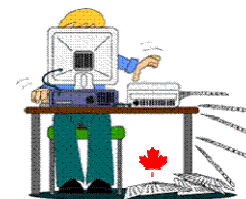


## Media Watch...

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

26 November 2012 Edition | Issue #281



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

Compiled & Annotated by Barry R. Ashpole

Patient wishes and end-of-life care: Scroll down to [Specialist Publications](#) and 'Physician perspectives and compliance with patient advance directives: The role external factors play on physician decision making' (p.7), in *BMC Medical Ethics*.

## Canada

### Debate home-care policy in public

ONTARIO | *The Record* (Kitchener) – 20 November 2012 – The board of directors of the Waterloo Wellington Community Care Access Centre is appropriately undertaking to review a controversial clause it has with its service provider agencies. But quite inappropriately, the review by this public board will be carried out in private. But the decision to go behind closed doors for a review of a highly contentious matter of significant public interest is wrong for several reasons. Since 2007, this clause has either formally gagged – or been perceived in such a manner that it has had the effect of gagging – front-line providers of publicly funded home-care health service from commenting publicly about the quality and volume of this form of care being delivered in this region. In effect, it stood as a punitive barrier to would-be whistleblowers from informing the public that the vulnerable and isolated citizens in need of this care have seen periods where their access to such care and its quality suffered. What's more ... those service reductions flowed from organizational dysfunction at the community care access centre and often came about with little notice to those on the centre's caseload, to the front-line care providers or to the firms they work for. <http://www.therecord.com/opinion/editorial/article/838991--debate-home-care-policy-in-public>

### Hassan Rasouli Case: Status

### Family to take end-of-life fight to Supreme Court of Canada

ONTARIO | CTV News (Toronto) – 19 November 2012 – A Toronto family is fighting to keep their father alive, going all the way to the Supreme Court of Canada in a battle against a hospital medical team that believes the man is in a vegetative state and will not recover.<sup>1</sup> The court ruling comes on the heels of a medical breakthrough in London, Ontario, that saw a patient who had been in a vegetative state for more than a decade actually answer questions related to his care based on brainwave analysis. A team of doctors at the University of Western Ontario said last week that they now know 39-year-old Scott Routley isn't in pain, and are touting the finding as a new way to possibly improve such patients' quality of care.<sup>2</sup> <http://www.ctvnews.ca/canada/family-to-take-end-of-life-fight-to-supreme-court-of-canada-1.1043995>

Cont.

1. *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Published online – 8 April 2011 – **'Court rules that withdrawal of life support is a plan of treatment requiring consent.'** Ontario doctors cannot withdraw life-sustaining treatment from patients without their consent or that of their substitute decision-makers. Rasouli's spouse ... objected, primarily on the grounds that withdrawal of life-sustaining treatment violated a tenet of the Shia Muslim faith... [Noted in Media Watch 11 April 2011.] [http://www.cmaj.ca/earlyreleases/8april11\\_court-rules-that-withdrawal-of-life-support-is-a-plan-of-treatment-requiring-consent.dtl](http://www.cmaj.ca/earlyreleases/8april11_court-rules-that-withdrawal-of-life-support-is-a-plan-of-treatment-requiring-consent.dtl)
2. *THE NATIONAL POST* | Online report – 17 November 2012 – **'Trapped in a motionless body? Scientific advances raise new questions about the 'vegetative' state.'** [Advances in] science raises numerous clinical and ethical issues, including the question of whether awareness of the world outside makes it more imperative to keep vegetative patients alive – or turns their severe disability into a "living hell." The research even opens the door to asking patients themselves whether they want life sustaining treatment to continue. [Noted in Media Watch, 23 November 2012.] <http://news.nationalpost.com/2012/11/17/trapped-in-a-motionless-body-scientific-advances-raise-new-questions-about-the-vegetative-state/>

## **U.S.A.**

### **Care at the end of life**

*NEW YORK TIMES* | Online OpEd – 24 November 2012 – Three years ago, at the height of the debate over health care reform, there was an uproar over a voluntary provision that encouraged doctors to discuss with Medicare patients the kinds of treatments they would want as they neared the end of life. That thoughtful provision was left out of the final bill after right-wing commentators and Republican politicians denounced it falsely as a step toward euthanasia and "death panels." Fortunately, advance planning for end-of-life decisions has been going on for years and is continuing to spread despite the demagoguery on the issue in 2009. There is good evidence that, done properly, it can greatly increase the likelihood that patients will get the care they really want. And, as a secondary benefit, their choices may help reduce the cost of health care as well. Many people sign living wills that specify the care they want as death nears and powers of attorney that authorize relatives or trusted surrogates to make decisions if they become incapacitated. Those standard devices have been greatly improved in recent years by adding medical orders signed by a doctor – known as Physician Orders for Life Sustaining Treatment, or POLST – to ensure that a patient's wishes are followed, and not misplaced or too vague for family members to be sure what a comatose patient would want. [http://www.nytimes.com/2012/11/25/opinion/sunday/end-of-life-health-care.html?emc=eta1&\\_r=0](http://www.nytimes.com/2012/11/25/opinion/sunday/end-of-life-health-care.html?emc=eta1&_r=0)

