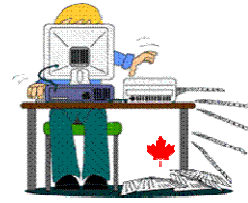


## Media Watch...

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.

1 June Edition | Issue #99



Compilation of Media Watch 2008, 2009 ©

Compiled & Annotated by Barry R. Ashpole

**Barriers to end of life care: Scroll down to [U.S.A.](#) and 'Terminally ill patients delay talk of hospice.'**

## Canada

### Canada faces crisis in caring for elderly

ONTARIO | Canwest News Service – 30 May 2009 – Canada will soon face a serious crisis in caring for the elderly unless policy-makers act now to head it off, says a Carleton University researcher. Gabrielle Mason ... says lifestyle changes combined with an aging population are about to create a serious eldercare crunch in Canada. Mason said that policy-makers should keep Canada's aging society in mind so that the (government) can adjust and design infrastructure, policies, plans and resources which celebrate increased longevity and reduce dependencies on family. By 2015 there will be more people in Canada over the age of 65 than under the age of 15, according to Statistics Canada's. And the number of seniors is expected to double over the next 25 years. "Canadian citizens deserve and should expect good quality of life in their elder years," said Mason. "A minimum level of care shouldn't be considered a luxury." <http://www.canada.com/Life/Canada+faces+crisis+caring+elderly+researcher/1647275/story.html>

### Media Watch: Supplement

#### Assisted (or Facilitated) Death: The Debate in Canada

Summarized are notably "developments" – also highlighting those in other countries – that inform discussion in Canada on end-of-life issues, specifically the debate on assisted (or facilitated) death.

Compiled & Annotated by Barry R. Ashpole

This document was distributed 25 May 2009 to recipients of Media Watch and is available on request from this office (contact information below).

## U.S.A.

### **Yearning for heaven, but declining to go**

NEW YORK | *New York Times* (OpEd) – 1 June 2009 – Like my mother, I have always assumed that religion exists largely to offer comfort about death, with visions of an afterlife soothing both the survivors and the people facing their final days. But the (recent) *Journal of the American Medical Association* report seems to contradict that. If people believe in heaven, why are they holding on so tightly to this life? <http://newoldage.blogs.nytimes.com/2009/06/01/yearning-for-heaven-but-declining-to-go/>

From Media Watch dated 03.30.09.30

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2009;301(11):1140-1147. 'Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer.' <http://jama.ama-assn.org/cgi/content/abstract/301/11/1140>

### **Tragic metamorphosis: Ethical debates turn personal for university professor**

UTAH | *Salt Lake Tribune* – 30 May 2009 – The moment Brooke Hopkins' heart stopped beating, Peggy Battin found herself in a scene whose ending she had written time and again. Doctors, nurses and aides swarmed Hopkins' hospital bed, urgently working to save his life. Battin watched in horror as his eyes rolled back and his face grew ashen. A burly aide screamed at her to get out, but she didn't budge. She couldn't leave her husband of more than 20 years. Not now. Not ever. "Oh, my God," she thought. "This could be it." It was a time of decision and pain that Battin had described often through decades of studying the issue of death. Beginning in the 1970s, she was a pioneer in the field of medical ethics, specializing in end-of-life questions. Suicide. [http://www.sltrib.com/utah/ci\\_12480371](http://www.sltrib.com/utah/ci_12480371)

### **Maine Senate fails to enact critical protection for family caregivers**

MAINE | *Exception Magazine* – 29 May 2009 – The Maine Senate indefinitely postponed an act to protect family caregivers. Despite a bi-partisan committee endorsement and an overwhelming 100-40 vote in support of the measure in the Maine House of Representatives, the Maine Senate failed to act to pass the bill. <http://exceptionmag.com/politics/advocacy/0001101/maine-senate-fails-enact-critical-protection-family-caregivers>

