# 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.

# 19 September 2011 Edition | Issue #219



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Fulfilling the principles of a good death: Scroll down to <u>Specialist Publications</u> and 'Information of imminent death or not: Does it make a difference?' (p.9), published in the *Journal of Clinical Oncology.* 

# <u>Canada</u>

# New nursing research initiative helps at the end of life

BRITISH COLUMBIA | Delta Optimist (Ladner) – 15 September 2011 – Not all people with chronic life-limiting illness such as lung, heart and kidney disease cancer or dementia require specialized palliative care services. They do, however, require care aimed at improving their quality of life, by preventing and relieving suffering through early identification, assessment and treatment of physical, psychosocial and spiritual concerns. However, according to a recen study by the Canadian Institute for Health Information, three-quarters of the British Columbians who die, do so without being identified as people who could benefit from the services associated with palliative care, such as pain management, psychosocial support and advance care planning. That could soon change, thanks to ongoing research undertaken by some of the province's universities and health authorities.1 http://www.deltaoptimist.com/news/nursing+research+initiative+helps+life/541 5348/story.html

1. Initiative for a Palliative Approach in Nursing: Evidence & Leadership (iPANEL) website: <u>http://www.ipanel.ca/</u>

**N.B.** Canadian Institute for Health Information website: <u>http://www.cihi.ca/CIHI-ext-portal/internet/EN/Home/home/cihi000001</u>

**Specialist Publications** 

Of particular interest:

**'Patient navigators becoming the norm in Canada'** (p.7), published in the *Canadian Medical Association Journal.* 

'Family caregivers' ideal expectations of Canada's Compassionate Care Benefit' (p.8), published in Health & Social Care in the Community.

# <u>U.S.A.</u>

### New panel to review New Jersey's end-of-life care services

NEW JERSEY | Associated Press – 18 September 2011 – New Jersey has a new advisory council that proponents say will help make end-of-life care decisions easier for residents and their families. The 21-member panel's main mission will be conducting a comprehensive study on the quality and cost-effectiveness of end-of-life care services and how easily they can be accessed. It also will develop policy recommendations relating to state agencies, policymakers, health care providers and third-party payers. <a href="http://www.necn.com/09/18/11/New-panel-to-review-NJs-end-of-life-care/landing\_politics.html?&apID=de4b70fdbf494a04b9f19329da1d275a">http://www.necn.com/09/18/11/New-panel-to-review-NJs-end-of-life-care/landing\_politics.html?&apID=de4b70fdbf494a04b9f19329da1d275a</a>

From Media Watch dated 11 July 2011:

NEW JERSEY | Associated Press – 10 July 2011 – 'Lawmakers send Governor Christie two measures to help residents with end-of-life care decisions.' One bill would mandate that the state create a document that enables patients to indicate their preferences regarding life-sustaining treatment. The other creates an advisory council that would conduct a comprehensive study on the quality and cost-effectiveness of end-of-life care services and how easily they can be accessed. http://www.therepublic.com/view/story/2d6fd7b4b4f546d9acceb81cd962fce6/NJ-XGR--Legislative-Preview/

#### <u>Dignity Thera</u>py

### For the dying, a chance to rewrite life

NATIONAL PUBLIC RADIO | Online report -12 September 2011 – For several decades, psychiatrists who work with the dying have been trying to come up with new psychotherapies that can help people cope with the reality of their death. One of these ... asks the dying to tell the story of their life. This end-of-life treatment, called dignity therapy, was created by a man named Harvey Chochinov. When Chochinov was a voung psychiatrist working with the dving, he had a powerful experience with one of the patients he was trying to counsel – a man with an inoperable brain tumor. "One of the last times that I went into his room to meet with him, on his bedside table was a photograph of him when he had indeed been young and healthy and a bodybuilder, and it was this incredible juxtaposition of these two images," says Chochinov. So in the bed there's his patient – this skeleton of a man – very pale and weak. On the bedside table, there's this portrait of a

glistening, muscled giant. And Chochinov says that sitting there, it was very clear to him that by placing this photograph in such a prominent position, the man was sending a message: This was how he needed to be seen.<u>http://www.npr.org/2011/09/12/140336</u> <u>146/for-the-dying-a-chance-to-rewrite-life</u>

# **Specialist Publications**

Of particular interest:

'Dignity conserving care at end-of-life: A narrative review' (p.8), European Journal of Oncology Nursing.

