legalised. The controversial issue has been brought back into focus by the case of George Martin – an 86-year-old terminally-ill man from Nottingham who wants to be allowed to die. Exactly 280 people said that he should have his wish granted, with only 29 people saying that he shouldn't. <http://www.thisisnottingham.co.uk/Post-readers-say-assisted-suicide-legalised/story-18332634-detail/story.html#axzz2MmDwT43M>

### Specialist Publications

**'News media coverage of euthanasia: A content analysis of Dutch national newspapers'** (p.10), in *BMC Medical Ethics*.

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

### **Patient experience is next measurement in value-based care**

*AMERICAN MEDICAL NEWS* | Online – 4 March 2013 – While "patient satisfaction" has been a well-known term for a while, it's being replaced or augmented by the "patient experience." Patient satisfaction is about what patients think about their treatment. The patient experience – focusing on care coordination, communication with caregivers and staff responsiveness – is about protocols designed to reduce patient stress, experts said. The patient experience movement has been growing for years, but it has gained momentum, thanks in part to the Affordable Care Act and a push to tie payments increasingly to value and quality of care. Physician organizations ... are offering doctors insight on how to create the best patient experience. Some hospitals are more prescriptive, outlining what actions their employed physicians must take at every visit for the best patient experience. <http://www.ama-assn.org/amednews/2013/03/04/bisa0304.htm>

Noted in Media Watch, 28 June 2010:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 23 June 2010 – **"I'm sitting here by myself...": Experiences of patients with serious illness at an urban public hospital.** <http://www.liebertonline.com/doi/abs/10.1089/jpm.2009.0352>

### **Transmural palliative care by means of teleconsultation: A window of opportunities and new restrictions**

*BMC MEDICAL ETHICS* | Online – 6 March 2013 – This paper aims at describing elements of both the physical workplace and the cultural-social context of the palliative care practice, which are imperative for the use of teleconsultation technologies. Respondents [i.e., study participants] assume: 1. Teleconsultation will hinder physical proximity, thereby compromising anamnesis and diagnosis of new or acutely ill patients as well as "real contact" with the person behind the patient; 2. Teleconsultation will help patients becoming more of a pivotal figure in their own care trajectory; 3. They can use teleconsultation to keep a finger on the pulse; 4. Teleconsultations have a healing effect of their own due to offered time and digital attention; 5. Teleconsultation to open up an additional "gray" network outside the hierarchical structures of the established chain of transmural palliative care. This network could cause bypassing of caregivers and uncertainty about responsibilities; and, 6. Teleconsultations lead to an extended flow of information which helps palliative care professionals to check the stories of patients and medical specialists. <http://www.biomedcentral.com/content/pdf/1472-6939-14-12.pdf>

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

### **Hospice enrollment saves money for Medicare and improves care quality across a number of different lengths-of-stay**

*HEALTH AFFAIRS*, 2013;32(3):552-561. Despite its demonstrated potential to both improve quality of care and lower costs, the Medicare hospice benefit has been seen as producing savings only for patients enrolled 53-105 days before death. Using data from the Health & Retirement Study, 2002-2008, and individual Medicare claims, and overcoming limitations of previous work, the authors found \$2,561 in savings to Medicare for each patient enrolled in hospice 53-105 days before death, compared to a matched, non-hospice control. Even higher savings were seen, however, with more common, shorter enrollment periods: \$2,650, \$5,040, and \$6,430 per patient enrolled 1-7, 8-14, and 15-30 days prior to death, respectively. Within all periods examined, hospice patients also had significantly lower rates of hospital service use and in-hospital death than matched controls. Instead of attempting to limit Medicare hospice participation, the Centers for Medicare & Medicaid Services should focus on ensuring timely enrollment of qualified patients who desire the benefit. <http://content.healthaffairs.org/content/32/3/552.abstract>

Of related interest:

- *HEALTH AFFAIRS*, 2013;32(3):526-525. **'A strategic vision to improve value by organizing around patients.'** Primary care in the U.S. struggles to attract new physicians and to garner investments in infrastructure required to meet patients' needs. The authors believe the absence of a robust overall strategy for the entire spectrum of primary care is a fundamental cause of these struggles. <http://content.healthaffairs.org/content/32/3/516.short>

### **Does our society have the proper understanding of death?**

*JOURNAL OF THE KOREAN MEDICAL ASSOCIATION*, 2013;56(2):129-134. Recent developments in medicine in our society have drawn attention to various phenomena related to death, such as brain death, cardiac death, vegetative death, euthanasia, death with dignity, near-death experiences, hospice, and suicide. The definition and conception of death is significant because its reductionist determination may bring about a denial or taboo of death and a certain limitation on the modes of life and death. <http://www.jkma.org/DOLx.php?id=10.5124/jkma.2013.56.2.129>

Noted in Media Watch, 15 October 2012:

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 12 October 2012 – **'Death: 'Nothing' gives insight.'** <http://www.springerlink.com/content/r838268511656w51/>

### **Recent articles on hospice in America noted in Media Watch**

'Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009,' *Journal of the American Medical Association*, 2013; 309(5):470-477.

