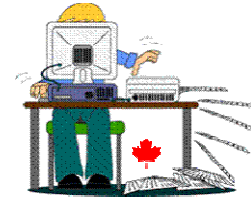


Media Watch...

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.

21 December 2009 Edition | Issue #128



Compilation of Media Watch 2008, 2009 ©

Compiled & Annotated by Barry R. Ashpole

Principles of prognosticating: Scroll down to [Specialist Publications](#) and *Canadian Family Physician* and an article titled "How long have I got?" (p.5)

Canada

New Directions for Facility-Based Long-Term Care

CANADIAN HEALTH ASSOCIATION | Online report – Accessed 17 December 2009 – Facility-based long term care is not an insured service under the Canada Health Act. Unlike services currently defined as medically necessary (hospital and physician services) that receive public funding (termed 'first-dollar coverage'), long term care is an 'extended' service, and hence there is no obligation on the part of governments to provide a standard range of services. Consequently, differences exist not only among provinces and territories but also within them. There is variability in access to and provision of long term care services and differences in the application of co-payments and user fees. The delivery of appropriate facility-based long term care services will continue to be a challenge until policy-makers realize its importance to the changing health system and focus on making services more equitable across the country. Facility-based long term care must be included in the pan-Canadian health planning agenda in order to ensure the principle of access to quality health care for Canadians now and in the future. *New Directions for Facility-Based Long-Term Care* highlights the need to achieve the appropriate balance of health services. http://www.cha.ca/documents/CHA_LTC_9-22-09_eng.pdf

U.S.A.

National Hospice & Palliative Care Organization strategic plan

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online posting – 20 December 2009 – The organization has released its new strategic plan, a roadmap that will guide its work through 2012. The plan spells out specific objectives and initiatives, and it also looks at some of the organization's long-range goals. Download a digital version of the strategic plan at: <http://www.nxtbook.com/nxtbooks/nhpc/strategicplan2010-2012/#/1/OnePage>

Preparing for the inevitable

MAINE | GateHouse News Service – 19 December 2009 – The discussion usually comes a bit late. And oftentimes it's personal: It's about you, what you will do, how you want things to be handled when your time comes. When you get old. You talk about your independence, about your desire not to be hooked up to a machine, or to spend your last years in an institution. But the discussion arises because of what you're going through – with your parents or siblings. You're getting a real education, a virtual Master's Degree in Aging. Instead of two years though, the course is often compressed into a few frantic weeks and, it seems, no matter how hard you study, you are guaranteed to fail. But it doesn't have to be that way. <http://www.wickedlocal.com/plymouth/lifestyle/x1682951118/SPECIAL-EDITION-Preparing-for-the-inevitable>

Of related interest:

- *BUSINESS WEEK* | Online report – 16 December 2009 – **'Life expectancy in U.S. hits new high.'** Average life expectancy in the U.S. has reached almost 78 years. From birth in 2007, women can expect to live to 80.4 years on average and men to 75.3 years, according to the U.S. Centers for Disease Control & Prevention.¹ Life expectancy in the U.S. is still lower than in many other industrialized countries. <http://www.businessweek.com/lifestyle/content/healthday/634143.html>

1. Life Expectancy, U.S. Centers for Disease Control & Prevention, 2009 <http://www.cdc.gov/nchs/fastats/lifexpect.htm>

Expressions of grief

Hospice Santa volunteers face grief, kids' hard questions

USA TODAY | Online report – 15 December – By Christmas Day, a career Santa can name the top 10 toys for girls and boys in a heartbeat. He has sat smiling patiently, swathed in red velvet on his gilded throne, and listened to countless children whisper their innermost desires. A volunteer hospice Santa hears a different sort of wish list. Sometimes, the children he visits don't want to talk. Others ask questions no one feels brave enough to answer. 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 Santas are an elite and bearded group from all backgrounds: Some are retired, others work at jobs that range from salesmen to psychologists. Before visiting a home or hospital, they memorize names of family members and pets; they undergo a rigorous background check and receive ongoing instruction in grief, bereavement, symptom management and spirituality. http://www.usatoday.com/news/health/2009-12-16-hospicesanta16_st_N.htm

Specialist Publications

Of particular interest:

'The stress process in palliative cancer care: A qualitative study on informal caregiving and its implications for the delivery of care.' Scroll down to p.4 for the findings of a recent study published in the *American Journal of Hospice & Palliative Medicine*.

