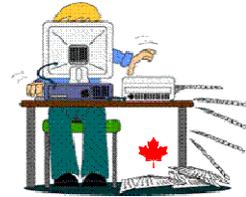


Media Watch...

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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Compiled & Annotated by Barry R. Ashpole

Planning life's end: Scroll down to [International](#) and 'GPs told to quiz elderly with serious health problems about how they want to die' (p.6), published in the U.K.'s *Daily Mail* newspaper.

[U.S.A.](#)

Prison dilemma: Surging numbers of older inmates

ASSOCIATED PRESS | Online report – 27 January 2012 – In corrections systems nationwide, officials are grappling with decisions about geriatric units, hospices and medical parole as elderly inmates – with their high rates of illness and infirmity – make up an ever increasing share of the prison population. At a time of tight state budgets, it's a trend posing difficult dilemmas for policymakers. They must address soaring medical costs for these older inmates and ponder whether some can be safely released before their sentences expire. The latest available figures from 2010 show that 8% of the prison population – 124,400 inmates – was 55 or older, compared to 3% in 1995, according to a report being released by Human Rights Watch.¹ This oldest segment grew at six times the rate of the overall prison population between 1995 and 2010. <http://www.foxnews.com/us/2012/01/27/prison-dilemma-surging-numbers-older-inmates/>

1. 'The Aging Prison Population in the U.S.,' Human Rights Watch, January 2012. <http://www.hrw.org/reports/2012/01/27/old-behind-bars>

N.B. Articles and reports focused on the provision and delivery of end of life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at foot of (p.13).

[Specialist Publications](#)

Of particular interest:

'Teaching end-of-life care in the home' (p.9), published in *Canadian Family Physician*.

'Policy lens to focus integration of home care under development' (p.9), published in the *Canadian Medical Association Journal*

Can 'living wills' tie a surgeon's hands? University of Wisconsin study indicates so

WISCONSIN | *The Cap Times* (Madison) – 26 January 2012 – High-risk surgeons can get caught in a "Catch-22" when trying to save a life: what if the patient doesn't want extraordinary measures taken to keep living? A new study¹ from a University of Wisconsin (UW)-Madison surgical professor suggests advance directives, or "living wills," don't work in the surgical suite. Dr. Margaret "Gretchen" Schwarze ... discovered that only 50% of surgeons who do high-risk operations discuss advance directives with their patients before surgery. An even higher percentage, 54%, of the surgeons said they wouldn't operate if a patient had a directive limiting the use of life support in post-operative care, if the surgeon thought it was necessary for the patient's survival.
http://host.madison.com/ct/news/local/health_med_fit/can-living-wills-tie-a-surgeon-s-hands-uw-study/article_c711ae70-4846-11e1-b34a-0019bb2963f4.html

1. 'Use of advance directives for high-risk operations: A national survey of surgeons,' *Annals of Surgery*, published online 1 December 2011.
http://journals.lww.com/annalsofsurgery/Abstract/publishahead/Use_of_Advance_Directives_for_High_Risk.98960.aspx

How do you relate to death?

HUFFINGTON POST | Online article – 25 January 2012 – We don't do death well in this country which results in a lot of unnecessary suffering. Most of us do not talk about death and are terribly uncomfortable being in death's presence. Yet, death is normal. By treating death like an invisible elephant sitting in the room, we deprive ourselves of making peace with our mortality, of deeply communicating with and comforting each other in the face of death and of taking the opportunity to make meaningful plans for the end of our life's journey. Talking about and dealing with death is our last great social taboo. We all know that we will die someday as will our beloved ones and cherished pets and everybody else. Yet, most of us relate to death as wrong – as something that shouldn't happen. The taboo against talking about or dealing with death runs deep in our culture. As a result, most of us relate to death much like children squeezing our eyes shut behind our covering hands, as though what we were looking at has disappeared because we aren't seeing it.
http://www.huffingtonpost.com/judith-johnson/dealing-with-death_b_1228061.html

Support legislation to help hospice

SOUTH CAROLINA | *Aiken Standard* (Letter) – 25 January 2012 – The center for Medicare & Medicaid Services has promoted hospice services for the last two decades. That growth could face challenges in the coming years as a result of the Affordable Care Act, which recommends changes to hospice payment authority and a new face-to-face requirement for Medicare hospice patients ... throughout the U.S. But the proposed HELP Hospice Act can help patients adjust to those changes, while making the transition easier. The HELP Hospice Act, which has already received bipartisan support in the U.S. House of Representatives, features three core segments: any new payment methodology must first go through a two-year, 15-site demonstration program; the HELP Hospice Act would increase hospice survey frequency, on average, to once every three years; and, the HELP Hospice Act would modify the face-to-face physician encounter requirement by allowing clinical nurse specialists and physician assistants to also conduct the encounter, and allow hospice agencies seven days after the initial election of services to complete the requirement. <http://www.aikenstandard.com/story/0126-Zizziama-Letter-hospice--3742221>

