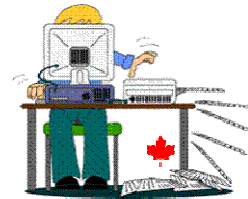


## Media Watch...

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.

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Compiled & Annotated by Barry R. Ashpole

Comfortable and homely environment: Scroll down to [Specialist Publications](#) and 'Exploring health professionals' views regarding the optimum physical environment for palliative and end of life care in the acute hospital setting: A qualitative study' (p.4), published in *BMJ Supportive & Palliative Care*.

## Canada

### Health-care reform needs political support, doctors say

CBC NEWS | Online report – 10 August 2011 – Canadians are asking for political leadership to help fix a broken health-care system, the head of the Canadian Medical Association [CMA] said. Dr. Jeff Turnbull ... [presenting] ... results of the CMA's national dialogue on health-care transformation ... said the CMA heard from Canadians that they respect the health-care system and feel a deep attachment to it, but that it is failing many of them and they want to be involved in building a renewed system. The CMA held six town hall meetings across the country over the last year and online consultations that Turnbull said provoked an enormous

response. About 4,000 comments were posted on the CMA's website and 1,500 people attended the public meetings.  
<http://www.cbc.ca/news/politics/story/2011/08/10/pol-cma-report.html>

#### Extract from CBC report:

There was a strong consensus ... on a need to expand the scope of the Canada Health Act. The CMA heard that people want it to include dental and eye care, long-term care, home care, and palliative care.

## Specialist Publications

Of particular interest:

'Resource use and costs of end-of-life/palliative care: Ontario adult cancer patients dying during 2002 and 2003' and 'Prognosticating in palliative care: A survey of Canadian palliative care physicians' (p.4), published in the *Journal of Palliative Care*.

## U.S.A.

### **Government spending more than \$12 billion on hospice care**

ABC NEWS | Online report – 9 August 2011 – The amount of money Medicare spent on hospice care increased more than 53% between 2005 and 2009 to \$12 billion, according to a government report. Medicare covers certain hospice care costs provided a person has a terminal illness, six months or less to live, and receives care in an approved facility. The rise in spending is largely due to a big increase in the number of people who use hospice services. In 2009, more than 1 million people received hospice care, a 25% increase over 2005. People can receive this type of care at home, in a long-term care facility, in hospitals or in facilities that specialize in hospice care. <http://abcnews.go.com/Health/spending-hospice-care-jumps-50-percent-years/story?id=14255103>

From Media Watch dated 1 August 2011:

- U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES | Office of Inspector General – 18 July 2011 – **'Medicare hospices that focus on nursing facility residents.'** Medicare spending on hospice care for nursing facility residents has grown nearly 70% since 2005. Hundreds of hospices had a high percentage of their beneficiaries residing in nursing facilities, and most of these hospices were for-profit. <http://oig.hhs.gov/oei/reports/oei-02-10-00070.asp>

### **Census data reveal a new, masculine trend in eldercare**

*LONG TERM CARE NEWS & ASSISTED LIVING* | Online report – 8 August 2011 – A recently released census brief ... found in the last decade ... the number of males between the ages of 60 and 74 increased by more than 35%, while their female counterparts increased by only 29%. As the life expectancy of men reaches that of women, it will, for the first time, create a gender balance among our seniors. This newly found equality ... will alter the dynamic of caregiving from a primarily female burden to a shared responsibility. <http://www.mcknights.com/census-data-reveal-a-new-masculine-trend-in-eldercare/article/209291/>

## International

### **Shortfalls in palliative care leading to high death rate: Report**

AUSTRALIA | *TopNews* (Arab Emirates) – 13 August 2011 – It has been reported that the palliative care of the Australia is lacking in providing care to the residents as over 50,000 Australians die because they are not provided with care. 'Caring for Older Australians' <sup>1</sup> has revealed that the timely treatment is not provided to the aged patients. It has emerged that because of lack of funds the aged are not cared timely. However, a few have criticized the findings of the report saying that commission does not acknowledge the poor pay in aged care or recommend pay equity for its registered nurses, who earn much less than their hospital counterparts. <http://topnews.ae/content/28604-shortfalls-palliative-care-leading-high-death-rate-report>

1. 'Caring for Older Australians,' Productivity Commission Inquiry Report, Australian Government, June 2011 (released 8 August 2011). <http://www.pc.gov.au/projects/inquiry/aged-care/report>

