# Media Watch...

is distributed weekly to my 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 also inform discussion and to encourage further inquiry and research.

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

Compiled & Annotated by Barry R. Ashpole

Impact of changing population demographics: Scroll down <u>Specialist Publications</u> and 'More doctors sought to meet hospice and palliative care demands' (p.7), published in *American Medical News*.

# Canada

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | Vancouver Sun 21 August 2012 -'Doctors dodge hot-button debate.' [At the Canadian Medical Association's annual meeting, MDs passed] a motion calling for a public debate that would lead to a free vote in the House of Commons on the issue of end-of-life care. That echoes an editorial in their CMA Journal, which called for a national debate on death and dying. 1 The country's leading medical journal said it's time for Canadians to debate whether we are prepared to embrace "therapeutic homicide." If the doctors truly want to engage in politics ... the least we should be able to expect from them ... is consistency. So why is it that the same doctors who, when it comes to euthanasia, are in favour of debate and open to rethinking when life ends, are at the same time opposed to discussion that might lead to a rethinking of when life begins?http://www.vancouversun.com/health/Doctors+dodge+ button+debate/7120823/story.html
  - 'Choosing when and how to die: Are we ready to perform therapeutic homicide?' Canadian Medical Association Journal, 2012;184(11):1227 (noted in Media Watch, 13 August 2012). <a href="http://www.cmaj.ca/content/184/11/1227.full">http://www.cmaj.ca/content/184/11/1227.full</a>

# **Corrections & Clarifications**

Noted in Media Watch, 26 March 2012 (p.2), was the publication of the report of the Quebec National Assembly's Select Committee on Dying with Dignity ('La Commission spéciale sur la question de mourir dans la dignité dépose son rapport). An English language edition of the report is now available at:

http://www.worldrtd.net/sites/default/files/newsfiles/Quebec Report%20in%20English.pdf

**N.B.** Canada was rated 9th (of the forty countries surveyed) in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, published by the Economist Intelligence Unit, July 2010. <a href="http://graphics.eiu.com/upload/QOD">http://graphics.eiu.com/upload/QOD</a> main final edition Jul12 toprint.pdf

# U.S.A.

## Inpatient hospice funding is a national crisis...

MICHIGAN LIVE | Online report – 23 August 2012 - The closing of Brian's House is not just a local issue, said Dr. Michael Parmer, medical director for Brian's House and vice president of medical affairs for McClaren's Homecare Group. "This is happening in virtually every community in Michigan and nationally as well," Parmer said. "The hospice in Mount Pleasant is losing huge amounts of money and there are two in northern Michigan where finances are as bad or worse (than at Brian's House). It's becoming a crisis." In the late 1990s, the federal government increased funding for end-of-life care like hospice. Because of this increased funding, Brian's House decided to become a certified inpatient hospice facility. Parmer said the government's emphasis on end-of-life care changed. The Centers for Medicare & Medicaid Services tightened the criteria to cover end-of-life care at inpatient facilities and it became more difficult for patients to qualify for reimbursement at facilities like Brian's House. "That's when the national turn happened," he said. "We have a unit here with 19 beds and we basically average four to six people at any time. Of those, only one or two have full inpatient level of care." http://www.mlive.com/news/baycity/index.ssf/2012/08/hospice inpatient fun ding is a.html

#### Of related interest:

GEORGIA | Atlanta Journal-Constitution - 22 August 2012 - 'Families face difficult decision as hospice care grows in Georgia.' The number of patients in hospice care has more than doubled since 2000, from 700,000 to more than 1.6 million, according to the Virginiabased National Hospice & Palliative Care Organization [NHPCO]. By definition, patients eligible for hospice care are generally in the final months - six months or less – of a life-limiting illness. But in some cases they survive longer. Still, Dr. Richard W. Cohen, medical director of the WellStar Health System's ethics program, said an ongoing problem is, "people don't realize that part of hospice is having the discussion early." http://www.aic.com/health/families-facedifficult-decision-1504042.html

#### **Aging Population**

#### Oldest Americans living longer...

NATIONAL PUBLIC RADIO | Online report - 21 August 2012 - Today's 65-year-olds can expect to live a tad over 20 more years. That's a jump from 1980, when 65-year-olds could expect 14 more years of life. A part of the reason is that deaths from heart disease and stroke have plummeted nearly 50%. A dozen developed nations had life expectancies higher than America's topped again by Japan, where today's 65-yearolds can expect (on average) to celebrate their 89th birthdays, almost four more years of life than their American counterparts. When it comes to the end of life, there may be some consolation that death is less likely to happen in a hospital today (32%) than in 1999 (49%), and more likely to be at home under the ministrations of hospice care.http://www.npr.org/blogs/health/2012/08/21/ 159521631/oldest-americans-living-longer-andare-fitter-and-richer-too