Of related interest:

- GEORGIA | *Albany Herald* – 23 January 2012 – **'Palliative care can be used for more than just hospice.'** "Initially [hospice] was used to take care of those at end-of-life, but it has evolved to the point that palliative care can be used for ongoing treatment," said Dr. Manouchka Joseph, a palliative care specialist at Phoebe Putney Memorial Hospital. Palliative care is a step that could occur at any time. However, since referrals generally come in late, it is primarily used for patients in hospice. <http://www.albanyherald.com/news/2012/jan/22/getting-involved-social-impact-disease/>

Republican presidential primaries

Santorum and Terri Schiavo

NEW YORK TIMES | Online posting – 24 January 2012 – [Republican presidential candidate] Rick Santorum, a former senator from Pennsylvania, was asked about his involvement in the case of Terri Schiavo, the young Florida woman who suffered brain damage in 1990. After her husband filed a petition to remove her feeding tube, a state court ruled in 2000 that she was in a persistent vegetative state. Her feeding tube was removed but then reinserted after her parents appealed the ruling. After the tube was removed once again, Congress intervened in 2005, enacting a law allowing for the parents' case to be heard in federal court. Mr. Santorum said he "didn't call for Congressional intervention, I called for a judicial hearing" to review a case in which the parents, who were constituents of his from Pennsylvania, and Ms. Schiavo's husband were on different sides. But a *New York Times Magazine* article in May 2005 about Mr. Santorum said he "not only push-

ed the Senate to intervene in the Terri Schiavo case, but he also traveled to Florida and prayed with her parents."

<http://thecaucus.blogs.nytimes.com/2012/01/23/tampa-fla-debate-fact-check/>

Terri Schiavo case a topic for GOP presidential candidates at debate

FLORIDA | *Tampa Bay Times* – 24 January 2012 – In the last half hour, Monday's Republican debate turned to the Terri Schiavo case as a discussion of government's role in making a medical decision about the life and death of someone in a persistent vegetative state.

<http://www.tampabay.com/news/health/medicine/terri-schiavo-case-a-topic-for-gop-presidential-candidates-at-debate/1212028>

N.B. GOP stands for Grand Old Party, as the Republic Party is often called.

1. 'The believer,' *New York Times Magazine*, 22 May 2005.
<http://www.nytimes.com/2005/05/22/magazine/22SANTORUM.html>

Take the profit out of dying

FLORIDA | *Palm Beach Post* (OpEd) – 22 January 2012 – In 2006, when the Legislature and then-Governor Jeb Bush allowed for-profit hospices to operate in Florida, this paper predicted that the move would undermine the successful hospice model. Six years later, it has done exactly that. Chief Financial Officer Jeff Atwater sponsored the bill as a state senator, claiming that competition would put non-profits "on notice that the best in the business" are coming to Florida. What Florida and taxpayers got was the most expensive in the business. The number of for-profit hospices in the state has doubled. A study by Florida Trend found that while most non-profit hospices lose money and use fund-raisers to make up the difference, for-profit hospices earn a 12-16% return. Medicare picks up a huge portion of the costs that generate those profits.

<http://www.palmbeachpost.com/opinion/editorials/take-the-profit-out-of-dying-2118554.html>

N.B. For-profit hospice in the U.S. has generated significant media attention: See Media Watch dated 16 January 2012 (p.2); 9 January 2012 (p.3); 12 December 2011 (p.3); 7 November 2011 (p.2); 10 October 2011 (p.2); 8 August 2011 (p.3); 1 August 2011 (p.5); 25 July 2011 (P.2); 3 July 2011 (p.2); 23 May 2011 (p.4); and, 7 February 2011 (p.3).

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>

Why doctors can't predict how long a patient will live

NEW YORK TIMES | Online commentary – 19 January 2012 – While not all assessments of how long someone has to live result in life-or-death clinical decisions, addressing prognosis remains a challenge for most doctors. And after struggling for several years with determining their own patients' prognoses, a group of physicians at the University of California in San Francisco set out to collect and study all the research that had been done on so-called prognostic indexes, tools that help with determining general prognosis in older patients. Given the growing use of age-based treatment and preventive care guidelines, the doctors assumed there would be plenty of data to help decide whether, for example, an 80-year-old patient might live long enough to benefit from a colonoscopy, a cancer screening procedure that can have its own set of complications. But they found little. Prognosis was rarely, if ever, alluded to in the most popular medical textbooks and on clinical Web sites used by practicing physicians. Even the widely used database PubMed, maintained by the National Library

of Medicine, had no specific indexing category for prognosis, making finding any published study on the subject like searching for a book in a library before the Dewey Decimal System. While the researchers were finally able to single out 16 indexes that hold promise in helping doctors predict how long a patient might live, there was "insufficient evidence at this time" to recommend any of them for widespread clinical use. <http://well.blogs.nytimes.com/2012/01/19/why-doctors-cant-predict-how-long-a-patient-will-live/>

Specialist Publications

Of particular interest:

'Discussions of life expectancy moderate relationships between prognosis and anxiety or depression in men with advanced cancer' (p.11), published in the *Journal of Palliative Medicine*.

