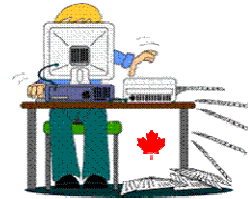


## Media Watch...

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

In the public mind: Scroll down to [Specialist Publications](#) and 'Palliative care specialists ponder public awareness campaign' (p.3), published in *Internal Medicine News*.

## [U.S.A.](#)

### Connecticut Senate passes compromise hospice bill

CONNECTICUT | Associated Press (Hartford) – 9 May 2012 – The Connecticut Senate has given final legislative approval to a compromise bill that would allow more hospice organizations to offer inpatient services to people with advanced, irreversible illnesses. Under the bill, two types of hospices are defined – a "short-term hospital special hospice" like Connecticut Hospice in Branford, and the new "hospice facility" category, which allows existing hospice organizations to create inpatient facilities. The Department of Public Health is currently reviewing draft regulations for hospices. First proposed two years ago, the changes initially pitted Connecticut Hospice against dozens of hospice providers who say more facilities are needed so families don't have to travel far. Connecticut Hospice had raised concerns about the level of care at those new inpatient facilities. [http://www.necn.com/05/09/12/Conn-Senate-passes-compromise-hospice-bi/landing\\_politics.html?&apID=acedb260fee64215b6597b4ffec959d6](http://www.necn.com/05/09/12/Conn-Senate-passes-compromise-hospice-bi/landing_politics.html?&apID=acedb260fee64215b6597b4ffec959d6)

### Veteran's Affairs to equip 1,000 family caregivers with iPads

MOBILE HEALTH NEWS | Online report – 7 May 2012 – Veterans Affairs [VA] expects to equip 1,000 family caregivers with iPads loaded with health apps to help these primary caregivers to better take care of veterans at home. The initiative is part of a pilot that is also testing distribution through a VA app store that is set to launch early next year. <http://mobihealthnews.com/17260/va-to-equip-1000-family-caregivers-with-ipads/>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- HAWAII | *The Civil Beat* – 6 May 2012 – '**Assisted suicide support strong.**' Hawaii voters support the rights of doctors to help terminally ill patients end their lives by better than a 2-to-1 margin, according to *The Civil Beat* Poll. Liberal, well-educated and wealthier voters were most likely to say physician-assisted suicide – also known as "death with dignity" – should be legal, the survey of 1,162 registered voters found. <http://www.civilbeat.com/articles/2012/05/04/15679-civil-beat-poll-assisted-suicide-support-strong/>

## International

### **Dementia patients are denied specialist care**

U.K. | *Daily Express* – 11 May 2012 – Thousands of dementia sufferers are being abandoned to see out their days at home rather than getting specialist care in nursing homes, a damning study has revealed. It is commonly thought that dementia victims end their lives being properly cared for by trained medical staff. But, for many, the grim reality is being left to cope in their own home, often with just untrained family members to help. There are 800,000 people with dementia in the U.K., two thirds of whom live in the community and a third in care homes. The new study reveals that many older adults with dementia live and die in the community rather than in nursing homes. <http://www.express.co.uk/posts/view/319346/Dementia-patients-are-denied-specialist-care>

### **Argentine Senate approves 'dignified death' law**

ARGENTINA | Associated Press (Buenos Aires) – 8 May 2012 – Argentina's senate overwhelmingly approved a "dignified death" law giving terminally ill patients and their families more power to make end-of-life decisions. The law passed by a vote of 55 to zero, with 17 senators declaring themselves absent. It passed the lower house last year. Now Argentine families won't have to struggle to find judges to order doctors to end life-support for people who are dying or in a permanent vegetative state. Getting such approval can be very difficult in many countries, particularly in Latin America, where opposition from the Roman Catholic Church still runs strong. <http://www.wxow.com/story/18246736/argentine-senate-approves-dignified-death-law>