### **Hospice owner fights rising Medicare debts**

MISSISSIPPI | CBS News – 28 May 2009 – Registered nurse Bobbie Flemming drives about 1,000 miles a week around the Mississippi Delta, making dozens of house calls. But Fleming, a hospice owner, is not out to save lives. Her goal is to help her terminally ill patients die in peace, by offering, as she says, "just a small amount of comfort and compassion on this end-of-life journey." But there's a problem: 11 years ago, Congress mandated that terminally-ill patients are entitled to unlimited hospice care – but Medicare only pays the hospices for six months' worth. So when the federal government realizes it has been paying for people like throat cancer patient Willie Ross for well over six months, Medicare demands its money back. Flemming ... owes more than \$3 million. <http://www.cbsnews.com/stories/2008/05/28/eveningnews/main4133110.shtml>

### Quotable Quotes

*These days, we don't have much clarity about how we care about one another during death and dying. It is as if, culturally, we are lost at night in the middle of a storm on the ocean, and we do not have a compass with which to point the way.* **Ira Byock**

## Some ailing Ohio inmates going to nursing homes

OHIO | *Coshocton Tribune* – 28 May 2009 – Ohio plans to send as many as 40 ailing inmates to nursing homes to ease prison overcrowding and save money. Prisons system assistant director Michael Randle says terminally ill or otherwise bedridden prisoners are expensive. He says the inmates going to homes will be considered released, as if on parole, making them eligible for Medicaid or Medicare. A law in effect since March allows for early parole for prisoners who meet certain medical criteria. The head of a group of nursing home operators says the inmates will have to be screened carefully. Peter Van Runkle, of the Ohio Health Care Association, says those coming to the homes will essentially be incapacitated, so patients and their families will have nothing to fear. <http://www.coshoctontribune.com/article/20090528/UPDATES01/90528009>

Of related interest:

- CALIFORNIA | *Sacramento Bee* – 29 May 2009 – **'Proposal cut back to reduce prison expenses.'** State corrections officials and the prison system's medical care receiver said Thursday they have reached the outlines of an agreement to build two new long-term health care facilities for inmates at a cost of \$1.9 billion. <http://www.sacbee.com/capitolandcalifornia/story/1900909.html>

**N.B.** Scroll down to [Specialist Publications](#) and *Criminal Justice & Behavior*, 2009;36(6):620-634. **'Factors influencing end-of-life treatment selection.'**

## Changes urged in care for Pennsylvania terminally ill children

PENNSYLVANIA | *Philadelphia Inquirer* – 28 May 2009 – Health-care advocates say that ... most of the 2,000 children in Pennsylvania who die each year from chronic or terminal illnesses or trauma, and their families, are not being presented with all the options for end-of-life care. In a report ... by the Department of Public Welfare, a 190-member task force concluded that the health-care system in Pennsylvania is not meeting the needs of those children and their families. [http://www.philly.com/inquirer/local/pa/20090528\\_Changes\\_urged\\_in\\_care\\_for\\_Pa\\_terminally\\_ill\\_children.html](http://www.philly.com/inquirer/local/pa/20090528_Changes_urged_in_care_for_Pa_terminally_ill_children.html)

## Terminally ill patients delay talk of hospice

MASSACHUSETTS | *Boston Globe* – 26 May 2009 – Americans tend to procrastinate when it comes to matters involving death and dying, but a Harvard Medical School study published yesterday finds that even many terminally ill patients and their doctors put off conversations about end-of-life choices.<sup>1</sup> The study, one of the largest to date on the issue, found that only about half of the 1,517 patients with metastasized lung cancer who were surveyed had discussed hospice care with their physician or healthcare provider within four to seven months of their diagnosis. [http://www.boston.com/news/health/articles/2009/05/26/terminally\\_ill\\_patients\\_delay\\_talk\\_of\\_hospice/](http://www.boston.com/news/health/articles/2009/05/26/terminally_ill_patients_delay_talk_of_hospice/)