'Ending end-of-life phobia – a prescription for enlightened health care reform.' Scroll down to p.6 and a recent OpEd in the *New England Journal of Medicine*.

Quotable Quotes

One of our most difficult duties as human beings is to listen to the voices of those who suffer. The voices of the ill are easy to ignore ... most of us would rather forget our own vulnerability ... listening is hard, but it is also fundamental moral act. **Arthur W. Frank**, *The Wounded Storyteller*

International

Health minister launches a public consultation on improving palliative and end of life care

U.K. (Northern Ireland) | Government online posting – 21 December 2009 – Launching the [public] consultation [on improving palliative and end of life care] Health Minister Michael McGimpsey said: "Most of us now live longer than ever before; however more of us as we age, have to live with the consequences of chronic conditions. In this context, good palliative and end of life care is increasingly an essential part of health and social care. I am committed to ensuring that people with palliative and end of life care needs have access to the highest quality care, and in particular that they have real and viable options and choice about how and where their care is provided. This five year strategy provides a vision and direction for service planning and delivery, and is designed to ensure that palliative and end of life care is firmly focused on the individual, their family and carers." <http://www.egovmonitor.com/node/32276>

'Dying Well Matters'

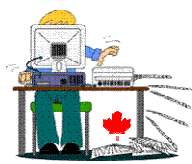
Palliative care experiences wanted

U.K. (Wales) | *Western Mail* (OpEd) – 21 December 2009 – The way we die lives on in the memory of those left behind. Every hour of every day somebody in Wales dies. Some are expected deaths but many deaths come as a terrible shock to families. And, let's face it, we're all pretty frightened of how we might die. Dying well matters, just as living well matters. That is why I am passionate about improving care of dying patients in Wales. There is so much that can be done that does not need a lot of money, but it does need National Health Services to be aware of just what they are doing well and what is not happening well, so that everyone can learn from good practice and problems can be addressed. For the first time ever, a whole nation is being asked to give feedback on services to shape the future. That is why we have launched 'Dying Well Matters.' <http://www.walesonline.co.uk/news/health-news/2009/12/21/palliative-care-experiences-wanted-91466-25434941/>

Palliative care cuts 'cruel'

AUSTRALIA (New South Wales) | *Manly Daily* – 15 December 2009 – The association representing local GPs has raised concerns palliative care services at Manly and Mona Vale hospitals have been cut in half because of a \$1.3 million funding reduction. The Manly Warringah Division of General Practitioners has sent a letter to Northern Sydney Central Coast Area Health Service chief executive Matthew Daley advising him a recent cut in State Government funding would have devastating impacts on palliative care. Local GPs were also forwarded a copy of the letter. <http://manly-daily.whereilive.com.au/news/story/palliative-care-cuts-cruel/>

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.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- INDIA | BBC News (U.K.) – 17 December 2009 – **'India court admits plea to end life of rape victim.'** India's Supreme Court has admitted a plea to end the life of a woman who has been in a vegetative state since 1973. It is being seen as a landmark case in India where euthanasia or mercy killing is illegal. http://news.bbc.co.uk/2/hi/south_asia/8417549.stm
- U.K. | *Daily Telegraph* – 17 December 2009 – **'Assisted suicide guidance will lead to 'legalised killing,' MPs and peers warn.'** New guidelines on assisted suicide prosecutions issued following the case of Debbie Purdy, the multiple sclerosis sufferer, will 'legalise killing,' a group of MPs and peers have warned. <http://www.telegraph.co.uk/news/newstoppers/politics/6826479/Assisted-suicide-guidance-will-lead-to-legalised-killing-MPs-and-peers-warn.html>
- U.K. | *Times* – 17 December 2009 – **'Assisted suicide debate is not a religious issue.'** Assisting suicide is a serious matter and legalisation is a complex question that does not lend itself to simple yes/no questions. <http://www.timesonline.co.uk/tol/comment/letters/article6959330.ece>
- AUSTRALIA | ABC News – 16 December 2009 – **'Net filter will restrict euthanasia.'** Philip Nitschke says the federal government's plan to filter the Internet will restrict information about euthanasia. <http://www.abc.net.au/news/stories/2009/12/16/2773774.htm?section=justin>
- U.K. | *Daily Telegraph* – 16 December 2009 – **'Half of MPs say doctors should be allowed to help a terminally-ill patient commit suicide.'** A survey of 112 MPs found that 53% thought there should be no prosecution "if a doctor in England or Wales helps a terminally ill, mentally competent adult patient to die when directly requested to do so, by the patient." A 10-week Crown Prosecution Service consultation on new rules to relax the rules on assisted suicide, which could make it easier for doctors to escape prosecution if they help patients kill themselves, has come to an end. <http://www.telegraph.co.uk/news/newstoppers/politics/lawandorder/6819147/More-than-half-of-MPs-believe-doctors-should-be-allowed-to-help-a-terminally-ill-patient-to-die.html>