## **Specialist Publications**

Of related interest:

'More doctors sought to meet hospice and palliative care demands' (p.7), published in *American Medical News*.





http://www.worldday.org/

# 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

# Religion and dying: How to address advance care planning in your faith community

MISSOURI | ABC News (Kansas City) - 22 August 2012 – None of the world's major religions insist on futile medical treatments or require adherents to demand of doctors what will not benefit patients. Religions differ on many matters of fact and faith; but most all of them teach compassion, the virtue of comforting the afflicted, and accepting the inevitability of physical death. No religion of which I'm aware condones torture - which is how futile medical treatments often are described by healthcare providers who feel forced to do things to patients that won't help and might harm. Advance directives, followed by direct conversations, address this sort of thing. They are a proven means of preventing the sort of situation that leads to family conflict and misunderstanding, and to

surrogate decisions favoring futile and harmful treatments rather than comfort care when we're terminally ill and dying. <a href="http://abcnews.go.com/blogs/health/2012/08/22/religion-and-dying-how-to-address-advance-care-planning-in-your-faith-">http://abcnews.go.com/blogs/health/2012/08/22/religion-and-dying-how-to-address-advance-care-planning-in-your-faith-</a>

### **Specialist Publications**

Of related interest:

community/

'The search for a higher power among terminally ill people with no previous religion or belief' (p.9), published in the *International Journal of Palliative Nursing*.

#### Of related interest:

■ FLORIDA | Sun-Sentinel (Fort Lauderdale) – 19 August 2012 – 'Jews wrestle with cremation vs. traditional burial.' A relative demands to be cremated, contrary to Jewish law, while the family wants a traditional Jewish burial. What to tell the family? Jewish leaders say the precedent is clear: Dead bodies should be buried, as Abraham buried his wife Sarah in the biblical Book of Genesis. Still, rabbis say they understand the burden. <a href="http://articles.sun-sentinel.com/2012-08-19/news/fl-jewish-burial-cremation-20120819">http://articles.sun-sentinel.com/2012-08-19/news/fl-jewish-burial-cremation-20120819</a> 1 keith-kronish-cremation-rate-burial-plot

# International

#### Palliative care in Russia

#### It's time to stop the suffering

RUSSIA | Open Democracy Russia - 23 August 2012 - In a country of population 140 million, there are still no more than a few palliative care initiatives and hardly any palliative care specialists. The authors estimate that in Moscow alone, about 3,500 children do not receive the palliative care they need... The Russian Ministry of Health is in the process of developing national regulations and requiring each region to establish a children's hospice or a dedicated hospital palliative care unit. This state-led approach contrasts quite sharply with the experience of other countries such as the U.K., where 20 years of concurrent development of palliative care and children's hospice movements preceded active governmental input. In the U.K., government input when it came was based around research, summary and an attempt at coordination, and has probably even now not come to the point of strict national regulation and policy. Describing the unusual development of a social commitment to care for the dying in such an extraordinary country as Russia is a difficult task. There are complex and intertwined barriers and numerous cultural nuances that we cannot hope to convey in totality. The problems associated with palliative care for children in Russia are so fundamental to its basic approach to human rights that they have to be given a chance of being summarised and presented to the world. http://www.opendemocracy.net/odrussia/anna-sonkin/palliative-care-in-russia-its-time-to-stop-suffering

Cont.

Noted in Media Watch, 23 July 2012:

 PALIAŢIA, 2012;5(3). 'Palliative care for children in Russia: Some steps forward.' http://www.paliatia.eu/modules/publisher/item.php?itemid=46

Noted in Media Watch, 25 July 2011:

WORLD WIDE PALLIATIVE CARE ALLIANCE | Online posting – Accessed 20 July 2011 – 'European Association for Palliative Care website in Russian language.'
 <a href="http://www.eapcspeaksrussian.eu">http://www.eapcspeaksrussian.eu</a>.