<http://jama.jamanetwork.com/article.aspx?articleid=1568250>

'Effect of the Medicare face-to-face visit requirement on hospice utilization,' *Journal of Palliative Medicine*, 2013;16(2):163-166.

<http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0349>

'Better, if not cheaper, care,' *The New York Times*, 4 January 2013.

<http://opinionator.blogs.nytimes.com/2013/01/03/better-if-not-cheaper-care/?emc=eta1>

'On the way to hospice, surprising hurdles,' *The New York Times*, 3 January 2013.

<http://newoldage.blogs.nytimes.com/2013/01/03/hospice-obstacles/>

'Hospices' enrollment policies may contribute to underuse of hospice care in the U.S.,' *Health Affairs*, 2012;31(12):2690-2698.

<http://content.healthaffairs.org/content/31/12/2690.abstract>

## Disenfranchised grief among lesbian and gay bereaved individuals

*JOURNAL OF LGBT ISSUES IN COUNSELING*, 2013;7(1):87-116. Experiences of grief among lesbian and gay (LG) individuals who have encountered the death of their partner remain invisible within the larger culture and within the counseling literature. This contribution provides a conceptual review of literature regarding the bereavement process of individuals who identify as sexual minorities. Special focus is given to the concept of disenfranchised grief and its impact on LG individuals. <http://www.tandfonline.com/doi/abs/10.1080/15538605.2013.758345>

Of related interest:

- *JOURNAL OF DEATH & DYING*, 2013;66(3):195-213. **'Meaning of the death of an elderly father: Two sisters' perspectives.'** Multiple bereaved adult children, as siblings, have rarely been studied. Two sisters participated in separate interviews, followed by standard qualitative analyses of the transcribed narratives. The findings yield contrasting perspectives of the sisters' disparate views of their family, of their father, and their views of each other, that provide insight into the complexity of the sharp differences in their reactions to their father's death. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,1,4;journal,1,262;linkingpublicationresults,1:300329,1>

## Palliative care programs still face obstacles in mainstream cancer care

*JOURNAL OF THE NATIONAL CANCER INSTITUTE* | Online – 2 March 2013 – By all accounts, the past several years has seen palliative care leap into the nation's health care headlines and perhaps its consciousness as never before. Many point to 2010 as a turning point, when Massachusetts General Hospital oncologist Jennifer Temel reported a landmark study ... showing that terminal lung cancer patients given palliative care at the time of diagnosis, along with curative cancer treatment, not only had a better quality of life but also lived a median of 3 months longer.<sup>1</sup> And in 2012, the American Society of Clinical Oncology released a report concluding that according to available evidence, all patients with metastatic cancer can receive palliative care – defined as symptom and pain management, and psychosocial and other supportive care aimed at improving quality of life – at the time of diagnosis.<sup>2</sup> While medical center palliative-care programs continue to gain visibility and grow in number across the country, experts say, many obstacles remain to integrating such programs into mainstream cancer care, particularly early in treatment. <http://jnci.oxfordjournals.org/content/early/2013/02/26/jnci.djt050.extract>

1. '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] <http://www.nejm.org/doi/full/10.1056/NEJMoa1000678>
2. 'American Society of Clinical Oncology... The integration of palliative care into standard oncology care,' *Journal of Clinical Oncology*, 2012;30(8):880-887. [Noted in Media Watch, 13 February 2012] <http://jco.ascopubs.org/content/early/2012/02/06/JCO.2011.38.5161.full.pdf+html>

Of related interest:

- *PALLIATIVE MEDICINE*, 2013;27(1):68-75. **'The association between in-patient death, utilization of hospital resources and availability of palliative home care for cancer patients.'** The findings of this population-based study suggest that a palliative home care team is associated with reduced in-patient deaths and overall hospitalization over the last two months of life. <http://pmj.sagepub.com/content/27/1/68.abstract>
- *PSYCHO-ONCOLOGY* | Online – 6 March 2013 – **'Do healthcare professionals discuss the emotional impact of cancer with patients?'** Only a third of cancer patients [i.e., study participants] discussed the emotional impact of a cancer diagnosis with their healthcare professional. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3258/abstract>