1. 'Prognostic indices for older adults,' *American Medical Association Journal*, 2012;307(2):182-192 (noted in Media Watch dated 16 January 2012) <http://jama.ama-assn.org/content/307/2/182.short>

From Media Watch dated 2 January 2012:

- *NEW YORK TIMES* | Online article – 27 December 2011 – **'The unspoken diagnosis: Old age.'** In a recent article¹ ... [researchers] suggested offering to discuss "overall prognosis," doctor-speak for probable life expectancy and the likelihood of death, with patients who don't have terminal illnesses. The researchers favor broaching the subject with anyone who has a life expectancy of less than 10 years or has reached age 85. <http://newoldage.blogs.nytimes.com/2011/12/29/the-unspoken-diagnosis-old-age/>

1. 'Discussing overall prognosis with the very elderly,' *New England Journal of Medicine*, 2011; 365(26):2149-2151. <http://www.nejm.org/doi/full/10.1056/NEJMp1109990>

From Media Watch dated 26 December 2011:

- *U.S. NEWS & WORLD REPORT* | Online report – 21 December 2011 – **'Most sick or disabled seniors want docs to say how long they have.'** Life expectancy is a topic many disabled seniors want to talk about with their doctors, but very few have that discussion, a new study finds.¹ <http://health.usnews.com/health-news/family-health/boomer-health/articles/2011/12/21/most-sick-or-disabled-seniors-want-docs-to-say-how-long-they-have>

1. "'Knowing is better": Preferences of diverse older adults for discussing prognosis,' *Journal of General Internal Medicine*, published online 30 November 2011. <http://www.springerlink.com/content/xjq36814q4355820/>

International

Call for regulation of home care services

IRELAND | RTÉ News – 30 January 2012 – The Law Reform Commission has called for the regulation of public and private professional home care services. In a new report,¹ the Commission also says that a register of professional home carers should be set up. The report says that home care provision by the State has been mirrored by the emergence of commercial home care providers. However, the sector is unregulated and the report says the Health Information and Quality Authority should be given the power to regulate public and private professional home care services. It says that the current regulatory standards only apply to residential nursing homes, which cover just 5% of the over 65s population. The Commission does not propose that the new regulation and inspection regime apply to informal carers, such as

family members. However, the new system would cover professional home care provided to any adult over 18 years, in their own home. <http://www.rte.ie/news/2012/0130/law.html>

Extract from the Law Reform Commission report

The Commission is of the opinion that palliative care is an important aspect of end-of-life care. The Commission also notes that many people wish to die at home. To ensure that this wish can be met, the Commission is of the opinion that palliative care must come within the definition of professional home care. The Commission thus recommends that palliative care be included in the definition of professional home care.

1. 'Legal Aspects of Professional Home Care,' Law Reform Commission, January 2012. http://www.rte.ie/news/2012/0130/lrc_homecare.pdf

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/CurrentNewsandEvents/tabid/88/Default.aspx> (Click on 'Current Issue' under 'Media Watch')

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>

Europe

HUNGARY | Hungarian Hospice Foundation: <http://www.hospicehaz.hu/en/training/> (Scroll down to 'Media Watch')

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/news.htm> (Scroll down to 'International End of Life Roundup')

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>

GPs told to quiz elderly with serious health problems about 'how they want to die'

U.K. | *Daily Mail* – 25 January 2012 – GPs must ask the elderly with serious health problems if they want 'do not resuscitate' orders put in their files, according to senior doctors.¹ They should also find out if patients want to die at home and whether they would rather refuse certain drugs or treatment in their final hours. Doctors who carried out a study found discussions about death helped prevent thousands of elderly patients being admitted to hospital against their will. There are concerns frail patients are being forced to remain on wards until they die and are given medical treatment that only prolongs their agony. But many doctors are reluctant to talk to their patients as death is seen as a taboo subject.
<http://www.dailymail.co.uk/news/article-2091377/GPs-told-quiz-elderly-want-die.html>