### Home care in England

# Wasteful town halls are 'denying home care to thousands of elderly people'

U.K. (ENGLAND) | *Daily Mail* – 23 August 2012 – Tens of thousands of pensioners are being denied home helps and other vital services because town halls are wasting millions on their health assessments, a report has found. Over recent years, more and more councils have been restricting free care such as meals on wheels and the installation of stair lifts to those with the most substantial needs. If councils spent their money more efficiently, they could free up at least £312 million from their social care budgets. This would be enough to fund a year's home help for 20,000 elderly people. <a href="http://www.dailymail.co.uk/news/article-2192297/Wasteful-town-halls-denying-home-care-thousands-elderly-people.html">http://www.dailymail.co.uk/news/article-2192297/Wasteful-town-halls-denying-home-care-thousands-elderly-people.html</a>

 'Reducing the cost of assessments and reviews: An adult social care briefing for councils,' Audit Commission, August 2012. <a href="http://www.audit-commission.gov.uk/nationalstudies/localgov/Pages/assessmentsandreviews.aspx">http://www.audit-commission.gov.uk/nationalstudies/localgov/Pages/assessmentsandreviews.aspx</a>

#### Palliative care in Australia

### Funding boost for palliative care...

AUSTRALIA (QUEENSLAND) | *The Australian* – 22 August 2012 – The government's razor gangs are working overtime to save \$4 billion over three years. But Health Minister Lawrence Springborg has told a parliamentary committee the [palliative care] sector will be immune from cuts, and funding will be boosted by 12.9%. The committee held a public hearing ... on issues affecting palliative care, and home and community care services. Palliative Care Queensland president Dr. Rohan Vora told the hearing Gladstone was about to lose after-hours palliative care. At Ipswich, west of Brisbane, the only palliative care physician was about to leave, she said. And on the Gold Coast four palliative care beds were shut earlier in the year and only cancer patients were being treated. Associate Professor Ann Rudden, from the Royal Australasian College of Physicians, said Queensland should have 66 palliative care specialists but only had 22. <a href="http://www.theaustralian.com.au/news/breaking-news/funding-boost-for-palliative-care-in-gld/story-fn3dxiwe-1226455833493">http://www.theaustralian.com.au/news/breaking-news/funding-boost-for-palliative-care-in-gld/story-fn3dxiwe-1226455833493</a>

**N.B.** Review of palliative care services in Queensland (Palliative Care Queensland fact sheet), February 2012): <a href="http://www.palliativecareqld.org.au/wp-content/uploads/2012/02/PCQ-Fact-Sheet-Palliative-Care-Services-in-Queensland.pdf">http://www.palliativecareqld.org.au/wp-content/uploads/2012/02/PCQ-Fact-Sheet-Palliative-Care-Services-in-Queensland.pdf</a>

#### Of related interest:

 AUSTRALIA (QUEENSLAND) | Brisbane Times – 22 August 2012 – "Death-denying' state needs better palliative care." http://www.brisbanetimes.com.au/queensland/deathdenying-state-needsbetter-palliative-care-20120822-24lgs.html

**N.B.** Australia was rated 2nd (of the forty countries surveyed) in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, published by the Economist Intelligence Unit, July 2010. <a href="http://graphics.eiu.com/upload/QOD">http://graphics.eiu.com/upload/QOD</a> main final edition Jul12 toprint.pdf

#### Palliative care in China

#### A new start for end-of-life care

CHINA | *Global Times* (Beijing) – 21 August 2012 – Shanghai Municipal Health Bureau has issued guidelines for a pilot program to set up hospice centers in each of the city's 17 districts by 14 September. The pilot program is one of the city's first steps toward developing end-of-life care in the city, where hospitals can't handle the burden of terminally ill patients. Some 36,000 terminal patients need hospice care in the city every year, according to the local health bureau. However, there are only two hospitals with 50 beds in total devoted to hospice care in the city. Some patients who require care but can't get one of those beds can obtain a regular hospital bed, but most end up at home. Most top-tier hospitals are already overloaded with patients and can't afford the demands of hospice care, said Cheng Wenwu, director of hospice care at the Shanghai Cancer Center. The guidelines advise every local district to set up at least one hospice center at a specific community health center that is capable of providing care to both terminally ill patients and their family members. Under the guidelines, a hospice center must have at least 10 beds designated for end-of-life care along with at least two doctors and four registered nurses, according to the health bureau. Hospices were also advised to obtain support from medical social workers and volunteers. http://www.globaltimes.cn/content/728297.shtml

Noted in Media Watch, 13 February 2012:

CHINA | Channel News Asia (Beijing) – 9 February 2012 – 'China faces shortage on hospice care.' <a href="http://www.channelnewsasia.com/stories/southeastasia/view/1181930/1/.html">http://www.channelnewsasia.com/stories/southeastasia/view/1181930/1/.html</a>