### **57% of family caregivers provide financial support to loved ones despite limited resources, according to new survey**

CARE IMPROVEMENT PLUS & NATIONAL FAMILY CAREGIVERS ASSOCIATION | Online report – 21 November 2012 – Seventy-five percent of people caring for Medicare beneficiaries with complex health care needs have an annual income of less than \$25,000, yet a majority provide financial support to their loved one. Financial worries, diabetes care and care coordination are among the greatest challenges facing "higher-burden" caregivers – those responsible for a wider range of activities associated with their loved one's care over a prolonged period of time. [http://www.nfcares.org/press\\_room/detail.cfm?num=176](http://www.nfcares.org/press_room/detail.cfm?num=176)

#### **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>

## Long-term care: A problem the Affordable Care Act didn't fix

COLORADO | *Colorado Springs Business Journal* – 21 November 2012 – The Patient Protection & Affordable Care Act failed to solve one health care riddle: how to pay for long-term care for the rising tide of the nation's aging population. Long-term care, at home or in nursing facilities, isn't cheap. In Colorado, a semi-private room in a nursing home runs more than \$72,000 a year. Home health care in Colorado Springs is \$19 an hour, and if round-the-clock care is needed, it costs more than a nursing home. The government tried to crack the code in the Obamacare legislation. The Community Living Assistance Services & Supports ... law provides long-term health insurance to anyone older than 18, regardless of illness or injury. The voluntary program would have clients pay into the program for five years, and they must be working three of those years. After that, they could tap into the benefits. But after 19 months, Secretary of

Health & Human Services Kathryn Sebelius threw in the towel. She cited difficulty in sorting out legal issues, solvency problems and rising health care costs as the reason she was unable to certify the program. <http://csbj.com/2012/11/21/long-term-care-a-problem-the-affordable-care-act-didnt-fix/>

### Specialist Publications

Of special interest:

**'Selecting the best instruments to measure quality of end-of-life care and quality of dying in long term care'** (p.9), in *Journal of the American Medical Directors Association*

**'The natural evolution for palliative care delivery in the U.S.'** (p.11), in *Journal of Pain & Symptom Management*.

Of related interest:

- MARYLAND | WYPR News (Baltimore) – 26 November 2012 – **'The need to discuss palliative care.'** Throughout the debate that resulted in the passage of the Affordable Care Act ... policy makers, economists, and medical ethicists all pointed to the fact that so much of our health care dollars are spent near the end of people's lives. For example, about 25% of Medicare dollars are spent in the last year of life. But end-of-life issues are not just economic issues, of course. When physicians and their patients are confronted with an incurable disease, how do both parties grapple with that challenge? <http://www.wypr.org/podcast/11-26-12-need-discuss-palliative-care>
- SOUTH CAROLINA | *The State* (Columbia) – 21 November 2012 – **'South Carolina cuts long-term nursing-home coverage.'** The state health plan will stop providing coverage for long-term nursing home care after June 2013. The change does not affect the 11,000 people who currently have the insurance. And anyone who signs up for the insurance before June would keep it. <http://www.thestate.com/2012/11/21/2528997/sc-cuts-long-term-nursing-home.html>

## International

### Indian cultural shift revolutionises care for the elderly

INDIA | *The National* (New Delhi) – 25 November 2012 - Indians view families who send their senior family members and relatives to retirement homes, or who hire help at home, as being failures, say experts. But a changing demographic means that a cultural shift is under way. According to the 2011 census, India has 100 million people over the age of 65, a number second only to China. While this accounts for only 8% of the population, the number is expected to double by 2040. Dr. Seema Puri, an associate professor at the Institute of Home Economics at the University of Delhi, said the market seniors' care is about five years old. She estimates there are less than 10 such companies in India. <http://www.thenational.ae/news/world/indian-cultural-shift-revolutionises-care-for-the-elderly>

## Hospice for terminally ill children – playing right until the end

*JAPAN TODAY* | Online article – 25 November 2012 – The astonishing thing is not that this facility exists but that nothing like it has in Japan until it opened on 1 November. It's a children's hospice attached to the Yodogawa Christian Hospital in Osaka. There are an estimated 200,000 children in Japan with illnesses serious enough to require constant care. Many of them are terminal. The world's first children's hospice was founded in England in 1982. Anglican Sister Frances Dominica Ritchie, a qualified nurse, was instrumental in its founding. She came to Japan three years ago with the intention of setting up something similar here. It was an uphill struggle. Public funding was available in Britain but not here. Moreover, attitudes here were negative and largely remain so. Children and death are two incompatible images, or so we like to think. It's painful to face the fact that children die and must be cared for with their imminent death in mind. Ritchie pushed hard and skillfully, thanks to which the Yodogawa facility is now a reality.

But there's no sign of it being in the vanguard of a gathering movement. With two doctors and 14 nurses it accommodates, at present, 30 children. What of the rest?