1. For an abstract of the published study, scroll down to [Specialist Publications](#) and *Archives of Internal Medicine*, 2009;169(10):954-962. **'Discussions with physicians about hospice among patients with metastatic lung cancer.'**

Of related interest:

- NEW YORK | *New York Times* – 28 May 2009 – **'Talking frankly at the end of life.'** These conversations are not a one shot deal, but often need to happen repeatedly, as patient preferences about end-of-life care change and their disease states can change. <http://www.nytimes.com/2009/05/28/health/28chen.html?pagewanted=1&r=1&ref=health>
- NEW YORK | *New York Times* – 26 May 2009 – **'Avoiding the call to hospice.'** Sometimes ... it's families who don't want to hear the word hospice. They think it's giving in, relinquishing hope. <http://newoldage.blogs.nytimes.com/2009/05/26/avoiding-the-call-to-hospice/>

**N.B.** Scroll down the *New York Times* article for reader feedback and a variety of different perspectives.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE CINEMA POST* | Online report – 28 May 2009 – '**Al Pacino signs up for HBO film about Dr Jack Kevorkian.**' Al Pacino is set to star in a HBO Films project about Dr. Jack Kevorkian who made worldwide headlines for his two decade campaign to assist patients to commit suicide. <http://www.thecinemapost.com/2009/05/28/al-pacino-signs-up-for-hbo-film-about-dr-jack-kevorkian/>

## International

### Living painlessly with terminal cancer

GUYANA | *Stabroek News* – 31 May 2009 – The term terminal cancer means that the cancer in a patient has progressed to such a stage that cure is not possible with the currently available modalities of treatment, and the patient is literally waiting for the last day of his life. The biggest challenge for most of the terminally ill cancer patients is not accepting the inevitable, but the fear of pain that lies ahead. <http://www.stabroeknews.com/2009/features/05/31/living-painlessly-with-terminal-cancer/>

### Illness shown through art

U.K. | *Birmingham Mail* – 28 May 2009 – People with life-threatening illnesses are being urged to tell their stories through the arts in a campaign which will make Birmingham the first city to discuss how citizens positively approach life as it draws to an end. Charity Rosetta Life has been working with hospitals and hospices in the West Midlands to encourage people to depict their experiences in a range of creative ways. 'Let's Talk About Living,' will mark the success of the work with a series of events in Birmingham during June. The campaign will culminate in a festival in October reflecting World Palliative Care Day and feature a conference of care specialists. <http://www.birminghammail.net/news/top-stories/2009/05/28/illness-shown-through-art-97319-23729453/>



### Preventable pain

PALLIATIVE CARE AUSTRALIAN (PCA) | Press release – 26 May 2009 – *Eol: Towards quality care at the end of life* presents views from leaders across the health sector on how the system can work better for people at the end of life, and their families, carers and communities.<sup>1</sup> "While great advances have been made in the delivery of quality specialist palliative care, in general, health and other care services do not always perform well for people who are dying. Our existing models of care and resourcing do not always match the needs of many living with a terminal condition, creating unnecessary stress and pain at this crucial time," said Prof. Margaret O'Connor, President of PCA. The document creates a platform for policy dialogue to take this issue forward, to ensure that as responsibility for end-of-life care is increasingly integrated through the whole of health, it is supported by systems and resources that make the delivery of quality care a reality for all. <http://www.palliativecare.org.au/Portals/46/Preventable%20pain%20-%20PCA%20media%20release.pdf>

1. *Eol: Towards quality care at the end of life*, Palliative Care Australia, 2009. <http://www.palliativecare.org.au/Portals/46/EoL%20-%20Winter%202009.pdf>

Of related interest:

- AUSTRALIA | *The West Australian* – 26 May 2009 – '**Fund to help terminally ill in rural areas.**' Health care services for the terminally ill will be made available to patients in all rural regions of Western Australia as part of a \$14 million project to improve palliative care services across the State. <http://www.thewest.com.au/default.aspx?MenuID=77&ContentID=144023>