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

The stress process in palliative cancer care: A qualitative study on informal caregiving and its implication for the delivery of care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 14 December 2009 – The authors of this study report that the absence of adequate support from the formal health care delivery system was a consistent message from all participants. There was evidence of financial stress primarily associated with the purchase of private home care to supplement formal care. In contrast, the resources that family caregivers relied on to moderate the stressful effects of caregiving included extended family, friends, and neighbors. While the stress of direct caregiving was high, the study revealed that formal care was also a significant source of stress for family caregivers. <http://ajh.sagepub.com/cgi/content/abstract/1049909109350176v1>

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/>

Associations between successful palliative cancer pathways and community nurse involvement

BMC PALLIATIVE CARE | Online article – 14 December 2009 – Community nurses (CNs) are often frontline workers in the patients' homes and CN involvement may be important in attaining successful palliative pathways at home. The authors examined associations between bereaved relatives' evaluation of palliative treatment at home, and place of death and CN involvement. <http://www.biomedcentral.com/content/pdf/1472-684x-8-18.pdf>

How long have I got?

CANADIAN FAMILY PHYSICIAN, 2009;55(12):1202-1206. "How long have I got?" This question, as well as its variations, is commonly asked of health care providers. An accurate prediction of length of survival (LOS), communicated gently and honestly, can be one way to help decision making during that time. Observation over a period of time will provide a sense of the momentum of functional decline, and this momentum can estimate the LOS most accurately. Perhaps what is most important is to determine what underlies the question and to provide the support needed to address those issues. The question "How long have I got?" does show some acceptance of a deteriorating condition. This can be an opportunity to gently encourage saying and doing things that have been left unsaid and undone. Life's last journey is one of mystery. We as caregivers, while attempting to predict the course, must appreciate the complexity of predicting and the importance of our presence and involvement with the patient and family – no matter how that course evolves. <http://www.cfp.ca/cgi/reprint/55/12/1202>

End-of-life issues in critically ill cancer patients

CRITICAL CARE CLINICS, 2010;26(1):219-227. Since the majority of deaths will occur after limiting or withdrawing life support, focus should be given to ensuring that multidisciplinary family meetings are convened to discuss end-of-life decision making. Throughout the process of transitioning from cure to comfort care, it is essential to support the patient and the patient's family cultural beliefs and spiritual values, and to ensure good pain and symptom management. The use of protocols facilitates a smooth transition and potentially reduces variability between health care providers. Integrating measures into the ICU routine that will help health care providers cope with the care of a dying patient is recommended to avoid moral distress or emotional burnout. [http://www.criticalcare.theclinics.com/article/S0749-0704\(09\)00106-7/abstract](http://www.criticalcare.theclinics.com/article/S0749-0704(09)00106-7/abstract)

Hospice nurses and genetics: implications for end-of-life care

JOURNAL OF CLINICAL NURSING, 2010;19(1-2):192-207. Hospice nurses' need genetics education focusing on the psychosocial implications of caring for patients and families affected by genetic conditions to enable them to provide the complex care and support in face of the difficult issues that arise in practice. <http://www3.interscience.wiley.com/journal/123217149/abstract>

Provision of spiritual care to patients with advanced cancer: Associations with medical care and quality of life near death

JOURNAL OF CLINICAL ONCOLOGY | Online Article – 14 December 2009 – Patients whose spiritual needs were largely or completely supported by the medical team received more hospice care in comparison with those not supported. High religious coping patients whose spiritual needs were largely or completely supported were more likely to receive hospice and less likely to receive aggressive care in comparison with those not supported. Spiritual support from the medical team and pastoral care visits were associated with higher QOL (quality of life) scores near death. <http://jco.ascopubs.org/cgi/content/abstract/JCO.2009.24.8005v1>