<http://www.japantoday.com/category/kuchikomi/view/hospice-for-terminally-ill-children-playing-right-until-the-end>

### Moscow to get first children's hospice

RUSSIA | *The Moscow News* – 23 November 2012 – Plans to build a hospice for Moscow's terminally ill children have finally got rolling as City Hall offered up a choice of eight land plots for the sorely missing institution. Two charities, Vera and Podari Zhizn, have teamed up to push for change in palliative care for young patients, and will be in charge of the project. The hospice will be able to treat up to 20 patients at a time, in compliance with international standards.

<http://themoscownews.com/local/20121123/190903275.html>

### Media Watch: Editorial Practice

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

### Distribution

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

### Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

## Needs of dying overlooked by health reforms, claims charity

U.K. (ENGLAND) | *The Daily Telegraph* – 22 November 2012 – New organisations that are meant to be the link between the National Health Service and local councils are failing to consider the needs of dying people, a charity is warning. Less than half (46%) of health and wellbeing boards which have published their strategies mention the needs of people at the end of their lives, said the National Council for Palliative Care (NCPC). A report by the NCPC found that of 152 of the boards, 83 have published their strategies online.<sup>1</sup> But of those 83, only 38 have explicitly considered dying people. The boards have been set up under the Government's health reforms. Eve Richardson, chief executive of the NCPC and the Dying Matters coalition, said: "We really want to encourage these new boards to have a public debate with their communities about the priorities for good end of life care and support." She said the boards needed to "seize the opportunity to join up support for people approaching the end of life. History shows us that overlooking end of life care in major strategies leads to costly fragmentation in care and support that does not meet peoples' needs or wishes." Mike Hobday, director of policy and research at Macmillan Cancer Support, said it was "incredibly disap-

pointing" that so few had considered how social and end-of-life care should work together. <http://www.telegraph.co.uk/health/healthnews/9694529/Needs-of-dying-overlooked-by-health-reforms-claims-charity.html>

1. 'What about end of life care: Mapping England's Health & Wellbeing Boards' vision for dying people,' National Council for Palliative Care, November 2012. <http://www.ncpc.org.uk/sites/default/files/NCPC%20Mapping%20EOLC%20Health%20and%20Wellbeing%20strategy%20briefing%20October2012.pdf>

### Quality of care suffering, says regulator

U.K. (ENGLAND) | BBC News – 22 November 2012 – The quality of services provided to people across the health and care sectors in England is beginning to suffer, according to the regulator. The Care Quality Commission's warning comes after it looked at data from more than 13,000 inspections. The regulator said staff pressures and the rise in complex cases seen in the ageing population meant everyone from hospitals to care homes was struggling. Overall, one in four services failed at least one of the 16 key standards. <http://www.bbc.co.uk/news/health-20442760>

## 56,876 sign palliative care petition

AUSTRALIA (NEW SOUTH WALES) | *The Maitland Mercury* – 21 November 2012 – A palliative care petition with 56,876 signatures will be debated in the Parliament. Last week government bowed to public pressure in promising an extra \$35 million – in addition to the \$86 million a year already allocated – to palliative care over four years starting in March 2013. Health Minister Jillian Skinner invited submissions for the extra funding from organisations with a track record in providing palliative care services. <http://www.maitlandmercury.com.au/story/1134572/56876-sign-palliative-care-petition/?cs=171>

## Terminal cancer patients 'given pointless treatment'

U.K. | *The Daily Telegraph* – 21 November 2012 – Cancer patients who do not have long to live are being given surgery or other treatment even though it will bring them no benefit, doctors are warning. Medics sometimes let the cancer diagnosis "cloud other considerations in their management," leading to substandard care, according to the Royal College of Physicians [and the Royal College of Radiologists].<sup>1</sup> Members of the college have written a report highlighting problems with the care of cancer patients with "urgent" medical needs and making recommendations for improving their care. <http://www.telegraph.co.uk/health/healthnews/9690683/Terminal-cancer-patients-given-pointless-treatment.html>

Cont.

1. 'Cancer patients in crisis: Responding to urgent needs,' Report of a Working Party of the Royal College of Physicians and the Royal College of Radiologists, November 2012.  
<http://www.rcplondon.ac.uk/sites/default/files/documents/cancer-patients-in-crisis-report.pdf>

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

Representative sample of recent news media coverage:

- CHINA | *South China Morning Post* (Hong Kong) – 20 November 2012 – '**Is legalisation of assisted suicide an option for China?**' China needs to talk about saving lives before talking about ending them. <http://www.scmp.com/article/1086568/legalisation-assisted-suicide-option-china>

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

#### **A model for emergency department end-of-life communications after acute devastating events – Part II: Moving from resuscitative to end-of-life or palliative treatment**

*ACADEMIC EMERGENCY MEDICINE*, 2012;19(11):1300-1308. The model ... addresses decision-making capacity, surrogates, and advance directives, including legal definitions and application of these steps.<sup>1</sup> Part II concerns communications moving from resuscitative to palliative and end-of-life treatments. After completing the steps involved in determining decision-making, emergency physicians should consider starting palliative measures versus continuing resuscitative treatment. As communications related to these end-of-life decisions increasingly fall within the scope of emergency medicine practice, we need to become educated about and comfortable with them. <http://onlinelibrary.wiley.com/doi/10.1111/acem.12018/abstract;jsessionid=F8937FB14D25F997527DEFF5C7A8F0F3.d04t02?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