'America's care of serious illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospital' (p.9), published in the *Journal of Palliative Medicine.* 

From Media Watch dated 11 July 2011:

MANITOBA | PostMedia News – 6 July 2011 – 'Therapy helps dying patients tend to unfinished business, Canadian study says.' Researchers have come up with a list of questions to help terminally ill people share their memories, hopes and regrets as they look back on their lives. Their approach helps terminally ill patients tend to unfinished business and find peace in their final days. <a href="http://www.canada.com/health/Therapy+helps+dying+patients+tend+unfinished+business+Canadia">http://www.canada.com/health/Therapy+helps+dying+patients+tend+unfinished+business+Canadia</a> <a href="http://www.canada.com/health/Therapy+helps+dying+patients+tend+unfinished+business+Canadia">http://www.canada.com/health/Therapy+helps+dying+patients+tend+unfinished+business+Canadia</a> <a href="http://www.canada.com/health/Therapy+helps+dying+patients+tend+unfinished+business+Canadia">http://www.canada.com/health/Therapy+helps+dying+patients+tend+unfinished+business+Canadia</a> <a href="http://www.canada.com/health/Therapy+helps+dying+patients+tend+unfinished+business+Canadia">http://www.canada.com/health/Therapy+helps+dying+patients+tend+unfinished+business+Canadia</a> <a href="http://www.canada.com/health/Therapy+helps+dying+patients+tend+unfinished+business+Canadia</a>

#### Code status

#### For many older gays, a toll of time and isolation

*NEW YORK TIMES* | OpEd – 12 September 2011 – Long after I had asked the paramedics to stop chest compression, I was more dejected and frustrated by this patient's death than by almost any I had experienced as a physician. Sure, performing CPR after cardiopulmonary arrest on a frail man in his late 90s was likely to be an exercise in futility. And, in retrospect, we should have been more aggressive at the nursing home about suggesting he change his status from "full code" to "do not resuscitate." But that wasn't the main reason this man's death continued to gnaw at me. My patient was gay, and as a gay geriatrician I had felt a connection with him unlike any I'd had with my other patients. We never directly discussed his sexuality; initially, I only knew that he was a lifelong bachelor and a retired history professor who had taught for many years at Emory University in Atlanta. http://www.nytimes.com/2011/09/13/health/views/13cases.html? r=1

# International

#### €58m replacement care centre and hospital opens in Cork

IRELAND | *Irish Times* – 19 September 2011 – A new €58 million palliative care centre and hospital was officially opened in Curraheen, Cork, following the transfer of patients from the facility's previous home on the city's northside at a site that was in operation for more than 100 years. Kevin O'Dwyer, chief executive of St Patrick's/Marymount, said emotions ran high as 47 residents and patients moved ... to the new building. The new facility ... replaces the 63-bed St Patrick's Hospital and 24-bed Marymount Hospice in St Luke's. It has an additional 20 beds bringing to 44 the number of hospice beds. The number of beds for elderly respite care remains at 63. <u>http://www.irishtimes.com/newspaper/ireland/2011/0919/1224304355489.html</u>

#### 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.

# How half our hospitals and care homes are failing the nation's elderly

U.K. | *Daily Mail* – 16 September 2011 – Half of the U.K.'s hospitals and care homes are failing to look after patients, a damning report warns.<sup>1</sup> Campaigners warned that the basic care of the most vulnerable in society was being 'cast aside' as it was deemed 'too costly or difficult.' This latest report is yet further evidence of the poor treatment and neglect of the elderly in hospital wards and care homes. Of the 137 hospitals visited by inspectors ... in the last year, 49% were found to be failing basic standards of care and wellbeing. <u>http://www.dailymail.co.uk/health/article-</u>2037974/Hospitals-care-homes-failing-elderly.html