#### [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/all/>

### Get end of life care right first time

#### **Final wishes of the dying 'too often ignored' as half die in hospital despite not needing to be there**

U.K. | *Daily Mail* – 11 August 2011 – End-of-life care needs a shake-up and a 'new deal' to ensure that people die in the way they wish and where they wish, says a new report.<sup>1</sup> Seven out of ten people say they would like to die at home but more than half die in hospitals, even though many had no medical need to be there. Many people are not getting their end of life wishes met, it says, when end of life care should be seen as a must-get-right priority for every organisation involved. Although more than half of people (59%) are scared of dying in hospital, only a minority are able currently to die at home or elsewhere in the community. <http://www.dailymail.co.uk/health/article-2024740/Final-wishes-dying-ignored-half-die-hospital-despite-needing-there.html?ito=feeds-newsxml>

1. 'No dress rehearsals: Four key priorities to ensure we get end of life care right first time,' National Council for Palliative Care and the Dying Matters Coalition, August 2011. <http://www.dyingmatters.org/news/ncpc-calls-new-deal-dying>

### Expressions of public interest

#### **Hundreds respond to end of life questionnaire**

U.K. (ISLE OF MAN) | BBC News – 11 August 2011 – Hundreds of people have responded to a ... government questionnaire aimed at improving end of life care. A government spokesperson said about 800 people have already submitted their views, a week before the deadline. Survey questions include topics such as where people want to die, who they want with them, and whether they have discussed it with their families. It is hoped the questionnaire will help to reduce taboos around the issue of death. <http://www.bbc.co.uk/news/world-europe-isle-of-man-14491042>

Of related interest:

- AUSTRALIA (NEW SOUTH WALES) | *North Shore Times* – 11 August 2011 – '**Palliative care funding restored.**' More than \$1 million in funding cut from palliative care services in northern Sydney will be restored. The Health Minister pledged to give back funding to the Northern Sydney Local Health District after a petition containing 23,000 signatures was tabled in parliament last night. <http://north-shore-times.wherelive.com.au/news/story/palliative-care-funding-restored/>
- *IRISH TIMES* | Online report – 9 August 2011 – '**Palliative care hospital opens to public.**' More than 1,800 people have signed up for a tour of a new €60 million palliative care hospital in Cork before its official opening next month. The Health Service Executive is providing €17.5 million for the [75-bed hospital and 44-bed hospice] facility, and the Atlantic Philanthropies foundation ... is providing €10 million. <http://www.irishtimes.com/newspaper/ireland/2011/0809/1224302094263.html>

### Pediatric palliative care

#### **Local square table learning and evaluation report**

U.K. | CHILDREN'S HOSPICES U.K. & ASSOCIATION FOR CHILDREN'S PALLIATIVE CARE (ACT) – 8 August 2011 – Each Square Table brought together life-limited and life-threatened young people and their families, a range of health, education and social care professionals, and providers from the voluntary and statutory sectors, commissioners as well as representatives from respective communities, including faith and business leaders. The report ... captures the open and honest discussions between those who provide children's palliative care, those who use the services, and those who play a wider part in supporting children, young people and families. <http://www.act.org.uk/news.asp?itemid=1154&itemTitle=Local+square+table+learning+and+evaluation+report&section=94&sectionTitle=News>

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

### **Exploring health professionals' views regarding the optimum physical environment for palliative and end of life care in the acute hospital setting: A qualitative study**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online article – 9 August 2011 – [Study] participants agreed that provision of appropriate privacy options was key to achieving an optimum physical environment. However, there was little consensus as to whether single room accommodation or multi-bed accommodation was the most appropriate. A comfortable and homely environment is important, but difficult to achieve in a clinically focused environment. The hospital environment may also be sub-optimal for staff provision of care. The environmental needs of families should be considered alongside the needs of patients. Many deficiencies exist in physical hospital environments for patients at the end of life. However, changes to the hospital environment are limited by resource restrictions, increasing rules and regulations, and a focus on clinical aspects of care. <http://spcare.bmj.com/content/early/2011/08/09/bmjspcare-2011-000045.abstract>

### **Resource use and costs of end-of-life/palliative care: Ontario adult cancer patients dying during 2002 and 2003**

*JOURNAL OF PALLIATIVE CARE*, 2011;27(2):79-88. The total Ontario Ministry of Health-funded cost of EOL/PAL [end-of-life and palliative] care for cancer patients is estimated to be about CAD\$544 million per year, with an average per patient cost of about \$25,000 in 2002-2003. The authors' findings suggest that acute care consumes 75% of EOL/PAL funding and that only a small proportion of health care services used by EOL/PAL care cancer patients is likely to be formal palliative care. <http://www.ncbi.nlm.nih.gov/pubmed/21805942>