1. *ACADEMIC EMERGENCY MEDICINE*, 2012;19(9):e1068-e1072. '**A model for emergency department end-of-life communications after acute devastating events – Part I: Decision-making capacity, surrogates, and advance directives.**'  
<http://onlinelibrary.wiley.com/doi/10.1111/j.1553-2712.2012.01426.x/abstract>

#### **Unique and universal barriers: Hospice care for aging adults with intellectual disability**

*AMERICAN JOURNAL ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES*, 2012;117(6): 509-532. As life expectancy of people with intellectual disability (ID) has increased, there has been a concurrent increase in age-related illnesses and conditions similar to that of the general population. These circumstances result in people with ID dying from typical life-ending conditions, and thus, they require similar end-of-life services such as palliative and hospice care. Although there are notable barriers to hospice for all, people with ID face additional challenges in accessing the benefits of these services. This article presents a review of the literature on these issues, underscoring the multiple challenges and the importance of a more collaborative approach between hospice and palliative care workers with people with ID, their families, and other important stakeholders. <http://www.aaidjournals.org/doi/abs/10.1352/1944-7558-117.6.509>

**N.B.** This article is published in a special issue of the journal focused on aging and end of life. Contents page: <http://www.aaidjournals.org/toc/ajmr/117/6>

Noted in Media Watch, 1 October 2012:

- *JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES* | Published online – 21 September 2012 – '**End-of-life care and dying: Issues raised by staff supporting older people with intellectual disability...**' <http://onlinelibrary.wiley.com/doi/10.1111/jar.12000/abstract>

**N.B.** See Media Watch of 24 September 2012 (p.9) for additional articles on end-of-life care for people with intellectual disabilities noted in past issues of the weekly report.

## Physician factors that influence patient referrals to end-of-life care

*AMERICAN JOURNAL OF MANAGED CARE*, 2012;18(11):e416-e422. Participants [in this cross-sectional, web-based survey] were most commonly U.S. born (69.1%), married (83.8%), and male (66.0%) with a mean age of 47 years. About half were Caucasian (51.7%). Family/internal medicine physicians were nearly 9 times more likely to make EOL [end of life] referrals, and physicians comfortable discussing EOL care were nearly 7 times more likely to refer. This study highlights factors associated with EOL referrals that may be enhanced at the organizational level through training and educating physicians. Results suggest that organizations should work toward improving physician ease and comfort with EOL conversations. This study serves as an important step toward understanding and reducing physician-level barriers to EOL referrals. <http://www.ajmc.com/articles/Physician-Factors-That-Influence-Patient-Referrals-to-End-of-Life-Care>

Of related interest:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Published online – 23 November 2012 – '**Association between referral-to-death interval and location of death of patients referred to a hospital-based specialist palliative care service.**' Longer referral-to-death interval was associated with death outside the hospital for patients enrolled in a hospital-based service. The study highlights the importance of early referral in predicting the last place of care and location of death of palliative care patients. [http://www.jpmsjournal.com/article/S0885-3924\(12\)00469-1/abstract](http://www.jpmsjournal.com/article/S0885-3924(12)00469-1/abstract)

## Physician perspectives and compliance with patient advance directives: The role external factors play on physician decision making

*BMC MEDICAL ETHICS* | Published online – 21 November 2012 – Following passage of the Patient Self Determination Act in 1990, health care institutions that receive Medicare and Medicaid funding are required to inform patients of their right to make their health care preferences known through execution of a living will and/or to appoint a surrogate-decision maker. The authors evaluated the impact of external factors and perceived patient preferences on physicians' decisions to honor or forgo previously established advance directives (ADs). Physician views regarding legal risk, patients' ability to comprehend complexities involved with their care, and impact of medical costs related to end-of-life care decisions were explored. Their findings highlight the impact, albeit small, external factors have on physician AD compliance. Most respondents based their decision on the clinical situation at hand and interpretation of the patient's initial wishes and preferences expressed by the AD. <http://www.biomedcentral.com/content/pdf/1472-6939-13-31.pdf>

### Qualitative study

#### **Professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but ...'**

*PALLIATIVE MEDICINE* | Published online – 21 November 2012 – While professionals agreed that advance care planning was a good idea in theory, implementation in practice presented them with significant challenges. The majority expressed uncertainty over the general value of advance care planning, whether current service provision could meet patient wishes, their individual roles and responsibilities and which aspects of advance care planning were legally binding; the array of different advance care planning forms and documentation available added to the confusion. In dementia care, the timing of when to initiate advance care planning discussions was an added challenge. This study has identified the professional, organisational and legal factors that influence advance care planning implementation; professional training should target these specific areas. There is an urgent need for standardisation of advance care planning documentation. <http://pmj.sagepub.com/content/early/2012/11/15/0269216312465651.abstract>

Cont.