1. 'The state of health care and adult social care in England,' Quality Care Commission, 2011. http://www.cqc.org.uk/\_db/\_documents/State\_of\_Care\_final\_-\_tagged.pdf

Of related interest:

UNITED NATIONS NEWS CENTRE | Online report - 16 September 2011 -'Governments must make health of older people a priority, says UN rights chief.' "Regrettably, prejudice against and stigmatization of older persons [known as ageism] are consistently reported everywhere in the world," High Commissioner for Human Rights Navi Pillay [recently] told the UN Human Rights Council's panel on the right to health of older persons, citing discrimination based on age in areas as vital as social protection policies, employment laws, and access to public services.http://www.un.org/apps/news/st ory.asp?NewsID=39583&Cr=pillay&Cr1 \_

# Palliative care expert says "healthcare is at the heart of British society"

BRITISH EMBASSY WASHINGTON | Online posting – 14 September 2011 – German physician Claudia Bausewein discusses the U.K.'s leadership in palliative care. The film is one of the 'See Britain through my eyes' series featuring individuals from home and abroad talking about their experiences of modern Britain in the run up to the London 2012 Olympic and Paralympic Games. Claudia's film is being released to coincide with a palliative care conference for visiting German doctors at St Christopher's Hospice in London. <u>http://ukinusa.fco.gov.uk/en/news/?view=News&i</u> d=654415482

# Healthy savings in care at home

*THE AUSTRALIAN* | Online report – 15 September 2011 – Hundreds of thousands of patients could be treated at home, \$108 million could be saved and the equivalent of a 500-bed hospital could be freed up in each state if Medicare rebates better funded home visits by doctors, a new study shows. A Deloitte study of the Hospital in the Home service<sup>1</sup> has found that when patients are discharged from hospital early and get treated by nurses and doctors at home it is 32% more cost-effective for governments. <u>http://www.theaustralian.com.au/national-affairs/health/healthy-savings-in-care-at-home/story-fn59nokw-1226137269913</u>

1. 'Economic Analysis of Hospital in the Home,' Hospital in the Home Society of Australia, 2011. <u>http://webcache.googleusercontent.com/search?q=cache:2kviwwwpvclJ:www.hithsociety.org.au/ lit</u> <u>erature 62557/Economic Analysis\_of\_Hospital\_in\_the\_Home+Economic+analysis+of+hospital+in</u> <u>+the+home&cd=1&hl=en&ct=clnk&gl=ca</u>

# Ellesmere Port Santa wants to deliver early presents to terminally ill children

U.K. | *Ellesmere Port Pioneer* (Cheshire) – 14 September 2011 – Father Christmas wants to bring some festive cheer early – for those children who will not make it to 25 December. Bobby Highton ... has been dressing up as Santa for 20 years and is now offering his services to anyone who knows a child with a terminal illness who may not be around to wake up on Christmas morning. http://www.ellesmereportpioneer.co.uk/ellesmere-port-news/local-ellesmere-port-news/2011/09/14/ellesmere-port-santa-wants-to-deliver-early-presents-to-terminally-ill-children-55940-29414431/

Cont.

From Media Watch dated 21 December 2009:

 USA TODAY | Online report – 15 December 2009 – 'Hospice Santa volunteers face grief, kids' hard questions.' The non-profit national volunteer service organization known as Santa-America has 175 hospice-trained Santas, scattered over more than 40 states, who visit terminally ill children or youngsters who are grieving because of the loss or impending loss of a parent. The volunteer Santa's receive ongoing instruction in grief, bereavement, symptom management and spirituality. http://www.usatoday.com/news/health/2009-12-16-hospicesanta16\_st\_N.htm.