**N.B.** China was rated 37th (of the forty countries surveyed) in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, published by the Economist Intelligence Unit, July 2010. <a href="http://graphics.eiu.com/upload/QOD">http://graphics.eiu.com/upload/QOD</a> main final edition Jul12 toprint.pdf

# Right-to-life patient's family 'want to believe' he can respond, says expert

U.K. (ENGLAND & WALES) | The Guardian – 21 August 2012 - The family of a Muslim man left in an apparently persistent vegetative state after a heart attack five weeks ago "strongly feel" that he is able to understand and respond to them, contrary to what medical experts believe [see sidebar, right]... One expert told the court of protection in London it was a case of family members "wanting to believe" that the braindamaged patient, referred to as L, was capable of responding The 55-year-old patient's family ... are fighting a legal battle for him to receive life-saving treatment if his condition worsens. Pennine Acute Hospitals NHS trust ... is seeking a court declaration that it would not be in his best interests to offer treatment if there was "a life-threatening event," and that treatment should be limited to what doctors consider reasonable to maintain his dignity and relieve pain and discomfort. http://www.guardian.co.uk/law/2012/aug/21/right-to-lifepatient-expert

# Muslim man in court case no longer in 'vegetative state'

U.K. | BBC News – 23 August 2012 – A Muslim man at the centre of a right-to-live court battle is no longer in a persistent vegetative state, London's High Court has heard. http://www.bbc.co.uk/news/uk-england-manchester-

Noted in Media Watch, 30 January 2012:

JOURNAL OF THE ISLAMIC MEDICAL ASSOCIATION OF NORTH AMERICA, 2011;43(3). 'The
end of life, the ends of life: An anthropological view.' <a href="https://jima.imana.org/article/view/7037">https://jima.imana.org/article/view/7037</a>

**N.B.** This issue of *Journal of the Islamic Medical Association of North America* includes several articles on end of life care (contents page: <a href="http://jima.imana.org/index">http://jima.imana.org/index</a>). Several articles on end-of-life care from an Islamic perspective are also noted in Media Watch, 28 March 2011 (p.10).

#### Palliative care in Scotland

# Living and dying well: Reflecting on progress

U.K. (SCOTLAND) | Scottish Partnership for Palliative Care – Accessed 21 August 2012 – This is a report on the implementation of 'Living & Dying Well,' a national action plan for palliative and end of life care, compiled by Scottish Partnership for Palliative Care on behalf of the Living & Dying Well National Advisory Group. <a href="http://www.scotland.gov.uk/Topics/Health/NHS-scotland/LivingandDyingWell/ProgressMarch2012/LivingandDyingWell/ProgressReport">http://www.scotland.gov.uk/Topics/Health/NHS-scotland/LivingandDyingWell/ProgressMarch2012/LivingandDyingWell/ProgressReport</a>

#### Of related interest:

U.K. (ENGLAND) | Department of Health – 21 August 2012 – 'Applying for Capital Grant Scheme funding for hospices.' Details of how to apply for funding from the Capital Grant scheme for hospices are now available. Up to £60m is available as part of the scheme, open to all adults' and children's hospices in England. <a href="http://www.dh.gov.uk/health/2012/08/capital-grant-scheme-funding/">http://www.dh.gov.uk/health/2012/08/capital-grant-scheme-funding/</a>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW ZEALAND HERALD (Auckland) | Online report 23 August 2012 'Palliative Care appalled by Key's euthanasia statement.' Prime Minister John Key's statement that euthanasia already happens in the country's hospitals has appalled the Australian & New Zealand Society of Palliative Care. Speaking on Newstalk ZB, Mr. Key said: "I think there's a lot of euthanasia that effectively happens in our hospitals." But Sinead Donnelly, a palliative medicine specialist and chair of the Australian & New Zealand Society of Palliative Care Aotearoa has hit out, and said Mr. Key seriously misrepresented the care by doctors and nurses in hospitals. http://www.nzherald.co.nz/politics/news/article.cfm?c\_id=280&objectid=10829012
  - Aotearoa is the most widely known and accepted Māori name for New Zealand. It is used by both Māori and non-Māori.
- U.K. | CNN 22 August 2012 'Paralyzed U.K. man dies after losing assisted-suicide case.' Tony Nicklinson, 58, had been refusing food since last week, contracted pneumonia over the weekend, and "went downhill rapidly." The former rugby player was left paralyzed from the neck down by a catastrophic stroke seven years ago, and lost a High Court battle last week to gain a legal right to end his life when he chose. <a href="http://www.cnn.com/2012/08/22/world/europe/uk-locked-in-death/index.html">http://www.cnn.com/2012/08/22/world/europe/uk-locked-in-death/index.html</a>