Of related interest:

- *THE GERONTOLOGIST* | Published online – 15 November 2012 – **'Pathways from religion to advance care planning: Beliefs about control over length of life and end-of-life values.'** <http://gerontologist.oxfordjournals.org/content/early/2012/11/14/geront.gns128.abstract>
- *JOURNAL OF APPLIED GERONTOLOGY*, 2012;31(6):734-742. **'Acceptors and rejecters of life-sustaining treatment differences in advance care planning characteristics.'** <http://jag.sagepub.com/content/31/6/734.abstract>
- *JOURNAL OF MEDICAL ETHICS*, 2012;2012;38:719-720. **'Difficulties in judging patient preferences for shared decision-making.'** <http://jme.bmj.com/content/38/12/719.extract>

### **Can e-learning be used to teach end-of-life care?**

*BMJ SUPPORTIVE & PALLIATIVE CARE*, 2012;2(4):292-293. Caring for people approaching the end of their lives is intensely personal. Experiential teaching is regarded as one of the more reflective and suitable ways of teaching about end-of-life care. Doctors and medical students are used to bedside teaching. Lectures, especially didactic ones, may be comfortingly familiar, but their impact is variable. E-learning has been around for quite some time, but in terms of learning about end-of-life care, it is a relatively 'new kid on the block.' Many clinicians and educators regard e-learning with scepticism, especially in relation to a subject as personal and sensitive as end-of-life care. This is especially the case if they have been exposed to poorly designed e-learning programmes, or those that appear irrelevant, simplistic or not rooted in the real world of practice. The increasing pressure to complete requirements for statutory and mandatory training through e-learning programmes has increased the aversion that some clinicians have toward this whole way of learning. <http://spcare.bmj.com/content/2/4/292.extract>

### **Coordinate My Care: A clinical service that coordinates care, giving patients choice and improving quality of life**

*BMJ SUPPORTIVE & PALLIATIVE CARE*, 2012;2(4):301-307. If palliative care is to lead the way towards a new model for integrated care, the ability to share information across the whole of health and social care is essential. Coordinate My Care (CMC) is a service dedicated to preserving dignity and autonomy at the end of life. Its care pathways enable health professionals from primary and secondary care to put the patient at the centre of health care delivery. This service is underpinned by an electronic solution. The CMC record can be accessed 24/7 by all health and social care professionals who have a legitimate relationship with the patient. <http://spcare.bmj.com/content/2/4/301.abstract>

### **Paediatric palliative care**

### **Using end of life care pathways for the last hours or days of life**

*BRITISH MEDICAL JOURNAL* | Published online – 21 November 2012 – Amongst the recent negative media attention and controversy surrounding the Liverpool Care Pathway, we would like to draw attention to the positive news stories that are quietly emerging around an increasingly relevant and important aspect of palliative care, that of children and young people with life-limiting illness. There are increasing numbers of children and young people with complex, life-limiting conditions living in the community. Department of Health statistics estimate that there are around 20,100 children and young people (aged 0-19 years) who require access to palliative care services in England. 3,900 (67%) of the estimated 5,800 children who die in England per year will have had palliative care needs. Around 10,400 young adults (aged 20-39 years) die each year, and of these, around 4,200 (40%) will have been diagnosed with a life-limiting condition before their 19th birthday. With advances in paediatric medicine, the mortality rate is falling and an increasing number of children are outliving their life expectancies and transitioning in to adult palliative care services. <http://www.bmj.com/content/345/bmj.e7718/rr/616253>



## End-of-life care in Ireland

### **Resistance to prospect of palliative care cuts**

*IRISH MEDICAL TIMES* | Online report – 20 November 2012 – The Irish Hospice Foundation (IHF) has urged the Government to maintain the palliative care budget at 2012 levels "to prevent further fragmentation of the sector." In its pre-Budget submission, the IHF called on the Government to support mainstreaming of existing end-of-life care initiatives "so that the momentum and progress already underway in these programmes is not lost." It urged legislative change to underpin quality standards for end-of-life care in hospitals. There is a need to facilitate training to ensure staff can deliver palliative care confidently in all care settings, the Foundation said. There is also a need to develop mechanisms to facilitate planning for good end-of-life care (including supportive and palliative care) across all care directorates, it stated. The IHF called on the Government to recognise the strategic importance of, and potential of, palliative care within the new and evolving healthcare structures. <http://www.imt.ie/news/latest-news/2012/11/resistance-to-prospect-of-palliative-care-cuts.html>

### **Past, present, and future of palliative care in Japan**

*JAPANESE JOURNAL OF CLINICAL ONCOLOGY* | Published online – 19 November 2012 – Palliative care in Japan has developed through a number of transition stages. The first of these was the recognition of costs for care received at a palliative care unit as eligible for reimbursement under the medical insurance system. The second stage was the recognition of costs for care received from a hospital-based palliative care team as eligible for reimbursement under the medical insurance system. The third stage was government policy relating to palliative care, including establishment of the Cancer Control Act formulation of the Basic Plan to Promote Cancer Control Programs and implementation of the Promotion Plan for the Platform of Human Resource Development for Cancer. A total of 350,000 cancer patients died during fiscal 2011, of which 9% made use of a palliative care unit. The use of palliative care is steadily growing with a trend away from palliative care units toward palliative care teams and care in the home. Whereas it was once seen as the limited treatment of terminal care, palliative care is increasingly becoming integrated into mainstream treatment. Basic palliative care education programs for physicians not specializing in palliative care and other medical practitioners are bringing about the spread of basic palliative care in Japan, thus putting in place broad foundations for the practice of palliative care. Improving the quality of palliative care and providing specialized palliative care are essential in Japan. <http://jjco.oxfordjournals.org/content/early/2012/11/18/jjco.hys188.abstract>