#### Economic trends

# Cost of dying rises as funeral costs soar, says Bath University researchers

U.K. | This is Bath - 14 September 2011 -The cost of dying ... has risen by a fifth in just the last four years, according to researchers from a West university. Increased funeral costs, which now normally easily exceed £3,000 are key to the increase, with the whole package - from service to headstone and a wake - rising by £400 to £7,248 on average. Researchers ... found the cost of dying was rising faster than the cost of living. Inflation may have topped 4.5% this week, but the rise in costs of funerals is more than five per cent. And, according to sociology lecturer Kate Woodthorpe ... the number of people dying will rocket in the next 20 years. "Currently the number of deaths each year is at an alltime low," she said. "In 2009, 491,348 deaths were registered. It is anticipated, that the number of deaths will rise significantly and by 2030. This equates to a rise of 17%

in the death rate in less than 20 years," she added. <u>http://www.thisisbath.co.uk/Cost-</u> <u>dying-rises-funeral-costs-soar-says-</u> Bath/story-13327275-detail/story.html

#### Burial customs

# Beating a spiritual path to the country's war dead

VIETNAM | *The Economist* – 10 September 2011 – Many Vietnamese believe it is vital to give a proper burial to dead ancestors to ensure that they become guardian spirits rather than angry ghosts tormenting their descendants, bringing illness and misfortune. Nearly four decades after North Vietnam defeated the American-backed south, hundreds of thousands of bodies of fallen Vietnamese soldiers remain missing, causing anguish and (many say) bad luck for their families.<u>http://www.economist.com/node/2152865</u> <u>8</u>

#### Assisted (or facilitated) death

Representative sample of recent news media coverage:

AUSTRALIA (SOUTH AUSTRALIA) | *The Australian* – 17 September 2011 – 'Row over end-of-life legislation.' Adelaide intensive care specialist Peter Sharley doesn't mince words: "This bill has enormous shortcomings. It needs to be dropped. It's not fixable." The bill in question concerns physician-assisted dying or, more bluntly, voluntary euthanasia. And as president of the Australian Medical Association's South Australian branch, Sharley has enormous influence over its fate. Although this bill is state-specific, it raises issues that have ebbed and flowed – mostly ebbed – nationwide during recent years as legislators attempt to tackle two intertwined questions: Is voluntary euthanasia ever justified? And, if so, can laws safeguard the dying? <a href="http://www.theaustralian.com.au/news/row-over-end-of-life-legislation/story-e6frg6n6-1226138904622">http://www.theaustralian.com.au/news/row-over-end-of-life-legislation/story-e6frg6n6-1226138904622</a>

#### 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. <a href="http://www.pcn-e.com/community/pg/file/world/">http://www.pcn-e.com/community/pg/file/world/</a>

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

### Grief in children and adolescents bereaved by sudden parental death

ARCHIVES OF GENERAL PSYCHIATRY, 2011;68(9):911-919. Grief reactions abate over time for most children and adolescents bereaved by sudden parental death; however, a subset shows increased or prolonged grief reactions, which in turn increases the risk of functional impairment and depression. Research regarding interventions designed to relieve the burden of grief in bereaved children and adolescents are needed. Such efforts also should assess and address grief reactions in the surviving parent. http://archpsyc.ama-assn.org/cgi/content/abstract/68/9/911

From Media Watch dated 12 September 2011:

 JOURNAL OF CHILD & ADOLESCENT TRAUMA, 2011;4(3):233-257. 'Complicated grief reactions in children and adolescents.' Until recently, scales to assess complicated grief in youth were based on adult constructs of complicated grief and did not include many of the symptoms and reactions proposed for post trauma grief. Much can be learned from adult theories and findings. <u>http://www.tandfonline.com/doi/abs/10.1080/19361521.2011.599358</u>

# Family berates doctor for refusing to follow law and remove feeding tube from woman in a coma

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online article – 15 September 2011 – Ramona Estévez, a woman aged 91 with Parkinson's disease and in an irreversible coma after a massive stroke, died on 6 September 14 days after doctors were told by the government of the autonomous community of Andalusia to remove her feeding tube. This is the first time that a public administration in Spain has had to intervene and force doctors to abide by the law. Ms. Estévez had repeatedly expressed her desire not to die suffering, although she had not put her wishes down in writing. <a href="http://www.bmj.com/content/343/bmj.d5868.extract">http://www.bmj.com/content/343/bmj.d5868.extract</a>