## Journey from pediatric intensive care to palliative care

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 4 March 2013 – This study suggests that there is a feasible alternative location for withdrawal of intensive care and/or compassionate extubation. The study found that one-third of children transferred to hospice for end-of-life care survived the initial withdrawal of intensive therapy; hence, parallel planning should be discussed prior to transfer to hospice. Information gained from this study has contributed toward the creation of a national care pathway to support extubation within a children's palliative care framework. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0448>

## In search of a good ending

*MEDICAL JOURNAL OF AUSTRALIA*, 2013;198(4):175. Despite much development and increasing complexity in health care, humankind's mortality rate remains at 100%. Given the ubiquity of this experience, it could be argued that an important, universal health outcome measure is a "good death." In the late 1990s, a qualitative study identified five things that people want when they approach the end of life: avoiding suffering; avoiding the prolongation of dying; achieving a sense of control; and relieving burdens on, and strengthening relationships with, loved ones.<sup>1</sup> More recently, Australian researchers involved with the Respecting Patient Choices Program in Victoria conducted a randomised controlled trial that objectively demonstrated that advance care planning – "whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care ... should the patient become incapable of participating in treatment decisions"<sup>2</sup> – improved end-of-life care and patient and family satisfaction and reduced stress, anxiety and depression in surviving relatives.<sup>3</sup> <https://www.mja.com.au/journal/2013/198/4/search-good-ending>

### Changing expectations concerning life-extending treatment: The relevance of opportunity cost

*SOCIAL SCIENCE & MEDICINE* | Online – 5 March 2013 – Rising public expectations and health care costs along with demographic ageing raise questions about whether individuals should consider the drain on community resources when deciding whether to have expensive, life-extending medical interventions toward the end of their lifespan. All respondents in this novel, policy-capturing study were prepared to nominate an age along their life trajectory where they would likely decline a life-extending medical intervention indicating a "sense of limits" or "reasonableness" associated with the concept of a natural lifespan. The results suggest possibilities for building on this sense of reasonableness in public discussions of the opportunity cost of current health care resource allocation and by having physicians consider appropriate ways of presenting cost of treatment in end-of life contexts. <http://www.sciencedirect.com/science/article/pii/S0277953613001330>

1. 'Quality end-of-life care: Patients' perspectives,' *Journal of the American Medical Association*, 199;281(2):163-168. <http://jama.jamanetwork.com/article.aspx?articleid=188362>
2. 'Bioethics for clinicians: Advance care planning,' *Canadian Medical Association Journal*, 1996;155(12):1689-1692. <http://www.cmaj.ca/content/155/12/1689.abstract>
3. 'The impact of advance care planning on end of life care in elderly patients,' *British Medical Journal*, 2010;340:c1345. <http://www.bmj.com/content/340/bmj.c1345>

**N.B.** This issue of the *Medical Journal of Australia* includes several articles on end-of-life care. Contents page: <https://www.mja.com.au/journal/2013/198/4> (Scroll down to 'Perspectives' and 'Ethics & Law')

Cont.

Of related interest:

- *JOURNAL OF PARAMEDIC PRACTICE*, 2013;5(3):130131. **'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)

### **Generalist plus specialist palliative care – creating a more sustainable model**

*NEW ENGLAND JOURNAL OF MEDICINE* | Online – 6 March 2013 – The demand for palliative care specialists is growing rapidly, since timely palliative care consultations have been shown to improve the quality of care, reduce overall costs, and sometimes even increase longevity. The field grew out of a hospice tradition in which palliative treatment was delivered only at the end of life, but its role has expanded so that palliative care specialists now also provide palliative treatment in the earlier stages of disease alongside disease-directed medical care, improving quality of care and medical decision making regardless of the stage of illness. In an era when health care organizations [in the U.S.] may soon receive capitated payments for all services that patients receive, many are investing in palliative care to improve overall value. Although this trend has fostered rapid growth of the palliative care specialty, the current model adds another layer of specialized care for seriously ill patients on top of an already complex, expensive health care environment. As in any medical discipline, some core elements of palliative care, such as aligning treatment with a patient's goals and basic symptom management, should be routine aspects of care delivered by any practitioner. Other skills are more complex and take years of training to learn and apply, such as negotiating a difficult family meeting, addressing veiled existential distress, and managing refractory symptoms. Now that the value of palliative care has been recognized, specialists are sometimes called on for all palliative needs, regardless of complexity. <http://www.nejm.org/doi/full/10.1056/NEJMp1215620>