Ending end-of-life phobia – a prescription for enlightened health care reform

NEW ENGLAND JOURNAL OF MEDICINE | Online OpEd – 16 December 2009 – Leaders have been remarkably reticent with respect to one aspect of the health care system: end-of-life care. Given that patients with terminal illness require a disproportionate concentration of expenditures, the silence is deafening. Sure, the summer's controversy over "death panels" provided fodder for late-night comedians, but just under the surface of the joking there was evidence of America's uneasiness with the hard conversations that lay ahead. Why has it been so difficult to initiate a dialogue about matters pertaining to a subject that defines the human experience? As a cancer specialist, I am actually not surprised by this state of affairs. Patients, family members, and (yes) even many of my colleagues have great difficulty in coping with thoughts of death. Sophisticated mechanisms, ranging from the modern approach to dying (i.e., doing so outside the home, supported by high-tech equipment) to the use of euphemisms and gallows humor, have been developed to help us deny and sanitize death. People in general are most comfortable deferring questions that relate to their finitude. <http://healthcarereform.nejm.org/?p=2580&query=home>

First-year college students' attitudes about end-of-life decision-making

OMEGA (Journal of Death & Dying), 2010;60(2):143-163. This study analyzes attitudes about treatment of the terminally ill among a group of first-year undergraduate students – a cohort that was in high school when intense publicity and extensive political and judicial involvement in the Terri Schiavo case occurred [2001-2005]. Students clearly make distinctions in the propriety of active euthanasia, passive euthanasia, and physician-assisted death. Presented with a situation of a terminally ill patient in considerable pain, 65.1% of the students supported or strongly supported withdrawal of life-sustaining technology, 34.3% supported the physician providing the means of death to the patient, and 28.3% supported the physician actually administering a lethal injection. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,4,6;journal,1,237;linkingpublicationresults,1:300329,1>

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 14 December 2009 – '**Continuous deep sedation until death: Palliation or physician-assisted death?**' Published literature have not discerned end-of-life palliative versus life-shortening effects of pharmacologically maintaining continuous deep sedation until death (i.e., dying in deep sleep) compared with common sedation practices relieving distress in the final conscious phase of dying. <http://ajh.sagepub.com/cgi/content/abstract/1049909109348868v1>
- *BRITISH JOURNAL OF NURSING*, 2009;18(22):1396-1397. '**New guidelines on assisted suicide: will nurses be prosecuted?**' In the recent decision by the House of Lords ... the Director of Public Prosecutions was directed to publish a prosecutorial policy on when to seek charges ... in cases relating to assistance with dying. http://www.britishjournalofnursing.com/cgi-bin/go.pl/library/article.html?uid=45569;article=BJN_18_22_1396_1397
- *BRITISH MEDICAL JOURNAL* | Online report – 15 December 2009 – '**Dutch law leads to confusion over when to use life ending treatment in suffering newborns.**' The Dutch Medical Association is to scrutinise how doctors treat newborn babies with very serious abnormalities after it emerged that uncertainty exists among the profession over the criteria for mercy killing. http://www.bmj.com/cgi/content/extract/339/dec15_1/b5474
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2009;38(6):807-815. '**Mental health outcomes of family members of Oregonians who request physician aid in dying.**' Comparing family members of those who requested aid in dying to those who did not revealed no differences in primary mental health outcomes of depression, grief, or mental health services use. [http://www.jpmsjournal.com/article/S0885-3924\(09\)00707-6/abstract](http://www.jpmsjournal.com/article/S0885-3924(09)00707-6/abstract)

Assessing and improving out-of-hours palliative care in a deprived community: a rapid appraisal study

PALLIATIVE MEDICINE | Online article – 16 December 2009 – Recent changes to out-of-hours primary care in the U.K. have generated concerns about care for palliative care patients. The aim of this study was to identify key challenges and improvements to out-of-hours palliative care in a mixed urban and rural deprived area. Key issues in the provision of care were the importance of good communication and having information available, the unwieldy process of accessing medical care out of hours, professionals bypassing routine out-of-hours care for palliative care patients, and out-of-hours care being provided by practitioners unaware of local services. They recommend provision to out-of-hours services of an enhanced 'special note' for palliative care patients, to be completed early in the course of the illness and updated regularly.