## **Locals fight hospice for terminally ill**

AUSTRALIA | *Sunshine Coast Daily* – 26 May 2009 – Community opposition to the opening of a hospice ... has left the operators "stunned and saddened." But they remain confident opponents to the vitally needed hospice are in the minority and will one day be convinced their fears are unfounded. Katie Rose Cottage hospice was supposed to be a serene home for terminally ill people to live out their last days, but at least some neighbours believe its presence will lower property values. They list increased noise and traffic and even coffins being carried from the house among their key concerns. <http://www.thedaily.com.au/news/2009/may/26/residents-oppose-hospice-terminally-ill-doonan/>

## **Wide range of issues raised at Forum on End of Life in Ireland**

FORUM ON END OF LIFE IN IRELAND | Press release – 21 May 2009 – The Forum has so far received 132 submissions. Common themes include the problem of transport over long distances while patients are tired and in pain as well as the problem of despair for people facing long-term degenerative conditions. The range of issues includes the need for a detailed policy on the use of Do Not Resuscitate orders and to promote awareness of Advance Care Directives. Concerns are raised in some of the submissions about the impact of long-term caring on carers and the fact that care is often fragmented. Submissions also highlight that positive statements of inclusion were needed to re-assure many lesbian, gay and bisexual people that they did not have to hide their sexual orientation or social relationships when using an end-of-life service. It is also being said that palliative care should be extended to people with dementia as an integral part of their care pathway. <http://www.endoflife.ie/news/latest-updates.aspx?article=5a367424-e62f-4bf1-ba79-1cbd0fb87518>

**N.B.** Forum on End of Life in Ireland website: <http://www.endoflife.ie/home.aspx>

### **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 an abstract or introductory paragraph. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced and 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.

### **Links to Sources**

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

### **Something Missed or Overlooked?**

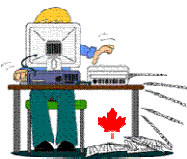
If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | UTV – 31 May 2009 – **'800 Britons on waiting list for Swiss suicide clinic.'** Almost 800 have taken the first step to taking their lives by becoming members of Dignitas, and 34 men and women, who feel their suffering has become unbearable, are ready to travel to Zurich and take a lethal drug overdose. <http://u.tv/News/800-Britons-on-waiting-list-for-Swiss-suicide-clinic/1f24a99b-a485-44b2-bbdd-5b63b8cb1e81>
- THE NETHERLANDS | Radio Netherlands – 29 May 2009 – **'Euthanasia reportings on the rise.'** Last year the number of euthanasia cases registered went up by ten percent compared to 2007. <http://www.radionetherlands.nl/news/zijlijn/6320527/Euthanasia-reportings-on-the-rise>
- U.K. | Christian Institute – 29 May 2009 – **'Bid to permit assisted suicide tabled by Peer.'** Lord Alderdice has tabled an amendment to the Coroners & Justice Bill that would make assisted suicide lawful under certain conditions. Under the amendment it would be legal to help someone to commit suicide if they were suffering from a terminal illness and were deemed by a coroner to be of sound mind. <http://www.christian.org.uk/news/20090529/bid-to-permit-assisted-suicide-tabled-by-peer/>
- U.K. (SCOTLAND) | Christian Institute – 28 May 2009 – **'MSPs set to discard assisted suicide bill.'** A bid to legalise assisted suicide in Scotland is set to fail, according to a survey of members of the Scottish Parliament. A poll of 97 MSPs showed that more than half of all respondents were opposed to the proposal. Only 19 MSPs said they would support the assisted suicide legislation, with 23 undecided. <http://www.christian.org.uk/news/20090528/msps-set-to-discard-assisted-suicide-bill/>
- U.K. | *Daily Telegraph* – 27 May 2009 – **'Right to die' row as family accuse hospital of 'wasting' liver on suicidal father.'** The children of a father-of-three left with brain damage after a suicide attempt have criticised doctors for giving him a life-saving liver transplant against the wishes of the patient and his family. <http://www.telegraph.co.uk/health/healthnews/5388223/Right-to-die-row-as-family-accuse-hospital-of-wasting-liver-on-suicidal-father.html>
- AUSTRALIA | *The Mercury* (Tasmania) – 26 May 2009 – **'Doctor challenges death Bill.'** Tasmanians will lose the ability to "grow" from the experience of death if euthanasia laws are passed. [http://www.themercury.com.au/article/2009/05/26/75655\\_tasmania-news.html](http://www.themercury.com.au/article/2009/05/26/75655_tasmania-news.html)  
**N.B.** The Dying with Dignity Bill was tabled in the Tasmanian House of Assembly 25 May 2009. It is the second attempt in Tasmania since 1998 to decriminalise and regulate voluntary euthanasia for terminally ill people.
- U.K. | *The Catholic Herald* – 15 May 2009 – **'Death by starvation rising in hospitals.'** Deaths from starvation on National Health Service hospital wards are at their highest levels for a decade, prompting new fears about a burgeoning culture of euthanasia. Figures show that 242 people died of malnutrition in 2007 and more than 8,000 left hospital more malnourished than when they arrived. <http://www.catholicherald.co.uk/articles/a0000544.shtml>