From Media Watch dated 16 May 2011:

SPAIN | Associated Press – 13 May 2011 – 'Terminally ill could get right to die faster under law approved by Spanish government.' The Spanish government has approved a law that gives terminally ill patients the right to hasten their deaths by halting medical treatment. Halting medical treatment in terminal cases is common practice in Spanish hospitals but was never explicitly permitted. <a href="http://www.washingtonpost.com/world/terminally-ill-could-get-right-to-die-faster-under-law-approved-by-spanish-government/2011/05/13/AF9N3g2G\_story.html">http://www.washingtonpost.com/world/terminally-ill-could-get-right-to-die-faster-under-law-approved-by-spanish-government/2011/05/13/AF9N3g2G\_story.html</a>

#### 'Do Not Attempt Cardiopulmonary Resuscitation' discussions at the point of discharge: A case note review of hospice practice following local integrated policy implementation

*BMJ SUPPORTIVE & PALLIATIVE CARE*, 2011;1(2):123-126. Two retrospective case note reviews of 50 patients discharged over two 4-month periods (2007 and 2009) [found] there was a high proportion ... of CPR discussions for patients discharged from the hospice. Reasons for not discussing CPR were: potential for excess distress ... and lack of time. Of those discussing CPR on discharge, 90% took forms home in both years. The reasons patients did not take forms home were: form not taken in error; patients refusing a form at home; form to be arranged by general practitioner and one incomplete discussion. The proportion of patients with forms already at home increased from 10% (2007) to 28% (2009). <a href="http://spcare.bmj.com/content/1/2/123.abstract">http://spcare.bmj.com/content/1/2/123.abstract</a>



# Compassionate community networks: Supporting home dying

**BMJ SUPPORTIVE & PALLIATIVE CARE.** 2011;1(2):129-133. How may communities be mobilised to help someone dving at home? This article outlines the thinking behind an innovative compassionate community project being developed at Weston-Super-Mare, U.K. In this project, a health professional mentors the dying person and their carer to identify and match: a) the tasks that need to be done; and, b) the members of their social network who might help with these tasks. Network members may subsequently join a local volunteer force to assist others who are network poor. Performing practical tasks may be more acceptable to some family, friends and neighbours than having to engage in a conversation about dying, and provides a familiarity with dying that is often lacking in modern societies, so in this model, behavioural change precedes attitudinal change. The scheme rejects a service delivery model of care in favour of a community development model, but differs

from community development schemes in which the mentor is a volunteer rather than a health professional, and also from those approaches that strive to build community capacity before any one individual dying person is helped. The pros and cons of each approach are discussed by the authors. http://spcare.bmj.com/content/1/2/129.abstra ct

#### The personal value of being a palliative care Community Volunteer Worker [in] Uganda: A qualitative study

PALLIATIVE MEDICINE | Online article – 15 September 2011 – The aim of this study was to evaluate the motivation for becoming a volunteer and the personal impact of being a palliative care Community Volunteer Worker in Uganda. The results identified the cultural wish to help people as a key motivator in becoming a volunteer. http://pmj.sagepub.com/content/early/2011/09/14/ 0269216311413628.abstract

# Patient navigators becoming the norm in Canada

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article – 15 September 2011 – Where's the map to direct patients through the twists, turns and unmarked pathways of the health care system? Increasingly, the North American solution isn't a map but rather a personal guide known as a patient navigator. But unlike the U.S., where patient navigation is a somewhat helter-skelter unregulated occupation ... in Canada, it's slightly more regulated, with often-defined roles and responsibilities. <u>http://www.cmaj.ca/site/earlyreleases/15sept11\_patient-navigators-becoming-the-norm-in-canada.xhtml</u>

From Media Watch dated 1 August 2011:

 CANCER, 2011;117(15 Suppl):3590-3600. 'Patients, family caregivers, and patient navigators.' Navigation services may be strengthened by establishing a partnership between the patient, family/ caregiver, and the navigator. <u>http://onlinelibrary.wiley.com/doi/10.1002/cncr.26263/full</u>

# The role of the medical emergency team in end-of-life care: A multicenter, prospective, observational study

*CRITICAL CARE MEDICINE* | Online article – 15 September 2011 – The authors investigated the role of medical emergency teams in end-of-life care planning at ... university-affiliated hospitals in Australia, Canada, and Sweden. [Patient population comprised] 518 patients who received a medical emergency team call over one month. Issues around end-of-life care and limitations of medical therapy arose in approximately one-third of calls, suggesting a mismatch between patient needs for end-of-life care and resources at participating hospitals. These calls frequently occur in elderly medical patients and out of hours. Many ... do not return home, and half die in hospital. http://journals.lww.com/ccmjournal/Abstract/publishahead/The\_role\_of\_the\_medical\_emergency\_team\_in.98271.aspx

# Dignity conserving care at end-of-life: A narrative review

EUROPEAN JOURNAL OF ONCOLOGY NURSING | Online article – 14 September 2011 – [In this study] several care actions were identified related to all themes contained within the Dignity Model, except aftermath concerns. Examples include: controlling symptoms; listening to the patient and taking them seriously; providing advice concerning how to cope on a daily basis; treating patients as equals and with respect, and; encouraging the family members' presence. Evidence for supporting palliative care services has previously been found to be weak in determining solutions to meet individual's important needs. Drawing together primary research, as in this study, is therefore of importance. The suggested care actions will be used to develop a dignity care pathway for end-of-life care, which is currently being evaluated by the authors. The intention is to provide more valid evidence for the effectiveness of the care actions suggested. http://www.ejoncologynursing.com/article/S1462-3889(11)00126-8/abstract

### Family caregivers' ideal expectations of Canada's Compassionate Care Benefit

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online article - 15 September 2011 – The authors present the findings of 57 interviews conducted in 2007-2008 with Canadians who have cared for a dying family member to examine their ideal expectations of the Compassionate Care Benefit (CCB) – a social programme providing job security and income support for workers caring for a dying person. Findings reveal that there are gaps between respondents' ideal expectations and their experienced realities. Such gaps may lead to disappointment being experienced by those who believe they should be eligible for the programme but are not, or should be entitled to receive some form of support that is not presently available. This analysis plays an important role in identifying potential changes for the CCB that may better support family caregivers, in that the

From Media Watch dated 12 September 2011:

ideal expectations serve as a starting point for articulating desirable programme amendments.<u>http://onlinelibrary.wiley.com/d</u> <u>oi/10.1111/j.1365-</u> 2524.2011.01028.x/abstract

#### Extract from *Health & Social Care in the Community* article

For jurisdictions looking to create new social programmes to support caregivers based upon labour policy strategies and legislation, this analysis identifies considerations that should be made at the outset of development. For jurisdictions that already have employment-based caregiver support programmes, this analysis demonstrates that programme challenges may not always be met through legislative changes alone but also through measures such as increasing awareness.

 ONTARIO | *The Record* (Waterloo) – 3 September 2011 – 'Family battles debilitating disease, bureaucracy.' Over 5,900 Canadians received compassionate care benefits ... last year, a payment that lasts six weeks. Most people with ALS, however, can survive for years before succumbing to the disease, so the death-within-six-months criteria doesn't appear to make them eligible. <u>http://www.therecord.com/news/local/article/588949--family-battles-debilitating-diseasebureaucracy</u>

Of related interest:

 PALLIATIVE MEDICINE | Online article – 9 September 2011 – 'Adaptation and psychometric evaluation of the Preparedness for Caregiving Scale, Caregiver Competence Scale & Rewards of Caregiving Scale in a sample of Swedish family members of patients with lifethreatening illness.' Family members often take on many caring responsibilities, with complex issues and challenges to consider. Feelings of preparedness, competence and reward are ... concepts that may protect caregiver wellbeing and decrease negative outcomes related to caregiving. http://pmj.sagepub.com/content/early/2011/08/24/0269216311419987.abstract