### **New report captures the latest information on end of life care in England – the good and the bad**

U.K. | National End of Life Care Intelligence Network – 8 May 2012 – A report published by the National End of Life Care Intelligence Network marks a significant moment in the progress of the Department of Health's 2008 End of Life Care Strategy, which made clear the need to know more about the care people receive in their last year or months of life. 'What do we know now that we didn't know a year ago? New intelligence on end of life care in England' pulls together facts and figures from a wide range of recent studies and surveys that provide an important insight into the pattern of death and dying in England. The report highlights areas where improvements have been made as well as where further action is needed to improve care for people who are dying. The publication is divided into 16 categories ranging from place of care and death to latest trends in different settings, different disease types, costs, quality of care, workforce and public attitudes. <http://www.endoflifecare-intelligence.org.uk/news/default.aspx>

### **Care homes warned to discuss 'do not resuscitate' forms with families**

U.K. | *The Guardian* – 6 May 2012 – The National Health Service has warned GPs treating thousands of patients in care homes to follow the law and good practice on issuing "do not resuscitate" forms after apologising for not discussing the issue with a patient or his family. The "reminder" followed investigations into a complaint by the daughter of a 77-year-old man after she found out by chance that he had such a form in his medical notes. The GP and staff at the home for people with physical disabilities and long-term medical conditions in south London where he was staying did not consider the man to have the capacity to be involved in the decision – a verdict the family strongly disputes. <http://www.guardian.co.uk/society/2012/may/06/care-homes-do-not-resuscitate>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW ZEALAND | Stuff.co.nz – 6 May 2012 – '**Kiwis back euthanasia.**' New Zealanders are in favour of euthanasia for personal reasons, and often because they don't want money spent on themselves that could benefit younger, healthier people, a soon-to-be-released study will show. <http://www.stuff.co.nz/national/health/6867469/Unselfish-Kiwis-back-euthanasia>

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

### **Harm reduction services as a point-of-entry to and source of end-of-life care and support for homeless and marginally housed persons who use alcohol and/or illicit drugs: A qualitative analysis**

*BMC HEALTH RESEARCH* | Online article – 30 April 2012 – Harm reduction services (e.g., syringe exchange programs, managed alcohol programs, etc.) were identified as a critical point-of-entry to and source of end-of-life care and support for homeless and marginally housed persons who use alcohol and/or illicit drugs. Where possible, harm reduction services facilitated referrals to end-of-life care services for this population. Harm reduction services also provided end-of-life care and support when members of this population were unable or unwilling to access end-of-life care services, thereby improving quality-of-life and increasing self-determination regarding place-of-death. While partnerships between harm reduction programs and end-of-life care services are identified as one way to improve access, it is noted that more comprehensive harm reduction services might be needed in end-of-life care settings if they are to engage this underserved population. <http://www.biomedcentral.com/content/pdf/1471-2458-12-312.pdf>

From Media Watch, 11 April 2011:

- *PALLIATIVE MEDICINE* | Online article – 4 April 2011 – '**Illicit drug use as a challenge to the delivery of end-of-life care services to homeless persons: Perceptions of health and social services...**' <http://pmj.sagepub.com/content/early/2011/03/30/0269216311402713.abstract>

### **Palliative care specialists ponder public awareness campaign**

*INTERNAL MEDICINE NEWS* | Online report – 4 May 2012 – More than three-quarters of the general public have no idea what palliative care is, according to a national survey. And that, as it turns out, is actually excellent for the field's future growth prospects, according to one of the nation's top palliative care specialists. "This is good news for us. We can create the cognitive frame where there isn't one already in place," said Dr. Diane E. Meier, director of the Center to Advance Palliative Care and professor of geriatrics and internal medicine at Mount Sinai School of Medicine, New York. While the public is largely a blank slate with regard to palliative care, non-palliative care physicians and other health care professionals tend to believe that palliative care is simply end of life care. Many don't understand that palliative care is actually about relieving the pain, symptoms, and stress of serious illness in patients of any age and at any stage of disease, and that palliative care can be delivered alongside curative or life-prolonging therapies, Dr. Meier said at the annual meeting of the American Academy of Hospice and Palliative Medicine. <http://www.internalmedicineneeds.com/single-view/palliative-care-specialists-ponder-public-awareness-campaign/4ef71705c9e7b4f8c1a4803880a51cd1.html>