Noted in Media Watch, 20 August 2012:

- U.K. (ENGLAND & WALES) | BBC News 16 August 2012 'Tony Nicklinson loses High Court right-to-die case.' <a href="http://www.bbc.co.uk/news/health-19249680">http://www.bbc.co.uk/news/health-19249680</a>
- U.K. (ENGLAND & WALES) | Politics.com 20 August 2012 'Britain's options for legalising euthanasia.' These examples [cited by the author] suggest that in Europe there are more or less two options for legalising assisted suicide or euthanasia. These are: 1) Don't make it illegal in the first place (Switzerland); and, 2) Legalise euthanasia or assisted suicide through an Act of Parliament (Netherlands and Belgium) This first option clearly is not available to the U.K. assisted suicide was specifically made illegal in the Suicide Act 1961 (ironically the very Act that made suicide legal for the first time) and euthanasia is considered to be homicide under the law of murder in England & Wales. Therefore, the only likely option for legal change that remains is for right-to-die campaigners is to persuade MPs to take up this issue in the House of Commons. As the high court judges rightly ruled last week, the legal status of assisted suicide and euthanasia is a matter for democratically accountable parliament and not for the courts. <a href="http://www.politics.co.uk/comment-analysis/2012/08/20/analysis-britain-s-options-for-legalising-euthanasia">http://www.politics.co.uk/comment-analysis/2012/08/20/analysis-britain-s-options-for-legalising-euthanasia</a>

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

# More doctors sought to meet hospice and palliative care demands

AMERICAN MEDICAL NEWS | Online report – 21 August 2012 – The U.S. physician work force is failing to keep pace with increasing demands for hospice and palliative care services as more people live longer with chronic diseases, said the American Academy of Hospice & Palliative Medicine [AAHPM]. From 8,000 to 10,000 physician specialists are needed to meet demands in hospice and palliative care programs nationwide, according to the AAHPM. But only 4,500 doctors specialize in the field, and training programs are expected to produce only an additional 4,600 specialists in the next 20 years. Physician shortages will worsen with the aging of the population, said AAHPM President Timothy Quill, MD, director of the palliative care program at the University of Rochester Medical Center in New York. "Demand has grown faster than our ability to produce and train specialists," Dr. Quill said. http://www.ama-assn.org/amednews/2012/08/20/prsc0821.htm

Noted in Media Watch, 23 July 2012:

WASHINGTON DC | Senator for Oregon posting – 19 July 2012 – 'Bill works to make palliative and hospice care available to all Americans.' The Palliative Care and Hospice Education and Training Act focuses on training for new and existing doctors, those who teach palliative care, and other providers who are part of the palliative care team. <a href="http://www.wyden.senate.gov/news/press-releases/wyden-bill-works-to-make-palliative-and-hospice-care-available-to-all-americans">http://www.wyden.senate.gov/news/press-releases/wyden-bill-works-to-make-palliative-and-hospice-care-available-to-all-americans</a>

Noted in Media Watch, 16 July 2012:

HEALTH LEADERS | Online report – 13 July 2012 – 'Palliative care challenged by physician shortage.' While there is about one cardiologist for every 71 people experiencing a heart attack and one oncologist for every 141 newly diagnosed cancer patients, there is only one palliative care physician for every 1,200 people living with a serious or life-threatening illness, according to the Center to Advance Palliative Care. <a href="http://www.healthleadersmedia.com/content/MAG-282158/Palliative-Care-Challenged-by-Physician-Shortage">http://www.healthleadersmedia.com/content/MAG-282158/Palliative-Care-Challenged-by-Physician-Shortage</a>

Patient, caregiver, health professional and researcher views and experiences of participating in research at the end of life: A critical interpretive synthesis of the literature

BMC MEDICAL RESEARCH METHODOLOGY | Published online – 17 August 2012 – The evidence explored within this study demonstrates that the ethical concerns regarding patient participation in EoL [end-of-life] care research are often unjustified. Research studies ... require careful design and execution that incorporates sensitivity to participants' needs and concerns to enable their participation. <a href="http://www.biomedcentral.com/content/pdf/1471-2288-12-123.pdf">http://www.biomedcentral.com/content/pdf/1471-2288-12-123.pdf</a>