1. 'Anticipatory care planning and integration: a primary care pilot study aimed at reducing unplanned hospitalisation,' *British Journal of General Practice*, published online 25 January 2012. <http://www.ingentaconnect.com/content/rcgp/bigp/pre-prints/baker0212>

From Media Watch dated 23 January 2012:

- U.K. (ENGLAND & WALES) | *Daily Mail* – 19 January 2012 – **'One in five choosing to die in their own homes as figures reach highest level for ten years.'** More than one in five people die in their own homes, the highest figure for ten years. A total of 102,416 deaths took place at home in 2010, or just over 20%, compared with 93,907 in 2004 (18.3%). The previous highest figure was 108,086 home deaths in 1999. <http://www.dailymail.co.uk/news/article-2088619/One-choosing-die-homes-figures-reach-highest-level-years.html?ito=feeds-newsxml>

Of related interest

- U.K. | *The Telegraph* – 24 January 2012 – **'Elderly in crisis as councils cut care home funding.'** A survey by the House of Commons health committee found councils were cutting social care budgets by an average of 6.6% while raising charges for services such as home help. Funding cuts are becoming "more urgent day by day" and the Government needed to overhaul the social care system and raise funding. <http://www.telegraph.co.uk/health/healthnews/9034219/Elderly-in-crisis-as-councils-cut-care-home-funding.html>

Four patients die thirsty or starving every day on our hospital wards show damning new statistics

U.K. | *Daily Mail* – 22 January 2012 – Four patients are dying hungry and thirsty on hospital wards every day. Dehydration or malnutrition directly caused or was linked to 1,316 deaths last year in NHS [National Health Service] trusts and privately run hospitals. The revelation follows a series of damning reports accusing staff of failing to address the most basic needs of the vulnerable, particularly the elderly. Figures obtained by the *Daily Mail* from the Office for National Statistics show that in 2010, the most recent data, 155 patients died in hospital from dehydration while a further 48 died from malnutrition. A further 812 patients died with dehydration and another 301 with malnutrition, although the conditions did not directly cause their death. Officials who compiled the figures pointed out that not all deaths could be directly blamed on poor care. <http://www.dailymail.co.uk/news/article-2090332/Four-patients-die-thirsty-starving-EVERY-DAY-hospital-wards-damning-new-statistics.html>

From Media Watch dated 30 May 2011:

U.K. | *Telegraph* – 28 May 2011 – **'Why do the elderly so often bear the weight of neglect in our hospitals?'** Perhaps the most haunting detail of last week's damning Care Quality Commission report¹ on the treatment of elderly people in hospitals was that some doctors had resorted to writing prescriptions for drinking water on patients' charts. <http://www.telegraph.co.uk/comment/columnists/jeannymccartney/8543333/Why-do-the-elderly-so-often-bear-the-weight-of-neglect-in-our-hospitals.html>

1. 'Dignity and nutrition for older people,' Care Quality Commission, May 2011. <http://www.cqc.org.uk/reviewsandstudies/inspectionprogramme-dignityandnutritionforolderpeople.cfm>

Advancing palliative care

What is needed is a policy

INDIA | *The Hindu Times* (Bagalore) – 24 January 2012 – Far from being integrated into the public healthcare system and health-related policy planning, the idea of palliative healthcare is shrouded in "myth" and is deeply undervalued. Right from administering morphine tablets for pain relief to counselling and volunteer-based community support for the terminally ill, this important wing of healthcare has not got the attention it deserves, believes K.B. Lingegowda, Head of Department of Palliative Medicine, Kidwai Memorial Institute of Oncology. In all, in India, seven million deaths are recorded annually. Of these, around 4 million – many terminally ill – are in dire need of palliative healthcare. However, Dr. Lingegowda points out, existing networks and facilities are able to cater to barely one or two per cent of this requirement. What could truly be a game-changer in this field is framing a policy that

recognises the importance of palliative healthcare, creates an ecosystem to train volunteers and implements it through existing public health centres.
<http://www.thehindu.com/news/cities/bangalore/article2826441.ece>

Extract from *The Hindu Times* article

In 2008, Kerala became the first State to introduce a palliative healthcare policy. Dr. Lingegowda, who has collaborated with the Institute of Palliative Medicine in [the Kerala city of] Kozhikode, points out that in north Kerala the coverage of palliative care is around 70%.

N.B. The palliative care initiative in Kerala has generated significant media attention: See Media Watch dated 12 September 2011 (p.6), 5 September 2011 (p.7); 29 August 2011 (p.2); 9 May 2011 (p.3); 2 February 2011 (p.6): and, 10 January 2011 (p.6).