## **The role of social work in palliative care: A comparison across Canada's three northern territories**

*JOURNAL OF COMPARATIVE SOCIAL WORK* | Online article – Accessed 11 May 2012 – A ... study was conducted in northern Canada in 2007 which examined the realities and issues surrounding palliative care with seniors in remote northern settings. As a profession with a recognized role in supporting those who are dying and those who are bereaved, social work has been integral to the development of palliative care support services in northern Canada. In regions ... where the social work profession is less developed and less recognized, the role for social work remains understated. [http://jcsw.no/local/media/jcsw/docs/jcsw\\_issue\\_2012\\_1\\_7\\_article.pdf](http://jcsw.no/local/media/jcsw/docs/jcsw_issue_2012_1_7_article.pdf)

## **End-of-Life care from the perspective of primary care providers**

*JOURNAL OF GENERAL INTERNAL MEDICINE* | Online article – 4 May 2012 – Primary care providers (PCPs) [i.e., study participants] wanted to care for their dying patients and felt largely competent to provide end-of-life care. They and their staff reported the presence of five structural factors that influenced their ability to do so: 1) continuity of care to help patients make treatment decisions and plan for the end of life; 2) scheduling flexibility and time with patients to address emergent needs, provide emotional support, and conduct meaningful end-of-life discussions; 3) information-sharing with outside providers and within the primary care practice; 4) coordination of care to address patients' needs quickly; and, 5) authority to act on behalf of their patients. <http://www.springerlink.com/content/704667603775r717/>

## **Medical futility at the end of life: The perspectives of intensive care and palliative care clinicians**

*JOURNAL OF MEDICAL BIOETHICS* | Online article – 5 May 2012 – Interviewees associated futility with the failure to achieve goals of care that offer a benefit to the patient's quality of life and are proportionate to the risks, harms and costs. Prototypic examples mentioned are situations of irreversible dependence on LST [life-sustaining treatment], advanced metastatic malignancies and extensive brain injury. Participants agreed that futility should be assessed by physicians after consultation with the care team. Intensivists favoured an indirect and stepwise disclosure of the prognosis. Palliative care clinicians focused on a candid and empathetic information strategy. The reasons for continuing futile LST are primarily emotional, such as guilt, grief, fear of legal consequences and concerns about the family's reaction. Other obstacles are organisational routines, insufficient legal and palliative knowledge and treatment requests by patients or families. <http://jme.bmj.com/content/early/2012/05/04/medethics-2011-100479.abstract>

## **Consensus recommendations from the Strategic Planning Summit for Pain & Palliative Care Pharmacy Practice**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2012;43(5):925-944. Pain and symptoms related to palliative care are often undertreated. This is largely owing to the complexity in the provision of care and the potential discrepancy in education among the various health care professionals required to deliver care. Pharmacists are frequently involved in the care of PPC patients, although pharmacy education currently does not offer or require a strong curriculum commitment to this area of practice. [http://www.jpsmjournal.com/article/S0885-3924\(12\)00018-8/abstract](http://www.jpsmjournal.com/article/S0885-3924(12)00018-8/abstract)

### **[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>

## Uncertain cancer diagnosis: The expanded role of the palliative care consultant

*JOURNAL OF PALLIATIVE MEDICINE* | Online article – 2 May 2012 – As attending physicians in acute care hospitals consult palliative care services earlier for patients with a life-threatening illness, the role of the palliative care consultant (PCC) may expand, especially when there is diagnostic uncertainty. The diagnostic uncertainty that accompanies earlier palliative care consultation may hamper the PCC's ability to establish goals of care and the appropriateness of hospice palliative care unit admission. Attempts at resolving this diagnostic uncertainty may lead to an expanded role for the PCC, which ideally will occur in collaboration with the primary care team. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0409>