# Brain death: Justifications and critiques

CLINICAL ETHICS, 2012;7(3):128-132. Controversies about the diagnosis and meaning of brain death have existed as long as the concept itself. The authors review the historical development of brain death, and then evaluate the various attempts to justify the claim that patients who are diagnosed as brain dead can be considered dead for all legal and social purposes, and especially with regard to procuring their vital organs for transplantation. While they agree with most commentators that death should be defined as the loss of integration of the functioning of the organism as a whole, the authors conclude that patients diagnosed as brain dead have not, in fact, lost this integrated functioning. They close with reflections on the implications of this conclusion generally and particularly with regard to organ transplantation, and briefly make reference to alternative approaches to justifying the procurement of transplantable organs that do not depend upon a flawed approach to the diagnosis of death. <a href="http://ce.rsmjournals.com/content/7/3/128.abstract">http://ce.rsmjournals.com/content/7/3/128.abstract</a>

#### Of related interest:

 CLINICAL ETHICS, 2012;7(3):133-141. 'Loss of faith in brain death: Catholic controversy over the determination of death...' <a href="http://ce.rsmjournals.com/content/7/3/133.abstract">http://ce.rsmjournals.com/content/7/3/133.abstract</a>

## The paradox of increased efficacy and end-of-life care

CLINICAL ONCOLOGY | Published online - 21 August 2012 - This commentary focuses on the complex and often emotionally charged conflict between a patient's desire to "fight the cancer" and his or her unquestionably valid need to focus on end-of-life issues at some point in time. The necessity for honest, open and thorough discussions between patients and their health care team – which usually includes the oncologist, primary care physicians and nurses – about goals, symp-tom control, comfort measures and personal non-health-related decision making cannot be overstated. However, it is critical to acknowledge that this is a dynamic process that may be strongly affected by a number of clinical features unique to an individual patient, including the extent of disease, the severity of cancer-related symptoms and therapy-related toxicity and the presence of co-morbid conditions. Discussions and decisions will be influenced by available therapeutic options. http://www.clinicaloncology.com/ViewArticle.aspx?d=Policy%2 Band%2BManagement&d id=151&i=August+2012&i id=879 &a id=21499

#### Of related interest:

- CONTEMPORARY NURSE, 2012;43(1). 'Behind the rhetoric is palliative care equitably available for all?' Despite the general principle that palliative care is equitably available for all in need, it remains underutilised by certain groups in the community. Ethnic minorities, older people and patients with non-cancer diseases are found to be at a greatest risk for underutilisation of palliative care. <a href="http://www.contemporarynurse.com/archives/vol/43/issue/1/article/4858/behind-the-rhetoric--is-palliative-care">http://www.contemporarynurse.com/archives/vol/43/issue/1/article/4858/behind-the-rhetoric--is-palliative-care</a>
- JOURNAL OF AIDS CLINICAL RESEARCH, 2012;3(5).
   'Outcome measurement in palliative care: Quality of life.' Measuring changes in a patient's health over time, and finding out the reasons for those changes, can help service providers focus on learning and improving the quality of services. <a href="http://www.omicsonline.org/2155-6113/2155-6113-3-159.pdf">http://www.omicsonline.org/2155-6113/2155-6113-3-159.pdf</a>

# We're hands on: Exploring a supplemental approach to hospice care provision

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Published online - 23 August 2012 – The traditional model of hospice care provision is visit-centric and resourceintensive. The authors sought to describe current and prior use of and hospice clinician perspectives on implementing alternatives to the face-toface visit model to inform innovative, resource-conscious approaches to hospice care. Few hospices utilize other technologies, such as videophone, Web portals, or email. Focus group participants identified the need for a significant internal "culture shift" to implement such technologies. Based on these findings, the authors developed a testable conceptual model for implementing supplemental hospice visits utilizing technologic innovations. A number of technologies hold promise for enhancing the efficiency, accessibility, and quality of hospice care when used to supplement face-to-face visits.http://iournals.lww.com/ihp n/Abstract/publishahead/We re Hands On Exploring a Supplemental Approach.99988.aspx