<http://pmj.sagepub.com/cgi/content/abstract/0269216309356030v1>

Seriously ill patients' discussions of preparation and life completion: An intervention to assist with transition at the end of life

PALLIATIVE & SUPPORTIVE CARE, 2009);7(4):393-404. Patients approaching the end of life not only face challenges to physical well-being but also threats to emotional and spiritual integrity. Yet, identifying appropriate, effective, and brief interventions to address those concerns has proven elusive. The authors developed an intervention based on life review and emotional disclosure literatures and conducted a pilot study to determine feasibility and acceptability.

<http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=6681220&fulltextType=RA&fileId=S147895150999040X>

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

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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.

Only three ways to die

PSYCHOLOGY TODAY | Online article – 18 December 2009 – Death comes to many without warning, as a mid-sentence interruption (sometimes literally). We're simply here one minute and gone the next. Though this seems at first glance a horrible fate, there are some benefits to dying this way, including being able to avoid:

1. The stirring up of the fear of death. Most of us live by denying the possibility of death or at least by ignoring it. This enables us to function without fear that might otherwise significantly reduce the quality of our lives. How lucky to be able to die without having this fear stirred up at all.
2. Prolonged physical suffering. Most people seem to fear this more than death itself. I've certainly seen my share of horrible suffering at the end of life and how it tears patients and their families apart almost more than dying itself.
3. Anticipatory dread of your death on the part of your family and friends. The shock of losing a loved one suddenly, especially out of turn, is great. And yet even when anticipated, the shock is rarely diminished. How much better for your family to be able to avoid the active anticipation of your death. People often report anticipating something good is often better and anticipating something bad often worse than the actual experience of either.

Unfortunately, the drawbacks are significant. <http://www.psychologytoday.com/blog/happiness-in-world/200912/only-three-ways-die>

Interdisciplinary geriatric and palliative care team narratives: Collaboration practices and barriers

QUALITATIVE HEALTH RESEARCH, 2010;(20)1;93-104. Despite the development and implementation of team training models in geriatrics and palliative care, little attention has been paid to the nature and process of teamwork. Geriatrics and palliative care in the clinical setting offer an interdisciplinary approach structured to meet the comprehensive needs of a patient and his or her family. Fellowship members of an interdisciplinary geriatric and palliative care team participated in semi-structured interviews. Team members represented social work, chaplaincy, psychology, nursing, and medicine. A functional narrative analysis revealed four themes: voice of the lifeworld, caregiver teamwork, alone on a team, and storying disciplinary communication. The content-ordering function of narratives revealed a divergence in team members' conceptualization of teamwork and team effectiveness, and group ordering of narratives documented the collaborative nature of teams. The study findings demonstrate the potential for narratives as a pedagogical tool in team training, highlighting the benefits of reflective practice for improving teamwork and sustainability. <http://qhr.sagepub.com/cgi/content/abstract/20/1/93>

Of related interest:

- *CLINICAL NURSE SPECIALIST*, 2010;24(1):18-23. 'The clinical nurse specialist role in developing a geropalliative model of care.' The purpose of this article was to share the experiences and knowledge gained of the clinical nurse specialist's role in the development and implementation of an interdisciplinary geropalliative model of care. http://journals.lww.com/cns-journal/Abstract/2010/01000/The_Clinical_Nurse_Specialist_Role_in_Developing_a.7.aspx

Worth Repeating

Healing the healer: Poetry in palliative care

JOURNAL OF PALLIATIVE MEDICINE, 2005;8(2):382-389. Poetry plays an age-old role in the art of healing. Although medicine today seems distant from the world of poetic expression, there are surprising commonalities between the two. In this essay the authors reflect on three aspects of healing that are fostered by poetry. Practicing medicine with too many facts and not enough poetry leads to dissatisfaction, disappointment, and impaired healing, especially in the care of the terminally ill. Likewise, poetry deficiency cuts off an important avenue for physician self-awareness and reflectivity. Alternatively, three aspects of healing are fostered by poetry: the power of the word to heal (and also harm); the skill of "negative capability" that enhances physician effectiveness; and empathic connection, or compassionate presence, a relationship that heals without words. Reading and writing poetry can help physicians, especially those who care for dying patients, become more reflective, creative, and compassionate practitioners.
<http://www.liebertonline.com/doi/abs/10.1089/jpm.2005.8.382>

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