### Information of imminent death or not: Does it make a difference?

JOURNAL OF CLINICAL ONCOLOGY | Online article – 12 September 2011 – Informed patients significantly more often had parenteral drugs prescribed as needed (i.e., PRN), had his or her family informed, died in his or her preferred place, and had family who were offered bereavement support. There was no difference in symptom control (i.e., pain, anxiety, confusion, nausea, and respiratory tract secretions) between the [study] groups. Providing information of imminent death to a patient with cancer at the end of life does not seem to increase pain or anxiety, but it does seem to be associated with improved care and to increase the likelihood of fulfilling the principles of a good death. <a href="http://jco.ascopubs.org/content/early/2011/09/11/JCO.2011.34.6247.abstract">http://jco.ascopubs.org/content/early/2011/09/11/JCO.2011.34.6247.abstract</a>

### Palliative care in the genomic era

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2011;13(5):298-308. Have you wondered why certain diseases are more prevalent in some family members and not others? Why does morphine provide therapeutic relief of pain for some patients and not others with the same disease? Why should an individual diagnosed with Huntington disease receive palliative care at the time of diagnosis? How is a complete family health history and three-generation pedigree useful to hospice and palliative care nurses? All of these questions have the common thread of genetic and genomic factors that influence health. The purpose of this article [is to provide an] update on selected aspects in genetics and genomics that impact palliative care and provide resources such as the U.S. Surgeon General's Family History Initiative<sup>1</sup> including the online assessment program that results in an organized family pedigree. The selected topics are pharmacogenomics of morphine, family history, and palliative care for persons with genetic disorders.<u>http://journals.lww.com/jhpn/Abstract/2011/09000/Palliative\_Care\_in\_the\_Genomic\_Era\_9.aspx</u>

1. U.S. Surgeon General's Family History Initiative website: http://www.hhs.gov/familyhistory/

#### America's care of serious illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospital

JOURNAL OF PALLIATIVE MEDICINE | Online article – 16 September 2011 – Over the past ten years the number of palliative care teams in hospitals has more than doubled. Yet despite the myriad of benefits of palliative care, as well as its recent growth, much more progress is needed. Millions of Americans facing serious illness do not yet have access to palliative care from the point of diagnosis throughout the course of the illness. Availability also various considerably by region and by state. http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.9634

From Media Watch dated 18 July 2011:

- CENTER TO ADVANCE PALLIATIVE CARE (CAPC) | Online report 14 July 2011 'Palliative care in hospitals continues rapid growth for 10th straight year, according to latest analysis.' The number of hospitals with a palliative care team increased from 658 (24.5%) to 1,568 (63.0%) a steady 138.3% increase from 2000-2009 [according to a new analysis released by CAPC<sup>1</sup>]. http://www.capc.org/news-and-events/releases/07-14-11
  - 1. 'Growth of palliative care in U.S. hospitals 2011 snapshot,' Center to Advance Palliative Care, July 2011. http://www.capc.org/news-and-events/releases/capc-growth-snapshot-2011.pdf

N.B. See 2011 Public Opinion Research on Palliative Care: A Report Based on Research by Public Opinion Strategies, Center to Advance Palliative Care, July 2011 (noted in Media Watch dated 4 July 2011). http://www.capc.org/tools-for-palliative-care-programs/marketing/public-opinion-research/2011-public-opinion-research-on-palliative-care.pdf

# Heartsink encounters: A qualitative study of end-of-life care in out-of-hours general practice

JOURNAL OF THE ROYAL SOCIETY OF MEDICINE, 2011;2(9):70. The emotional effects of palliative care encounters on out-of-hours GPs should not be underestimated. The authors' interpretation distinguished the term 'heartsink' from its usual context, the "heartsink patient,' to a different meaning, that of the imminent palliative care encounter triggering a sensation of heartsink for some out-of-hours doctors. Therefore, the term 'heartsink encounter,' rather than heartsink patient, seemed more fitting. Pressed services may encourage a culture where discussion or debrief with a colleague after a palliative care encounter is not perceived as a practical option. <u>http://shortreports.rsmjournals.com/content/2/9/70.short</u>