# 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

## Institutional futility policies are inherently unfair

HEC FORUM¹ | Published online – 19 August 2012 – For many years a debate has raged over what constitutes futile medical care, if patients have a right to demand what doctors label as futile, and whether physicians should be obliged to provide treatments that they think are inappropriate. More recently, the argument has shifted away from the difficult project of definitions, to outlining institutional policies and procedures that take a measured and patient-by-patient approach to deciding if an existing or desired intervention is futile. The prototype is the Texas Advance Directives Act,² but similar procedures have been widely implemented both with and without the protection of the law. While this method has much to recommend it, there are inherent moral flaws that have not received as much discussion as warranted. Because these strategies adopt a semblance of procedural justice, it is assumed that the outcomes of such proceedings will be both correct and fair. The author argues there are three main irremediable defects in the policy approach: there is the potential for arbitrary decision-making about futility in specific cases; there are structural, pre-ordained consequences for ethnic minorities who would be disproportionately affected by the use of these procedures; and the use of rationing justifications to support the use of these policies. http://www.springerlink.com/content/q033k26474v2m877/

- 1. HealthCare Ethics Committee Forum
- 2. 'The courts, futility, and the ends of medicine,' *Journal of the American Medical Association*, 2012;307(2):151-152. http://jama.ama-assn.org/content/307/2/151.extract

### Spirituality in end-of-life care

# The search for a higher power among terminally ill people with no previous religion or belief

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2012;18(8):384-389. In a palliative care setting, there is evidence from the practice of spiritual care delivery to suggest that some terminally ill patients may seek, with varying degrees of openness and articulation, to connect with a higher power, or God, despite having expressed no previous interest in religion or belief. Developing a better understanding of the thoughts and feelings of such patients requires insight into the initial triggers of their search. In this small qualitative study ... fear, hope, and a natural connection are posited as possible prompts. The results highlight the complexity of ambivalent feelings toward a transcendent being that can be the focus of anger and blame while simultaneously offering a source of comfort and hope for an afterlife. Moreover, the study revealed something of the extent to which health professionals may feel limited in facilitating necessary discussion by a need to protect patients and themselves from entering an unfamiliar and complex area. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=93644;article=IJPN 18 8 384 389

# Systematic review and meta-analysis of comparative studies

# Do community specialist palliative care services that provide home nursing increase rates of home death for people with life-limiting illnesses?

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Published online – August 2012 – Systematic reviews and meta-analyses suggest that community specialist palliative care services (SPCSs) can avoid hospitalizations and enable home deaths. But more information is needed regarding the relative efficacies of different models. Family caregivers highlight home nursing as the most important service, but it is also likely the most costly. A meta-analysis found evidence to be inconclusive that community SPCSs that offer home nursing increase home deaths without compromising symptoms or increasing costs. But a compelling trend warrants further confirmatory studies. Future trials should compare the relative efficacy of different models and intensities of SPCSs. <a href="http://www.jpsmjournal.com/article/S0885-3924(12)00261-8/abstract">http://www.jpsmjournal.com/article/S0885-3924(12)00261-8/abstract</a>

# Paramedic's 'end-of-life' decision making in palliative emergencies

JOURNAL OF PARAMEDIC PRACTICE, 2012;4(7):413-419. Paramedics in Germany routinely treat palliative care patients at the end-of-life (EoL). They play a legally significant role in EoL decision making... This study was undertaken to determine paramedics' understanding of their role in withholding or withdrawing resuscitation/EoL-treatment of palliative care patients when an advance directive is present. <a href="http://www.paramedicpractice.com/cgi-bin/go.pl/library/article.cgi?uid=92932;article=pp">http://www.paramedicpractice.com/cgi-bin/go.pl/library/article.cgi?uid=92932;article=pp</a> 4 7 413 419;format=pdf

# Taking care of care providers: A wellness program for pediatric nurses

JOURNAL OF PEDIATRIC ONCOLOGY NURSING, 2012;29(5):294-299. The cumulative effect of professional stress and compassion fatigue within the health care profession has been receiving increasing attention. The impact can be especially worrisome for nurses who work with chronic illness populations, such as oncology. While interventions targeted at reducing nurses stress and promoting wellness are cited as necessary, they are often lacking in busy medical environments. In this article, the authors describe a newly developed 10-session wellness program that was offered on two occasions to both inpatient and outpatient nursing staff. The nursing staff chose the content areas, and each session used a combined approach of hands on and didactic learning. Overall, staff found the wellness series very helpful to themselves and to their ability to positively change their job performance. http://jpo.sagepub.com/content/29/5/294.short

# Professional autonomy in medicine: Defending the right of conscience in health care beyond the right to religious freedom