- **N.B.** India was rated 40th in *The Quality of Death: Ranking End-of-life-Care Across the World*, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- INDIA | *Hindustan Times* (New Delhi) – 29 January 2012 – **'Government not to make law on euthanasia.'** Almost a year after the Supreme Court legalised passive euthanasia (mercy killing), allowing withdrawal of life support for patients living in a permanent vegetative condition, the government has decided to stay out of the issue and not make any law on the subject.
<http://www.hindustantimes.com/India-news/NewDelhi/Government-not-to-make-law-on-euthanasia/Article1-803840.aspx>
- U.K. | *Daily Telegraph* – 28 January 2012 – **'Assisted suicide should be illegal throughout Europe, human rights body rules.'** Euthanasia and assisted suicide should be banned in every country in the Continent, the Council of Europe has ruled. In a declaration that will have legal implications in its 47 member states, the Strasbourg-based organisation announced that such practices "must always be prohibited." The move will represent a significant setback to assisted dying campaigners who want Britain to follow Holland, Belgium and Switzerland in allowing doctors to help end the lives of their patients. The explicit condemnation of euthanasia was inserted into a non-binding resolution entitled: "Protecting human rights and dignity by taking into account previously expressed wishes of patients." The resolution had originally simply focused on the human rights questions of so-called living wills, in which people set out how they wish to be treated should they become mentally incapacitated. But members of the Parliamentary Assembly of the Council of Europe argued that living wills ... were inextricably connected to euthanasia. They successfully moved an amendment forbidding euthanasia by 34 votes to 16 with six abstentions.
<http://www.telegraph.co.uk/news/uknews/law-and-order/9045770/Assisted-suicide-should-be-illegal-throughout-Europe-human-rights-body-rules.html>

Cont.

- U.K. | *Daily Mail* – 27 January 2012 – '**Assisted suicide one step closer after High Court paves the way for doctors to help terminally-ill patients kill themselves.**' High court judges ... took a step towards allowing doctors to help their desperately ill or dying patients to kill themselves. They cleared the way for lawyers in a test case to look for medical professionals who are prepared to help in the death of a stroke victim who wishes to end his "intolerable" life. Lawyers for the patient ... were also given clearance to get information from the Dignitas clinic in Switzerland, where 150 Britons have gone to take their own lives. The decision opens the way for a landmark judicial review case in which supporters of assisted dying will push for a change in the legal rules so that doctors, nurses or professional suicide assistants will be able to help people to kill themselves without being charged with a criminal offence. <http://www.dailymail.co.uk/news/article-2092815/Assisted-suicide-High-Court-takes-step-allowing-terminally-ill-patients-kill-themselves.html>
 - U.K. | *The Telegraph* – 23 January 2012 – '**14% rise in British members of Dignitas.**' Figures from the Swiss assisted suicide organisation show that it had 893 members from this country by the end of last year, up 14% on the figure for 2010. It means more Britons belong to Dignitas than people from every other country except Germany. In total, 182 people from this country have now ended their lives with the group's help since it was set up in 1998, although the annual figure fell from 26 in 2010 to 22 last year. <http://www.telegraph.co.uk/news/uknews/law-and-order/9028651/14-rise-in-British-members-of-Dignitas.html>
- U.K. | *Money Marketing* – 27 January 2012 – '**Call for providers to set out assisted suicide policy.**' Protection advisers have called on life [insurance] companies to clarify whether they will pay out in cases of assisted suicide. Highclere Financial Services partner Alan Lakey says: "It could be argued that if a person who is a beneficiary of a life policy caused their partner's death ... then they would be barred from getting that money because people cannot benefit from the proceeds of a crime." Pinsent Masons partner Bruno Geiringer adds: "I think in the U.K. most insurers would probably apply to the court for a declaration to see whether a claimant ... should benefit if he or she is found guilty of killing someone. I suspect the court would say this person should not benefit. This might be different if it occurred somewhere like Switzerland because Swiss law would apply." <http://www.moneymarketing.co.uk/protection/call-for-providers-to-set-out-assisted-suicide-policy/1044994.article>
- U.K. (SCOTLAND) | BBC News – 23 January 2012 – '**Margo MacDonald's End of Life Assistance Bill resurrected.**' Independent MSP [Member of the Scottish Parliament] Margo MacDonald is to launch a fresh attempt to give terminally ill people in Scotland the right to choose when to die. Ms. MacDonald's previous End of Life Assistance Bill fell in a free vote at Holyrood just over a year ago. The Lothians MSP, who has Parkinson's disease, claimed there was wide public support for the legislation. Her new consultation will clarify the extent to which a physician would be able to assist a patient. It is not illegal to attempt suicide in Scotland but helping someone take their own life could lead to prosecution for culpable homicide. <http://www.bbc.co.uk/news/uk-scotland-16692686>

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

Scales for the evaluation of end-of-life care in advanced dementia: Sensitivity to change