From Media Watch dated 25 April 2011:

 BMJ SUPPORTIVE & PALLIATIVE CARE | Online article – 20 April 2011 – 'What challenges good palliative care provision out-of-hours? A qualitative interview study of out-of-hours general practitioners.' Out-of-hours doctors ... were not confident about their palliative care knowledge and expressed a wish for more education. Lack of familiarity with patients requiring acute palliative care, compared with the closer bonds formed within the in-hours general practice setting, was perceived as troublesome and problematic, and lack of follow-up was felt to be a major factor. <u>http://spcare.bmj.com/content/early/2011/04/21/bmjspcare-2011-000015.abstract</u>

#### Assisted (or facilitated) death

#### Guarding the gates of St. Peter: Life, death and law making

*LEGAL STUDIES* | Online article – 14 September 2011 – In 2009 the [U.K.] legislature, judges and Director of Public Prosecutions (DPP) each turned their attention to issues around assisted suicide. The legislature decided not to change the law. The judges decided the existing law was insufficiently clear and required the Director to clarify it. The Director flirted with reforming the law, but then drew back from such a legislative role. His published prosecution policy has been considered as a contribution to the regulation of death and dying, and as such has been found wanting. However, considered in the context of the proper roles of Parliament, courts and prosecutors, and seen as an exercise in constitutional restraint, the Director's approach should be appraised rather differently. From this perspective, the decision of the Judicial Committee of the *House of Lords in R (Purdy) v DPP* raises significant concerns for the legitimacy of decision making in the contested moral issues that arise in healthcare ethics. In our democracy, courts should be wary of usurping legislative authority in areas where the Parliamentary position is clear. They should be reluctant to take sides in the protracted war over access to a 'good death.' http://onlinelibrary.wiley.com/doi/10.1111/j.1748-121X.2011.00205.x/abstract

From Media Watch dated 12 September 2011:

BRITISH MEDICAL JOURNAL | Online report – 6 September 2011 – 'Prosecutors have taken no action over cases of suspected assisted suicide since new guidance was issued.' Since the introduction of new guidance in February 2010 around 30 people who were suspected of assisted suicide have been referred to the Crown Prosecution Service, but no prosecutions have so far followed. <a href="http://www.bmj.com/content/343/bmj.d5668.extract">http://www.bmj.com/content/343/bmj.d5668.extract</a>

Of related interest:

 QUALITY HEALTH RESEARCH | Online article – 9 September 2011 – 'On euthanasia, resistance, and redemption: The moralities and politics of a hospice.' Euthanasia/assisted dying, the desire to hasten death, and religious supportive care at the end of life are controversial issues that have been heavily debated within the academic and medical communities. Little research has been done on hospice patients' views, despite hospices being political spaces, espousing a range of perspectives on assisted dying, religiosity, and "good deaths." http://ghr.sagepub.com/content/early/2011/09/02/1049732311421181.abstract

#### Media Watch Online

The weekly report can be accessed at several websites, among them:

#### Canada

Ontario | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: http://www.hnhbhpc.net/Resources/UsefulLinks/MediaWatch/tabid/97/Default.aspx

Ontario | HPC Consultation Services: http://www.hpcconnection.ca/newsletter/inthenews.html

Ontario | Mississauga Halton Palliative Care Network: http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1

#### U.S.A.

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

#### International

Global | Palliative Care Network Community: http://www.pcn-e.com/community/pg/file/all/

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

U.K. | Omega, the National Association for End of Life Care: http://www.omega.uk.net/news.htm



# 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: <a href="http://www.ipcrc.net/barry-r-ashpole.php">http://www.ipcrc.net/barry-r-ashpole.php</a>

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