### 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.

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

### Patient-physician communication

#### **Discussions with physicians about hospice among patients with metastatic lung cancer**

*ARCHIVES OF INTERNAL MEDICINE*, 2009;169(10):954-962. Many terminally ill patients enrol in hospice only in the final days before death or not at all. Discussing hospice with a health care provider could increase awareness of hospice and possibly result in earlier use. In this study, half (53%) of the patients had discussed hospice with a provider. Patients who were black, Hispanic, non-English speaking, married or living with a partner, Medicaid beneficiaries, or had received chemotherapy were less likely to have discussed hospice. Only 53% of individuals who died within 2 months after the interview had discussed hospice, and rates were lower among those who lived longer. Patients who reported that they expected to live less than 2 years had much higher rates of discussion than those expecting to live longer. Patients reporting the most severe pain or dyspnea were no more likely to have discussed hospice than those reporting less severe or no symptoms. A third of patients who reported discussing do-not-resuscitate preferences with a physician had also discussed hospice. Many patients diagnosed as having metastatic lung cancer had not discussed hospice with a provider within 4 to 7 months after diagnosis. Increased communication with physicians could address patients' lack of awareness about hospice and misunderstandings about prognosis. <http://archinte.ama-assn.org/cgi/content/abstract/169/10/954>

Of related interest:

- KENTUCKY | *Courier-Journal* (Louisville) – 28 May 2009 – **'Say what? Sometimes patients just don't get what doctors mean.'** Medical jargon can be mind-boggling, whether it's spoken or written, so it's important ... to take steps to bridge communication gaps. <http://www.courier-journal.com/article/20090528/FEATURES03/905280302/1010/FEATURES/Say+what?+Sometimes+patients+just+don+t+get+what+doctors+mean>

#### **Bereavement practices of physicians in oncology and palliative care**

*ARCHIVES OF INTERNAL MEDICINE*, 2009;169(10):963-971. Cancer physicians frequently interact with dying patients, but little is known about these physicians' practices. The purpose of this study was to evaluate the frequency and nature of bereavement practices among medical oncologists, radiation oncologists, and palliative care specialists; and to identify factors associated with bereavement follow-up. Among the specific practices, respondents to a survey were more likely to call a family at least sometimes than to send a condolence card or attend funeral services. Palliative care specialists reported the highest rates of bereavement follow-up. Few cancer physicians provide bereavement follow-up routinely. This suggests that consensus is lacking among cancer physicians regarding their role in bereavement care. <http://archinte.ama-assn.org/cgi/content/abstract/169/10/963>