ALZHEIMER DISEASE & ASSOCIATED DISORDERS | Online article – 23 January 2012 – The paucity of valid and reliable instruments designed to measure end-of-life experiences limits advanced dementia and palliative care research. Two end-of-life in dementia (EOLD) scales that evaluate the experiences of severely cognitively impaired persons and their health care proxies have been developed: 1) symptom management; and, 2) satisfaction with care. The aim of this study was to examine the sensitivity of the EOLD scales in detecting significant differences in clinically relevant outcomes in nursing home residents with advanced dementia. http://journals.lww.com/alzheimerjournal/Abstract/publishahead/Scales_for_the_Evaluation_of_End_of_Life_Care_in.99754.aspx

Use of electronic documentation for quality improvement in hospice

AMERICAN JOURNAL OF MEDICAL QUALITY | Online article – 20 January 2012 – Surveys concerning the use of ED [electronic documentation] for QI [quality improvement] practices and the monitoring of quality-related care and outcomes were collected from 653 hospices. Users of ED were able to monitor a wider range of quality-related data than users of non-ED. Quality components such as advanced care planning, cultural needs, experience during care of the actively dying, and the number/types of care being delivered were more likely to be documented by users of ED. <http://ajm.sagepub.com/content/early/2012/01/05/1062860611425103.abstract>

From Media Watch dated 24 October 2011:

- *PALLIATIVE MEDICINE*, 2011;25(7):673-674. **'Patient self-reporting in palliative care using information technology: Yes, there is hope!'** Patient self-report is especially critical in palliative care, particularly as palliative care moves earlier into the illness trajectory when patients are more functional and able to self-report. <http://pmj.sagepub.com/content/25/7/673.full>

House calls

Teaching end-of-life care in the home

CANADIAN FAMILY PHYSICIAN, 2012; 58(1):114-116. Caring for people at home, from the disabled to the frail elderly along the continuum to the end of life, together with their families, is a core professional task of family physicians. Thus, home-based care becomes an essential component of that task, especially with our aging population and more Canadians choosing to die at home. The role of the family doctor is to provide lifelong continuous care across multiple settings. It is thus imperative that we conduct house calls. The benefits of keeping patients in their homes have been widely documented, from saving on the high cost of hospital admission to patients' improved general well-being. Unfortunately, teaching care in the home environment is uncommon in undergraduate medical education. The home is an outstanding setting for education of medical students, providing wonderful opportunities to enrich students' appreciation of the patient-physician relationship; of interdisciplinary care; and of the challenging biomedical, psychosocial, and spiritual aspects of care. Physician educators get the

chance to show students what it really means to be a family physician.

<http://www.cfp.ca/content/58/1/114.full>

Policy lens to focus integration of home care under development

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online report – 26 January 2012 – In a bid to reduce confusion and disparities in the planning of home care policies across the country, the Canadian Home Care Association (CHCA) is drafting a national framework to outline the role of home care within the health care system. 'Home Care Policy Lens' will help authorities "develop and evaluate integrated care policies and identify issues that impact performance and responsiveness of the home and continuing care sector." It's hoped the lens will help policy-makers "to assess requirements for issues such as human resource needs and the optimal role for home care within integrated health care delivery models."

http://www.cmaj.ca/site/earlyreleases/26jan12_policy-lens-to-focus-integration-of-home-care-under-development.xhtml

From Media Watch dated 13 June 2011:

- FLORIDA | *Tampa Tribune* – 12 June 2011 – **'Doctors going home.'** Advocates say house calls eliminate the expensive, specialized transportation many patients with serious health problems need to get to the doctor. House calls also help doctors catch health problems before they turn into costly trips to the emergency room or, in the worst cases, life in a nursing home on the government's tab. <http://www2.tbo.com/news/news/2011/jun/12/MENEWSO1-doctors-going-home-ar-236838/>

The end of life, the ends of life: An anthropological view

JOURNAL OF THE ISLAMIC MEDICAL ASSOCIATION OF NORTH AMERICA, 2011;43(3). All known human societies have a worldview that deserves to be called religion; all religions must explain death. Anthropologists study the diversity of religious systems, present and past, in order to understand what is common to humanity. Rather than starting from the view of a particular revelation or set of doctrines, the anthropologist tries to step outside his or her own subjective worldview and identify patterns in the evolution of human thinking about the reality of physical death. Are humans the only animals that are conscious of death, or do we share sentiments observable in our closest living relatives, the chimpanzees? At what point in history did the concept of an afterlife, life in some spiritual sense after physical death, appear? Is the religious explanation of life and death a mere reflection of a communal social fact, as the sociologist Emile Durkheim suggested, or a shared psychological trait, as more recent scholars assert? Can and should the modern scientist make a definitive statement about the finality of death and human consciousness? <http://jima.imana.org/article/view/7037>