## Effects of a support group programme for family members of patients with life-threatening illness during ongoing palliative care

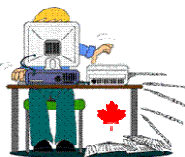
*PALLIATIVE MEDICINE* | Online article – 4 May 2012 – Health care systems in many countries are moving towards outpatient care in which family members are central in providing care for patients with life-threatening illness. Several studies show family members report lack of preparation, knowledge and ability to handle the caregiver role with a need for information and psychosocial support. The intervention, including a support group program delivered for family members of persons with life threatening illness during ongoing palliative care, proved to be effective in certain domains of caregiving. No negative outcomes were detected. The results indicate that this intervention could be implemented and delivered to family members during ongoing palliative care. <http://pmj.sagepub.com/content/early/2012/05/01/0269216312446103.abstract>

Of related interest:

- *PATIENT EDUCATION & COUNSELING* | Online article – 1 May 2012 – '**Conveying empathy to hospice family caregivers: Team responses to caregiver empathic communication.**' Although hospice team members frequently express emotional concerns with family caregivers during one-on-one visits, there is a need for more empathic communication during team meetings that involve caregivers. <http://www.sciencedirect.com/science/article/pii/S0738399112001607>

## The role of multi-disciplinary teams in decision-making for patients with recurrent malignant disease

*PALLIATIVE MEDICINE* | Online article – 4 May 2012 – It is mandatory in many countries for decisions for all new patients with cancer to be made within multi-disciplinary teams (MDTs). Whether patients with disease recurrence should also routinely be discussed by the MDT is unknown. During this study 54 MDT meetings included discussions regarding 304 new patients and 29 with disease recurrence. Referrals to the MDT for patients with recurrence came from outpatient clinics or following emergency admission. MDT recommendations were best supportive care, palliative chemotherapy, stent, palliative radiotherapy and further surgery, with 25 of these implemented. <http://pmj.sagepub.com/content/early/2012/05/01/0269216312445296.abstract>



### 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>

### **Diversity of patients' beliefs about the soul after death and their importance in end-of-life care**

*SOUTHERN MEDICAL JOURNAL*, 2012;105(5):266-272. Because beliefs about the soul after death affect the dying experience, patients and survivors may want to discuss those beliefs with their healthcare provider; however, almost no medical research describes such beliefs, leaving healthcare professionals ill prepared to respond. This exploratory study begins the descriptive process. Some beliefs varied little across the sample. For example, most participants said that the soul lives on after physical death, leaves the body immediately at death, and eventually reaches heaven. Many participants also said death ends physical suffering; however, other beliefs varied distinctly by ethnic group or sex. As death nears, patients or survivors may want to discuss beliefs about the soul after death with their healthcare provider. This study characterizes some of those beliefs. By suggesting questions to ask and responses to give, the study provides healthcare professionals a supportive, knowledgeable way to participate in such discussions. [http://journals.lww.com/smajournalonline/Abstract/2012/05000/Diversity\\_of\\_Patients\\_Beliefs\\_about\\_the\\_Soul.6.aspx](http://journals.lww.com/smajournalonline/Abstract/2012/05000/Diversity_of_Patients_Beliefs_about_the_Soul.6.aspx)

1. 'Where is the soul after death? Do we need to ask?' *Southern Medical Journal*, 2012;105(5):273.. [http://journals.lww.com/smajournalonline/Citation/2012/05000/Where\\_Is\\_the\\_Soul\\_after\\_Death\\_Do\\_We\\_Need\\_to\\_Ask\\_.7.aspx](http://journals.lww.com/smajournalonline/Citation/2012/05000/Where_Is_the_Soul_after_Death_Do_We_Need_to_Ask_.7.aspx)