LINACRE QUARTERLY, 2012;79(2):155-168. Health-care professionals [in the U.S.] currently have the right to conscientiously object to any procedure that they deem as morally illicit or that, in their opinion, could harm the patient. However, the right of conscientious refusal in medicine is currently under severe scrutiny. Medical procedures such as abortion and physician assisted suicide that are not commonly medically indicated, but that can be requested by the patient, represent a type of medical care that is the penultimate expression of patient autonomy. When a health care provider exercises his or her conscience in a way that denies the patient immediate access to such procedures, many claim that patient autonomy has been oppressed by the religious convictions of the health-care professional. As such, there is a growing opposition to the protection of conscience rights in health care that deserves attention. A common strategy used to defend conscience rights has been to claim that under the United States Bill of Rights, the health-care professional must be allowed to exercise their religious liberties in the context of their profession. This rationale seems to ignite a more intense opposition to conscience rights as it seems to validate the sense that a health-care professional's religious convictions are protected at the cost of patient autonomy. http://lq.cathmed.metapress.com/content/t41nq3516175658v/

Noted in Media Watch, 9 May 2011:

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2011;305(17):1804-1805. 'Would accommodating some conscientious objections by physicians promote quality in medical care?' <a href="http://jama.ama-assn.org/content/305/17/1804.extract">http://jama.ama-assn.org/content/305/17/1804.extract</a>

Noted in Media Watch, 14 March 2011:

- PRESS ASSOCIATION | Published online 7 March 2011 'House passes bill to resolve conscience conflict.' <a href="http://washingtonexaminer.com/news/2011/03/house-passes-bill-resolve-conscience-conflict">http://washingtonexaminer.com/news/2011/03/house-passes-bill-resolve-conscience-conflict</a>
- JOURNAL OF MEDICAL ETHICS | Published online 9 March 2011 'Conscientious refusals to refer: Findings from a national physician survey.' Data suggest there is no uncontroversial way to resolve conflicts posed when patients request interventions that their physicians cannot in good conscience provide. <a href="http://jme.bmj.com/content/early/2011/03/09/jme.2010.041194.abstract">http://jme.bmj.com/content/early/2011/03/09/jme.2010.041194.abstract</a>

# A 10-year literature review of family caregiving for motor neurone disease: Moving from caregiver burden studies to palliative care interventions

PALLIATIVE MEDICINE | Published online – 20 August 2012 – This ... review was consistent with previous research documenting the substantial burden and distress experienced by motor neurone disease family caregivers and revealed important points in the trajectory of care that have the potential for negative effects. This review has also implicated the need for improvements in access to palliative care services and highlighted the absence of interventions to improve care. http://pmj.sagepub.com/content/early/2012/08/17/0269216312455729.abstract

Noted In Media Watch, 4 July 2011:

PALLIATIVE MEDICINE | Published online – 28 June 2011 – 'Experiences of dying, death and bereavement in motor neurone disease: A qualitative study.' The needs of patients and carers are not being adequately met in the final stages of motor neurone disease and there appears a need for increased, co-ordinated support from palliative care services. Carer burden is excessive... http://pmj.sagepub.com/content/early/2011/06/28/0269216311410900.abstract

#### Of related interest:

■ PALLIATIVE & SUPPORTIVE CARE | Published online – 21 August 2012 – 'The extra burdens patients in denial impose on their family caregivers.' Caregivers of patients in denial experience added burdens, which they bear without most of the usual sources of support. The burden is accentuated when patients are noncompliant with care, placing themselves in dangerous situations. <a href="http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8676195&fulltextType=RA&fileId=S1478951512000491">http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8676195&fulltextType=RA&fileId=S1478951512000491</a>

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#### 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.

# Comparative health care use patterns of people with schizophrenia near the end of life: A population-based study in Manitoba, Canada

SCHIZOPHRENIA RESEARCH | Published online – 20 August 2012 – In the last six months of life, compared to their matched cohort: decedents with schizophrenia had higher rates and number of days residing in a nursing home; had higher ambulatory visit rates to general practitioners, higher rate of visits to psychiatrists and lower rates of seeing other specialists. They were less likely to have opioid analgesia or to receive palliative care. <a href="http://www.schres-journal.com/article/S0920-9964(12)00422-7/abstract">http://www.schres-journal.com/article/S0920-9964(12)00422-7/abstract</a>

#### **Media Watch Online**

#### 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

#### 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: <a href="http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c">http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c</a>

#### Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <a href="http://centres.sg/">http://centres.sg/</a> (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

e-mail: <u>barryashpole@bellnet.ca</u>

'phone: 905.563.0044