### **Selecting the best instruments to measure quality of end-of-life care and quality of dying in long term care**

*JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION* | Published online – 19 November 2012 – None of the instruments [evaluated] scored positively on all criteria. In both countries [i.e., the U.S. and The Netherlands], of the QOC [quality of end-of-life care] instruments, the End-of-Life in Dementia-Satisfaction With Care best met the criteria, followed by the Family Assessment of Treatment at the End-of-Life Short Version, the Family Perception of Care Scale, and Family Perception of Physician-Family Caregiver Communication. Of the QOD [quality of dying] instruments, the End-of-Life in Dementia-Comfort Assessment at Dying (EOLD-CAD) and Mini-Suffering State Examination (MSSE) met more of the criteria than others. The EOLD-CAD performed better on content and construct validity than the MSSE. The MSSE performed better on feasibility. [http://www.jamda.com/article/S1525-8610\(12\)00342-8/abstract](http://www.jamda.com/article/S1525-8610(12)00342-8/abstract)

Noted in Media Watch, 19 November 2012:

- *LONG-TERM CARE MANAGEMENT* | Published online – 14 November 2012 – '**Palliative care: A long-term care perspective.**' <http://long-term-care.advanceweb.com/Features/Articles/Palliative-Care-A-Long-Term-Care-Perspective.aspx>

## End of life care for people with mental illness

*JOURNAL OF ETHICS IN MENTAL HEALTH*, 2012;7:1-4. Research shows similar viewpoints on quality of life between persons with severe and persistent mental illness (SPMI) who are experiencing a palliative illness and the general population of people with palliative illness. These commonalities are expressed as hope for control of pain and other symptoms, control over levels of intervention to avoid prolonging the dying phase, and control over maintaining meaningful relationships. Yet the rights of the population of persons with SPMI and palliative illness to achieve these goals of care have not been as well honoured as compared to other members of society. [http://www.jemh.ca/issues/v7/documents/JEMH\\_Vol7EndofLifeCareforPeoplewithMentalIllness.pdf](http://www.jemh.ca/issues/v7/documents/JEMH_Vol7EndofLifeCareforPeoplewithMentalIllness.pdf)

Noted in Media Watch, 20 August 2012:

- *JOURNAL OF PSYCHOSOCIAL NURSING & MENTAL HEALTH* | Published online – 17 August 2012 – **'Hospice and palliative care for terminally ill individuals with serious and persistent mental illness...'** <http://www.healio.com/psychiatry/journals/JPN/%7BD0DB264A-B524-4930-9434-7914DF4E3DCC%7D/Hospice-and-Palliative-Care-for-Terminally-Ill-Individuals-with-Serious-and-Persistent-Mental-Illness-Widening-the-Horizons>

## Theories, relationships and interprofessionalism: Learning to weave

*JOURNAL OF INTERPROFESSIONAL CARE* | Published online – 14 November 2012 – The authors illustrate the application of a number of theoretical frameworks they have used to guide their work in interprofessional education (IPE) and collaborative interprofessional care (IPC). Although they do not claim to be experts in any one of these theories, each has offered important insights that have broadened their understanding of the complexities of interprofessional learning and practice. The authors have gained an appreciation for an increasing number of theories relevant to IPE and IPC, and, as a result, they have woven together more key principles from different theories to develop activities for all levels of interprofessional learners and clinicians. They pay particular attention to relational competencies, knotworking/idea dominance, targeted tension and situational awareness. <http://informahealthcare.com/doi/abs/10.3109/13561820.2012.736889>

Noted in Media Watch, 19 November 2012:

- *ILLNESS, CRISES & LOSS*, 2012;20(4):375-386. **'Interdisciplinary education in palliative care: A bold strategy, solution and...'** By combining different ways of knowing and being that are the underlying tenets of interdisciplinary education, we must – by design, curriculum, teaching strategies, and research – reflect the nature and practice of the interdisciplinary palliative care team. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,5,12;journal,1,72;linkingpublicationresults,1:103734,1>

## Grief and loss: A social work perspective

*JOURNAL OF LOSS & TRAUMA*, 2013;18(1):81-90. Despite the wealth of research that exists in the area of death, grief, and loss, the scarcity of literature examining the impact upon social work practitioners is troubling. This article initially draws upon a case study to explore this impact through the theoretical framework of disenfranchised grief. Further comment is made regarding the possible factors that have led to the profession as a whole experiencing disenfranchised grief. The article concludes by arguing that practitioners are best served through the use of "supervision," which enables them to not only examine their practice but also their response to death, grief, and loss. <http://www.tandfonline.com/doi/abs/10.1080/15325024.2012.684569>

Cont.