From Media Watch (**Worth Repeating**) dated 2 June 2007:

- MEDICAL NEWS TODAY | Online article – 12 July 2007 – **'Should doctor's attend patients funerals?'** Having a doctor attend a loved one's funeral validates and emphasizes the worth of that person. <http://www.medicalnewstoday.com/medicalnews.php?newsid=74897>

## **Euthanasia and free speech in Ireland**

*BRITISH MEDICAL JOURNAL* | Online OpEd – 27 May 2009 – I have long argued that both non-voluntary and voluntary euthanasia should be legalised under conditions that are strictly regulated.<sup>1 2 3</sup> Indeed it can be said that doctors already practise a form of euthanasia when they withdraw or decide not to initiate life sustaining treatment for severely brain damaged patients. In so doing they are taking positive steps to end lives that they (and others) deem to be of no further benefit to the patients concerned. The moral good inherent in such actions needs to be recognised and embraced. However, because non-voluntary euthanasia is illegal in the U.K., the death that is then clinically managed may be slow and distressing. It is this reality that lies at the heart of the case for the legalisation of active non-voluntary euthanasia.

[http://www.bmj.com/cgi/content/extract/338/may27\\_1/b2109](http://www.bmj.com/cgi/content/extract/338/may27_1/b2109)

### **Care alternatives in prison systems**

#### **Factors influencing end-of-life treatment selection**

*CRIMINAL JUSTICE & BEHAVIOR*, 2009;36(6):620-634. The authors examined age at the end of prison sentence, race, and psychosocial factors on end-of-life treatment preferences among 73 male inmates from the Alabama Aged & Infirm Correctional Facility. A significant amount of variance in treatment preferences for cardiopulmonary resuscitation, feeding tube, and palliative care was predicted by race, lifer status, and death anxiety. Inmates who were members of minority groups, non-lifers, and those with high death anxiety expressed greater desire for a feeding tube, whereas inmates who were Caucasian or lifers expressed a greater desire for palliative care. <http://cjb.sagepub.com/cgi/content/abstract/36/6/620>

#### **Harnessing nurses' passion**

*INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2009;15(5):211. Nurses are touching the lives of individuals who face advanced, progressive diseases and their families in many non-traditional palliative healthcare settings. In recent focus groups and a survey of nurses across a region in Canada, the authors were struck by the reach of nurses in caring for palliative populations in many diverse care settings. [http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=42343;article=IJPN\\_15\\_5\\_211](http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=42343;article=IJPN_15_5_211)

#### **Palliative care nursing in relation to people with intellectual disabilities**

*INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2009;15(5):226-232. It is becoming increasingly evident that personal factors (i.e., where you live, poverty, social class, gender, sexuality, age, ethnicity, religion and disability) can all affect the nature and quality of the palliative care received, and certain marginalized populations are likely to be perceived as 'disadvantaged dying.' People with intellectual disabilities are often regarded as a marginalized group, and never more so as when they are diagnosed with a life-limiting condition and as the end of life draws imminently closer. This article introduces (and discusses) the challenges faced by nurses caring for people with intellectual disabilities diagnosed with a life-limiting condition. [http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=42348;article=IJPN\\_15\\_5\\_226\\_232](http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=42348;article=IJPN_15_5_226_232)

### **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. PCN-e link: <http://www.pcn-e.com/>

## Pressure on ... to publish report on palliative care

*IRISH MEDICAL NEWS* | Online report – 27 May 2009 – Health Minister Mary Harney is being urged to publish the 'National Framework for Palliative Care Services 2009-2013,' and follow up on its recommendations. The Irish Hospice Foundation expressed concern that the report could be shelved to make short-term savings at the expense of failing to provide equality of access to palliative care services across the country. <http://www.imn.ie/index.php/current-issue/news/1585-pressure-on-harney-to-publish-report-on-palliative-care>