N.B. This issue of *Journal of the Islamic Medical Association of North America* includes several articles on end of life care. Contents page: <http://jima.imana.org/index>

The Catalonia World Health Organization Demonstration Project for Palliative Care Implementation: Quantitative and qualitative results at 20 Years

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 19 January 2012 – Catalonia (Spain) has a total population of 7.3 million citizens for whom the National Health Service (NHS) provides health care that is free at the point of access. The prevalence of terminally ill patients is between 30,100 and 39,600. Twenty years ago, the World Health Organization (WHO), in collaboration with the Catalan Department of Health and the Catalan Institute of Oncology, began a demonstration project (WHO Demonstration Project) in palliative care (PC) with the aim of implementing specialist PC services, generating experience in this field, identifying areas for improvement, and introducing educative procedures (clinical and nonclinical). Over the past 20 years, 237 PC clinical services (72 home care support teams, 49 hospital support teams, 60 units with 742 dedicated beds, 50 outpatient clinics, and six psychosocial support teams) have been implemented. In the five years since the previous evaluation, 57 new clinical services (15 new hospital support teams, 36 outpatient clinics, and six psychosocial support teams among others) and four nonclinical services (education, research, WHO Collaborating Center, and planning) have been implemented. <http://www.sciencedirect.com/science/article/pii/S0885392411004490>

N.B. Spain was rated 26th in *The Quality of Death: Ranking End-of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

End of life decisions: Using lectures, small groups and standardized patients to develop communication skills

JOURNAL OF PALLIATIVE CARE MEDICINE | Online article – Accessed 29 January 2012 – Students [i.e., study participants] felt better prepared to deliver bad news, manage family meetings and communicate with patients and families. More than 80% of students consistently demonstrated key skills during standardized patient encounters including: eliciting understanding, responding to emotion, and avoiding false reassurances. Four percent and 3% of students ... reported that they received inadequate palliative or end of life care instruction compared with 22% and 19% of all students nationally (respectively). <http://omicsgroup.org/journals/JPCM/JPCM-2-104.pdf>

Discussions of life expectancy moderate relationships between prognosis and anxiety or depression in men with advanced cancer

JOURNAL OF PALLIATIVE MEDICINE | Online article – 23 January 2012 – Oncologists avoid prognostic discussions due to concerns about increasing patients' anxiety or depression. The authors sought to determine if perceived prognosis or extent of prognostic discussions predicted anxiety or depression and whether prognostic discussions moderated the relationship between prognosis and anxiety or depression. Men who died within 6 months reported higher scores on depression but not anxiety. Men who estimated a lower likelihood of surviving at least 6 months were more depressed and anxious than men who estimated a higher likelihood of survival. A similar relationship was seen with oncologists' prognostications. Men who reported having had full prognostic discussions with their oncologist had less depression compared with men who reported having had brief or no discussions. Men for whom the oncologists reported a full discussion had greater anxiety. The relationships between patient-perceived prognosis and depression or anxiety were moderated by extent of prognostic discussions as reported by the patient or oncologist, respectively. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0249>

Factors associated with positive consequences of serving as a family caregiver for a terminal cancer patient

PSYCHO-ONCOLOGY | Online article – 24 January 2012 – Bereaved family caregivers [i.e., study participants] reported high levels of perceived rewards and burden. Among the characteristics of bereaved family members, older age, female gender, and having a religion were associated with some domains of perceived rewards, but being a spouse of a patient was negatively associated with some domains of perceived rewards. Caregiver depression or perceived burden did not affect positive consequences of caregiving. However, receiving bereavement care was significantly associated with positive outcome in all four perceived reward domains: sense of mastery; appreciation for others; meaning in life; and reprioritization about his/her life. Family caregivers of terminal cancer patients experience burdens, but caregiving also has positive consequences. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3033/abstract>

"You are weeping for that which has been your delight": To experience and recover from grief

JOURNAL OF DEATH & DYING, 2012;64(3): 223-239. A survey was distributed to people who had completed a grief recovery course. Results showed emotions, cognitions, physical expressions, and behaviors all characterize grief, but that emotions are the most central component. The course brought relief and was regarded favorably by those having at least one year between the grief trigger event and participation in the course. Writing a letter in which course participants express their feelings to the loss ... was perceived as the most successful aspect of the course. http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue_3_5_journal_1_254;linkingpublicationresults,1:300329_1

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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>

Of related interest:

- *INTERNATIONAL JOURNAL OF WORKPLACE HEALTH MANAGEMENT*, 2012;5(1). **'Family friendly policies: Accommodating end-of-life caregivers in workplaces.'** The findings of this study can directly inform workplace practice, both now and in the years to come, regarding how best to support workers who are also providing informal end-of-life care to family, friends, and others. <http://www.emeraldinsight.com/journals.htm?articleid=17014292&show=abstract>
- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2012; 307(4):398-403. **'Caregiving burden, stress, and health effects among family caregivers of adult cancer patients.'** This report describes a case that exemplifies caregiving burden and discusses the importance of identifying caregivers at risk of negative health outcomes and intervening to attenuate the stress associated with the caregiving experience. <http://jama.ama-assn.org/content/307/4/398.short>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 27 January 2012 – **'Family's difficulty scale in end-of-life home care: A new measure of the family's difficulties in caring for patients with cancer at the end of life at home from bereaved family's perspective.'** The validity and reliability of this new instrument [i.e., Family's Difficulty Scale] were confirmed. This scale should help home care providers to assess and focus on family difficulties and provide individualized care for the family who cares for a patient with terminal cancer at home. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0248>

Palliative care in Sweden

Identification and documentation of persons being in palliative phase regardless of age, diagnosis and places of care, and their use of a sitting service at the end of life

SCANDINAVIAN JOURNAL OF CARING SCIENCES | Online article – 26 January 2012 – Older persons and persons with diseases other than cancer are often discriminated against when applying for palliative care despite growing numbers of both older persons and individuals with chronic diseases. An intention for palliative care in Sweden is that all persons in the final stage of life, irrespective of age, domicile, diagnosis, and care place shall have access to palliative care on equal terms. One way to support these persons in final stage of life and their relatives is to offer sitting service [i.e. attending health care professional]. Among individuals deceased during 2007, 51% were identified and documented as being in palliative phase. The majority was older people with a non-cancer diagnosis (58%). Twenty-eight individuals (16%) had received a sitting service between 8 and 249 hours. It is indicated that sitting service significantly increased the possibility of dying at home, but did not affect how often the place of care changed during the last month of life. <http://onlinelibrary.wiley.com/doi/10.1111/j.1471-6712.2011.00966.x/abstract>

N.B. Sweden was rated 16th in *The Quality of Death: Ranking End-of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *MEDICAL LAW REVIEW* | Online article – 13 January 2012 – **'Suicide assistance for mentally disordered individuals in Switzerland and the State's positive obligation to facilitate dignified suicide.'** In principle, any individual in Switzerland may assist the suicide of another, provided that the assistance is not selfishly motivated. Moreover, the lawfulness of suicide assistance is not contingent on any particular status of the individual who dies (for example, whether he is terminally ill), although he must have capacity in order for the final act to be considered suicide. However, no great variation among assistors and the assisted is observable in Switzerland: in almost all cases, assisted suicide takes place with the involvement of a physician and a 'right to die' organisation, and the individual who dies suffers from a recognised medical condition. <http://medlaw.oxfordjournals.org/content/early/2012/01/18/medlaw.fwr033.extract>

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- *INDIAN JOURNAL OF PALLIATIVE CARE*, 2011;17(3):197-201. '**Attitudes toward euthanasia among doctors in a tertiary care hospital in South India: A cross sectional study.**' A majority of the respondents (69.3%) supported the concept of euthanasia. Relief from unbearable pain and suffering was the most commonly (80.3%) cited reason for being willing to consider the option of euthanasia. Majority of those who were against euthanasia (66.2%) felt that the freedom to perform euthanasia could easily be misused. Disapproval of euthanasia was associated with religious affiliation and speciality. <http://www.jpalliativecare.com/article.asp?issn=0973-1075;year=2011;volume=17;issue=3;spage=197;epage=201;aulast=Kamath;type=0>

Worth Repeating

Just caring: Health care rationing, terminal illness, and the medically least well off

JOURNAL OF LAW, MEDICINE & ETHICS, 2011;39(2):156-171. What does it mean to be a "just" and "caring" society in meeting the health care needs of the terminally ill when we have only limited resources to meet virtually unlimited health care needs? Put another way: relative to all the other health care needs in our society, especially the need for lifesaving or life-prolonging health care, how high a priority ought the health care needs of persons who are terminally ill have? On the one hand, we might see the terminally ill as being among the "medically least well off" and therefore deserving very high priority. On the other hand, we might see them as squandering vast medical resources for marginal medical benefits, thereby denying needed resources to others who would benefit much more. The authors begin the essay by making a number of morally relevant distinctions with regard to the category of "being terminally ill." They note, given contemporary medicine, that individuals may be terminally ill several times in the course of a life. Not all such circumstances make equal just claims to needed health care. <http://onlinelibrary.wiley.com/doi/10.1111/j.1748-720X.2011.00585.x/abstract>

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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.

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