Of related interest:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Published online – 19 November 2012 – **'Both maintaining hope and preparing for death: Effects of physicians' and nurses' behaviors from bereaved family members' perspectives.'** [http://www.jpsmjournal.com/article/S0885-3924\(12\)00460-5/abstract](http://www.jpsmjournal.com/article/S0885-3924(12)00460-5/abstract)
- *PALLIATIVE & SUPPORTIVE CARE* | Published online – 21 November 2012 – 22 November 2012 – **'Teaching cross-cultural aspects of mourning: A Hindu perspective on dying and death.'** <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8756425&fulltextType=BT&fileId=S1478951512000946>

#### Withdrawal of artificial nutrition and hydration

#### **Best interests and the sanctity of life after *W v M***

*JOURNAL OF MEDICAL ETHICS* | Published online – 21 November 2012 – The case of *W v M and Others*, in which the court rejected an application to withdraw artificial nutrition and hydration from a woman in a minimally conscious state, raises a number of profoundly important medico-legal issues. This article questions whether the requirement to respect the autonomy of incompetent patients, under the Mental Capacity Act 2005, is being unjustifiably disregarded in order to prioritise the sanctity of life. When patients have made informal statements of wishes and views, which clearly – if not precisely – apply to their present situation, judges should not feel free to usurp such expressions of autonomy unless there are compelling reasons for so doing. <http://jme.bmj.com/content/early/2012/11/20/medethics-2012-100907.abstract>

Noted in Media Watch, 3 October 2011:

- U.K. | *Daily Telegraph* – 28 September 2011 – **'Judge rejects family's right to die case.'** <http://www.telegraph.co.uk/health/healthnews/8794013/Judge-rejects-familys-right-to-die-case.html>

#### Community-based palliative care

#### **The natural evolution for palliative care delivery in the U.S.**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Published online – 19 November 2012 – Palliative care in the U.S. has evolved from a system primarily reliant on community-based hospices to a combined model that includes inpatient services at most large hospitals. However, these two dominant approaches leave most patients needing palliative care – those at home (including nursing homes) but not yet ready for hospice – unable to access the positive impacts of the palliative care approach. The authors propose a community-based palliative care (CPC) model that spans the array of inpatient and outpatient settings in which palliative care is provided and links seamlessly to inpatient care; likewise, it would span the full trajectory of advanced illness rather than focusing on the period just before death. Examples of CPC programs are developing organically across the U.S. As our understanding of CPC expands, standardization is needed to ensure replicability, consistency, and the ability to relate intervention models to outcomes. A growing body of literature examining outpatient palliative care supports the role of CPC in improving outcomes, including reduction in symptom burden, improved quality of life, increased survival, better satisfaction with care, and reduced health care resource utilization. Furthermore the examination of how to operationalize CPC is needed before widespread implementation can be realized. This article describes the key characteristics of CPC, highlighting its role in longitudinal care across patient transitions. [http://www.jpsmjournal.com/article/S0885-3924\(12\)00462-9/abstract](http://www.jpsmjournal.com/article/S0885-3924(12)00462-9/abstract)



## Memoir of "a good daughter"

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Published online – 19 November 2012 – This short memoir reflects on the experience of a "good daughter" caring for both parents through their late aging and deaths. The memoir contemplates their personalities as expressed in their aging and the "good daughter's" experience in the death room. Those on a similar journey, whether as travelers, guides, or witnesses, may draw comfort, perhaps reassurance, from this account. [http://www.jpmsjournal.com/article/S0885-3924\(12\)00501-5/abstract](http://www.jpmsjournal.com/article/S0885-3924(12)00501-5/abstract)

Noted in Media Watch, 24 November 2011:

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY*, 2011;59(12):2337-2340. **'When doctors and daughters disagree: Twenty-two days and two blinks of an eye,'** The article describes a case in which two daughters overruled a patient's explicit preference to refuse life-sustaining treatment, leading to burdensome illness before death. <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2011.03700.x/abstract>

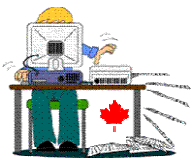
## Equality for followers of South Asian religions in end-of-life care

*NURSING ETHICS* | Published online – 19 November 2012 – Significant minority populations confer richness and diversity to British society. Responsive end-of-life care is a universal need that has ascended the public agenda following myriad reports of inadequate provision. Nevertheless, the potential exists for unwitting discrimination when caring for terminally ill patients on the basis of their religion or faith. Recent implementation of the [U.K.] Equality Act 2010, together with the government and professional initiatives, promises to positively impact upon this area of contemporary relevance and concern, although the extent to which facilitative policies can truly enhance patient care will depend upon how these are translated into care at the bedside. <http://nej.sagepub.com/content/early/2012/11/06/0969733012455567.abstract>

## Improving access to specialist multidisciplinary palliative care consultation for rural cancer patients by videoconferencing: Report of a pilot project