- *IRISH MEDICAL NEWS* | Online report – 29 May 2009 – **"Urgent' needs of the dying.'** *Palliative Care Services: A Five-Year Development Framework 2009-2013* ... says 272 extra full-time staff and 203 new specialist inpatient beds are "urgently" needed to care for dying patients. The plan will require €308.8-€237.3million for new capital projects and €71.5million in extra current spending until 2013 ... but, the current freeze on recruitment in the HSE is likely to delay implementation. [http://www.imt.ie/news/2009/05/urgent\\_needs\\_of\\_the\\_dying.html](http://www.imt.ie/news/2009/05/urgent_needs_of_the_dying.html)

## Surrogate decision makers' understanding of dementia patients' prior wishes for end-of-life care

*JOURNAL OF AGING & HEALTH*, 2009;21(4):627-650. This study examines how surrogate decision makers for dementia patients developed an understanding of patient preferences about end-of-life (EOL) care and patient wishes. Catalysts for and barriers to completing an advance directive or having EOL care discussions included factors that were both intrinsic and extrinsic to the patient. The most commonly reported wish for EOL care was to not be kept alive by "machines" or "extraordinary measures." Health care providers may be able to assist patients and families by normalizing discussions of dying, encouraging advance care planning, helping them identify goals for EOL care, and providing information to support treatment decisions consistent with patients' wishes. <http://jah.sagepub.com/cgi/content/abstract/21/4/627>

Of related interest:

- *BRITISH MEDICAL JOURNAL* | Online journal article – 28 May 2009 – **'Video decision support tool for advance care planning in dementia.'** Older people who view a video depiction of a patient with advanced dementia after hearing a verbal description of the condition are more likely to opt for comfort as their goal of care compared with those who solely listen to a verbal description. [http://www.bmj.com/cgi/content/abstract/338/may28\\_2/b2159](http://www.bmj.com/cgi/content/abstract/338/may28_2/b2159)

*British Medical Journal* article, as reported in the lay press:

- U.S. | *Time Magazine* – 29 May 2009 – **'Study: Videos help prepare for end-of-life care.'** The debilitating effects of advanced dementia – how it destroys communication, basic muscle control, even the ability to swallow – are difficult to describe in words. Often, it's not until the condition is witnessed up close that it can really be understood. <http://www.time.com/time/health/article/0,8599,1901734,00.html>

## Racial and ethnic differences in preferences for end-of-life treatment

*JOURNAL OF GENERAL INTERNAL MEDICINE*, 2009;24(6):695-701. The authors explored racial and ethnic differences in concerns and preferences for medical treatment at the end of life in a national sample, adjusting for socio-cultural co-variables. Greater preference for intensive treatment ... among minority elders is not explained fully by confounding socio-cultural variables. Still, most Medicare beneficiaries in all race/ethnic groups prefer not to die in hospital, to receive life-prolonging drugs that make them feel worse all the time, or to receive mechanical ventilation. <http://www.springerlink.com/content/e85620l2hq12h181/?p=2072358fb24c4d8180df2041956c47a8&pi=0>

### **The "good" rural death: a report of an ethnographic study in Alberta, Canada**

*JOURNAL OF PALLIATIVE CARE*, 2009;25(1):21-9. Little is known about the perspectives of people who live in rural and remote areas of Canada on the good death and how this good death might be enabled in those areas. This report is of an ethnographic study in rural Alberta involving English-speaking Albertans. Four themes ... highlight critical elements of the good rural death. These findings are expected to contribute to rural/remote palliative and end-of-life care developments. <http://www.ncbi.nlm.nih.gov/pubmed/19445339>