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

#### **I'm ready to go: Do-not-resuscitate orders**

*NURSING REVIEW* | Online – 5 March 2013 – All Australian states and territories now have some form of legislation supporting "advance care planning," and specifically do-not-resuscitate (DNR) orders. The legislation supports the right of a competent adult to refuse medical treatment, and the right of an appointed substitute decision-maker to refuse it on that person's behalf if they are no longer competent. What this end-of-life decision means is that in the event of a cardiac arrest there will be no medical treatments or other measures undertaken to prolong life. <http://www.nursingreview.com.au/pages/section/article.php?s=Breaking+News&idArticle=25166>

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

Representative sample of recent articles, etc:

- *BMC MEDICAL ETHICS* – 6 March 2013 – **'News media coverage of euthanasia: A content analysis of Dutch national newspapers.'** Of the 284 articles containing the term 'euthanasia,' 24% referred to practices outside the scope of the law, mostly relating to the forgoing of life-prolonging treatments and assistance in suicide by others than physicians. Of the articles with euthanasia as the main topic, 36% described euthanasia in the context of a terminally ill patient, 24% for older persons, 16% for persons with dementia, and 9% for persons with a psychiatric disorder. Arguments for included the importance of self-determination and the fact that euthanasia contributes to a good death. Arguments opposing were that suffering should instead be alleviated by better care, providing euthanasia can be disturbing, and society should protect the vulnerable. <http://www.biomedcentral.com/content/pdf/1472-6939-14-11.pdf>

Cont.

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 6 March 2013 – **'Moral differences in deep continuous palliative sedation and euthanasia.'** In palliative care there is much debate about which end of life treatment strategies are legitimate and which are not. Some writers argue there is an important moral dividing-line between palliative sedation and euthanasia, making the first acceptable and the latter not. The authors question this. A recent article has argued we are wrong on two accounts: first, we fail to account properly for the moral difference between continuous deep palliative sedation at the end of life and euthanasia, and, second, we fail to account properly for the difference between permanent loss of consciousness and death.<sup>1</sup> <http://spcare.bmj.com/content/early/2013/03/06/bmjspcare-2012-000431.abstract>
  1. 'Intention, procedure, outcome and personhood in palliative sedation and euthanasia,' *BMJ Supportive & Palliative Care*, 2012;2(1):9-11. <http://spcare.bmj.com/content/2/1/9.abstract> [Noted in Media Watch, 20 February 2012]
  
- *McGILL JOURNAL OF LAW & MEDICINE* | Online – 6 March 2013 – **""Is legalizing physician-assisted suicide a good idea?" – A debate between Professors Daniel Weinstock and Margaret Somerville.'** Part 2 of the journal's recap of the 2013 colloquium on physician-assisted suicide.<sup>1</sup> [http://mjhl.mcgill.ca/blog.php?blog\\_id=76](http://mjhl.mcgill.ca/blog.php?blog_id=76)
  1. Part 1: <http://mjhl.mcgill.ca/blog.php>
  
- *MEDICAL JOURNAL OF AUSTRALIA*, 2013;198(4):190. **'Doctors in support of law reform for voluntary euthanasia.'** <https://www.mja.com.au/journal/2013/198/4/doctors-support-law-reform-voluntary-euthanasia>

### Media Watch Online

#### Asia

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

#### Australia

AUSTRALASIAN PALLIATIVE INTERNATIONAL LINK: <http://www.palliativecarewa.asn.au/news.php> (Scroll down to 'International palliative care news and journal articles')

#### 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>

#### 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>

## Worth Repeating

On the 10<sup>th</sup> anniversary of the SARS epidemic

### **The challenge of providing holistic care in a viral epidemic: Opportunities for palliative care**

*PALLIATIVE MEDICINE*, 2004;18(1):12-18. Disease containment resulted in isolation, where isolation meant the disruption of connectedness. This disruption of connectedness took place at multiple levels: in the patient himself, between the patient and the family, within the family, between the patient and the health care worker, between the patient and society, and between health care workers. As the nature of the disease was uncertain, prognostication was inaccurate. This created difficulties in helping patients and their families prepare for death. The fear of facing the unknown led to safety-seeking behaviours, which could be overcome by repeated exposure to the feared situation. The process of bereavement was disturbed, as traditional death rituals could not be performed by the family. Informants perceived themselves to be suffering as they suffered the same anxieties, fears and grief

as the patient. Dealing with a novel viral epidemic creates spiritual and psychosocial issues similar to those encountered in a palliative care practice. Palliative care workers would do well to be aware of such issues and act proactively when such epidemics arise. <http://pmj.sagepub.com/content/18/1/12.abstract>

#### **Severe acute respiratory syndrome (SARS)**

SARS was first reported in Asia in February 2003. The illness spread to more than two dozen countries in North America, South America, Europe, and Asia before the SARS global outbreak of 2003 was contained. Since 2004, there have not been any known cases of SARS reported anywhere in the world.

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