*SUPPORTIVE CARE IN CANCER* | Published online – 19 November 2012 – The Virtual Pain & Symptom Control and Palliative Radiotherapy Clinic was piloted from January 2008 to March 2011. Cancer patients in rural northern Alberta attended local telehealth facilities, accompanied by nurses trained in symptom assessment. The multidisciplinary team at the Cross Cancer Institute in Edmonton was linked by videoconference. Team recommendations were sent to the patients' family physicians. Data were collected on referral, clinical, and consultation characteristics and symptom, cost, and satisfaction outcomes. Delivery of specialist multidisciplinary PC consultation by videoconferencing is feasible, may improve symptoms, results in cost savings to patients and families... <http://www.springerlink.com/content/hk41310g51401ju4/>

Cont. next page



### Barry R. Ashpole

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

Noted in Media Watch, 26 March 2012:

- *HEALTH COMMUNICATION* | Online article – 21 March 2012 – **'Family caregiver participation in hospice interdisciplinary team meetings: How does it affect the nature and content of communication?'** <http://www.tandfonline.com/doi/abs/10.1080/10410236.2011.652935>

**N.B.** See Media Watch, 30 April 2012 (p.8-9) for a listing of articles, reports, etc., on the provision and delivery of end-of-life care in the rural setting.

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Published online – 20 November 2012 – **'Euthanasia: India's position in the global scenario.'** Euthanasia requests have increased as the number of debilitated patients rises in both developed and developing countries such as India due to medical, psychosocial-emotional, socio-environmental, and existential issues amid fears of potential misuse. Following the Aruna Shanbaug case, the Supreme Court granted legal sanction to passive, but not active, euthanasia that is valid till the Parliament legislates on euthanasia. <http://ajh.sagepub.com/content/early/2012/11/18/1049909112465941.abstract>

Noted in Media Watch, 20 August 2012:

- *INDIAN JOURNAL OF PSYCHIATRY*, 2012;54(2):177-183. **'Euthanasia: An Indian perspective.'** <http://indianjpsychiatry.org/article.asp?issn=0019-5545;year=2012;volume=54;issue=2;spage=177;epage=183;aulast=Sinha>
- HEALTH LAW RESEARCH CENTER (Queensland University of Technology, Australia) | Published online – Accessed 20 November 2012 – **'How should Australia regulate voluntary euthanasia and assisted suicide?'** The purpose of this paper is to provide a basis from which to start an informed and rational dialogue about voluntary euthanasia and assisted suicide ... by seeking to chart the broad landscape of issues that can be raised as relevant to how this conduct should be regulated by the law. It is not the authors' purpose to persuade. Rather ... to address the issues as neutrally as possible and to canvass both sides of the argument in an even-handed manner. [http://eprints.qut.edu.au/54757/1/How\\_Should\\_Australia\\_Regulate\\_Voluntary\\_Euthanasia\\_and\\_Assisted\\_Suicide\\_A21\\_\(White\\_and\\_Willmott\).pdf](http://eprints.qut.edu.au/54757/1/How_Should_Australia_Regulate_Voluntary_Euthanasia_and_Assisted_Suicide_A21_(White_and_Willmott).pdf)

## Worth Repeating

### It's news, but is it true?

### **Disturbing questions about the incompatibility of science and news**

CANADA | CBC News (Commentary) – 5 October 2012 – Science 'evolves,' but news 'happens.' As reporters, we want to be able to tell you the 5 Ws, the Who, What, Where, When and Why of the story, with absolute certainty, even though in science it's almost impossible to be eternally certain about anything. Which is why I keep this "three scientists" joke pinned to the bulletin board over my desk: "Three scientists were on a train that had just crossed the border into Scotland. A black sheep was grazing on a hillside. The first scientist peered out of the window and said, 'Look! Scottish sheep are black.' The second scientist said, 'No no, some Scottish sheep are black.' The third scientist with an irritated tone in his voice said, 'My friends, there is at least one field, containing at least one sheep, of which at least one side is black some of the time.'"

<http://www.cbc.ca/news/health/story/2012/10/04/f-crowe-studies-false.html>

**From the archives:** Guyatt GH, Gibson NJ, Cook DJ, Ashpole B, *et al.* 'A Journalist's Guide to Writing Health Stories,' *American Medical Writers Association Journal*, 1999;14(1):32-42. The authors present a set of guidelines to help journalists and editors assess whether a biomedical study or claim like those above is *valid* (that is, close to the truth) and how the data bear on people's concerns about their health. <http://www.amwa.org/default/publications/journal/v14.1/vol.14.no.1.p32.feature.pdf>

## Media Watch Online

### **Canada**

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network:  
<http://www.hnhbpc.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>

### **U.S.A.**

Prison Terminal: <http://www.prisonterminal.com/news%20media%20watch.html>

### **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>

### **Asia**

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'What's New: Reading List Update')

### **International**

Australasian Palliative International Link: <http://www1.petermac.org/apli/links.htm> (Scroll down to 'Media Watch')

Palliative Care Network Community: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

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

---

**Barry R. Ashpole**  
Beamsville, Ontario CANADA

'phone: 905.563.0044  
e-mail: [barryashpole@bellnet.ca](mailto:barryashpole@bellnet.ca)