### **End-of-life care in hospital: a descriptive study of all inpatient deaths in 1 year**

*PALLIATIVE MEDICINE*, 2009 | Online journal article – 28 May 2009 – The objectives of this study are to ascertain how many patients who died in a district general hospital in England might have been able to be cared for at home, to obtain the cost of each inpatient stay, to make an estimate of the maximum resource implications of care packages for these patients, and to calculate the savings in hospital admissions that could be used for the development of community services. These objectives are dependent on full implementation of the End of Life Strategy. A descriptive study of all inpatient deaths in one year in a district general hospital in the south west of England was conducted. A total of 77 (13%) of patients were admitted from nursing homes and 53 (69%) of these could have stayed in the nursing home to die. A total of 44% of all patients who died within the district general hospital had chronic life threatening illnesses. A maximum of one third of all hospital deaths could have been looked after at home if excellent end of life services were in place. <http://pmj.sagepub.com/cgi/content/abstract/0269216309106460v1>

### **Evaluation of the implementation of a programme to improve end-of-life care in nursing homes**

*PALLIATIVE MEDICINE*, 2009 | Online journal article – 28 May 2009 – The Gold Standards Framework in Care Homes programme aims to improve the quality of end-of-life care for residents. The impact of introducing phase 2 of the programme to homes in England was evaluated. Forty-nine homes returned completed pre- and post-surveys, 44 returned pre- and post-data on deaths. Although some staff found completion of the programme challenging, homes that returned pre- and post-data demonstrated improvements in aspects of end-of-life care. There were statistically significant increases in the proportion of residents who died in the care homes and those who had an advanced care plan. Crisis admissions to hospital were significantly reduced. <http://pmj.sagepub.com/cgi/content/abstract/0269216309105893v1>

### **On dying and human suffering**

*PALLIATIVE MEDICINE* | Online journal article – 28 May 2009 – This review compares and contrasts the major reoccurring themes in two sources of research literature – social studies of dying and human suffering. The purpose of such a comparison is to employ the major insights of each field as a useful method of critically evaluating the insights of the other. Critical exchanges and comparisons between the research area of dying studies and on human suffering have been modest to date. This article will explain that the experience of dying benefits from being situated and analysed in a broader context of cultural experience, as suggested by the theory and study of human suffering. <http://pmj.sagepub.com/cgi/content/abstract/0269216309104858v1>

### **Specialist Publications ...but, without a link to an abstract or the article**

- *AMERICAN JOURNAL OF HEALTH SYSTEM PHARMACY*, 2009;66(11):968-969. 'For opiate management, FDA pledges to balance enforcement, palliative care needs.'

## Worth Repeating

Canadian Family Physician, 2008;54(6):840-843

### Should palliative care be a specialty?

#### Yes

Palliative medicine is the medical branch of the inter-professional approach known as palliative care. Because the doctor-patient relationship itself is the key to good palliative medicine, family physicians are ideally suited to providing palliative care. Physicians do not need to be palliative medicine specialists to provide excellent palliative care. This truth, however, does not eliminate the need for physicians who focus exclusively on this domain and possess specialized knowledge and skills in the care of patients with complex palliative needs. An argument in favour of palliative medicine being a specialty is not an argument against the ability of, or need for, family physicians to remain the primary providers of palliative care in Canada.

For the complete argument:

<http://www.cfp.ca/cgi/content/full/54/6/840>

#### No

Like birth, death is a normal not a pathologic event. The role of medicine is to help patients without over-medicalizing them. Medicine can provide patients with relief while still allowing them to be fully themselves. Palliative medicine focuses on all aspects of pain – physical, psychological, relational, social, spiritual, and religious. It centres on patients and patients' comfort as well as that of their families. Palliative medicine is holistic, global, multidimensional, and interdisciplinary, and works in intimate proximity to families. Training attentive family physicians who are able to coordinate treatment, share decision making with other professionals, and treat patients as individuals is, therefore, crucial. Is there an approach for which family medicine is better suited?

For the complete argument:

<http://www.cfp.ca/cgi/content/full/54/6/841>

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