### **Integrating speech-language pathology services in palliative end-of-life care**

*TOPICS IN LANGUAGE DISORDERS*, 2012;32(2):137-148. This article describes how the role of the SLP [speech-language pathologists] in palliative care services contrasts with more traditional impairment-based rehabilitation roles. Consultative services related to communication and swallowing should be informed by and align with overall palliative care goals of the patient, the family, and the team. Case examples illustrate how SLPs interact within an end-of-life care team, highlighting the importance of effective inter-professional communication. Speech-language pathologists are encouraged to consider how they might better integrate speech-language pathology into palliative care services in order to contribute to and learn from palliative care team members. [http://journals.lww.com/topicsinlanguagedisorders/Abstract/2012/04000/Integrating\\_Speech\\_Language\\_Pathology\\_Services\\_in.5.aspx](http://journals.lww.com/topicsinlanguagedisorders/Abstract/2012/04000/Integrating_Speech_Language_Pathology_Services_in.5.aspx)

### **The allied health care professional's role in assisting medical decision making at the end of life**

*TOPICS IN LANGUAGE DISORDERS*, 2012;32(2):119-136. This article provides an overview of the complex issues the practicing clinician needs to keep in mind when assisting clients with advance care planning. This service requires that clinicians step outside their roles as rehabilitation experts, a move that is supported by professional associations. The concepts of medical decision making and informed consent are discussed in the context of decisions made in advance of illness at the end of life. The professional needs also to be aware of the legalities of advance decision making, as laws and statutes differ between states/provinces. There are overarching pieces of legislation that inform local legal and policy issues; the impact of these is briefly addressed. The role of the allied health care professional in advocating for the client during the implementation is addressed. Understanding how the advance care plan should be implemented when a patient becomes incapable is essential when advocating for and protecting the rights of the patient. [http://journals.lww.com/topicsinlanguagedisorders/Abstract/2012/04000/The\\_Allied\\_Health\\_Care\\_Professionals\\_Role\\_in.4.aspx](http://journals.lww.com/topicsinlanguagedisorders/Abstract/2012/04000/The_Allied_Health_Care_Professionals_Role_in.4.aspx)

## Worth Repeating

### **Hope, truth, and preparing for death: Perspectives of surrogate decision makers**

*ANNALS OF INTERNAL MEDICINE*, 2008;149(12):861-868. Overall, 93% (166 of 179) of surrogates [i.e., study participants] felt that avoiding discussions about prognosis is an unacceptable way to maintain hope. The main explanatory theme was that timely discussion of prognosis is essential to allow family members to prepare emotionally and logistically for the possibility of a patient's death. Other themes that emerged included surrogates' belief that an accurate understanding of a patient's prognosis allows them to better support the patient and each other, a moral aversion to the idea of false hope, the perception that physicians have an obligation to discuss prognosis, and the notion that some surrogates look to physicians primarily for truth and seek hope elsewhere. A few surrogates (6 of 179) felt that physicians should withhold prognostic information because of a belief that discussing death could be emotionally damaging to the family or could negatively affect the patient's health. <http://www.annals.org/content/149/12/861.short>

#### 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 (Waterloo Region/Wellington County): <http://www.hpcconnection.ca/newsletter/inthenews.html>

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

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.palliativecareconsultation.ca/?q=mediawatch>

##### **U.S.A.**

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

##### **Europe**

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

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

##### **Asia**

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'What's New: Reading List Update')

##### **International**

Australasian Palliative International Link: <http://www1.petermac.org/apli/links.htm> (Scroll down to 'Media Watch')

Palliative Care Network Community: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

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

### Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy tool or change document.

### Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

### Links to Sources

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

### Something Missed or Overlooked?

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

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**Barry R. Ashpole**  
Beamsville, Ontario CANADA

'phone: 905.563.0044  
e-mail: [barryashpole@bellnet.ca](mailto:barryashpole@bellnet.ca)