Of related interest:

- *PALLIATIVE MEDICINE* | Online article – 10 August 2011 – '**Health system characteristics of quality care delivery: A comparative case study examination of palliative care for cancer patients in four regions in Ontario, Canada.**' The purpose of this study was to explore whether a set of modifiable health system factors could be identified that are associated with population palliative care outcomes, including less acute care use and more home deaths. This research further informs health system planners on important features to incorporate into evolving palliative care systems. <http://pmj.sagepub.com/content/early/2011/08/09/0269216311416697.abstract>

## Canadian Society of Palliative Care Physicians

### **Prognosticating in palliative care: A survey of Canadian palliative care physicians**

*JOURNAL OF PALLIATIVE CARE*, 2011;27(2):89-97. There was moderate agreement between respondents' perceptions of their own accuracy and that of other physicians. They believe that prognostication is important and use clinical factors to estimate survival. They often give different estimates to different information recipients. <http://www.ncbi.nlm.nih.gov/pubmed/21805943>



### 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>

### **Crisis in caregiving: When home-based end-of-life care is no longer possible**

*JOURNAL OF PALLIATIVE CARE*, 2011;27(2):117-25. The purpose of this study was to explore caregivers' perceptions of the crises that preceded and were resolved by relocation during end-of-life care. Relocation presents an opportunity for families to relinquish the burden of end-stage care so that they can resume and complete a lifelong relationship. Careful recognition of and attention to the intimate dynamics that accompany suffering and dying are essential elements of palliative care, which aims to uphold the dignity of the dying person and the integrity of the family in both caregiving and bereavement. <http://www.ncbi.nlm.nih.gov/pubmed/21805946>

### **The end-of-life family meeting in intensive care: Indications, outcomes, and family needs**

*JOURNAL OF PALLIATIVE MEDICINE* | Online article – 10 August 2011 – Family meetings in end-of-life care, especially when conducted prophylactically or proactively, have been shown to be effective procedures for improving family and staff satisfaction and even reducing resource utilization. The first part of the article outlines the family needs that should be addressed in such meetings, including clinician availability, consistent information sharing (especially of prognosis), empathic communication and support, facilitation of bereavement, and trust. The second part addresses family-centered, shared decision making and sources of conflict, as well as related communication and negotiation skills and how to end the meeting. Families and clinicians differ in 1) their understanding of the patient's condition and prognosis; 2) the emotional impact of the illness, particularly the personal meaning of pursuing recovery or limiting supports; and 3) their views of how to make decisions about life-prolonging treatments. The final part draws on the previous two sections to present a structured format and guide for communication skills in conflictual meetings. Ten steps for a humane and effective meeting are suggested, illustrated with sample conversations. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0038>

Of related interest:

- *JOURNAL OF MEDICINE & PHILOSOPHY* | Online article – 8 August 2011 – **'Informed consent and relational conceptions of autonomy.'** This paper argues that informed consent is not sufficient for patient autonomy, at least when autonomy is understood as a "relational" concept. Relational conceptions of autonomy, which have become prominent in the contemporary literature. <http://jmp.oxfordjournals.org/content/early/2011/08/08/jmp.jhr029.abstract>

### **Massachusetts' Pediatric Palliative Care Network: Successful implementation of a novel state-funded pediatric palliative care program**

*JOURNAL OF PALLIATIVE MEDICINE* | Online article – 10 August 2011 – U.S. children with life-limiting illness face barriers to accessing palliative care. In 2006, Massachusetts signed into law a statute providing for the creation and funding of the Pediatric Palliative Care Network. This innovative, exclusively state-funded program provides comprehensive direct and consultative community-based pediatric palliative care services including: 1) pain and symptom management; 2) case management and assessment; 3) social services, counseling, and bereavement services; 4) volunteer support services; 5) respite services; and, 6) complementary therapies. Provision of care is through a network of state-licensed hospice programs, and an array of professional and volunteer services. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0070>

Of related interest:

- *JOURNAL OF SUPPORTIVE ONCOLOGY*, 2011;9(4):136-140. **'Supporting children's grief within an adult and pediatric palliative care program.'** 'What about the kids?' is a dominant and consuming question for caregivers supporting children/youth around the dying and death of a family member. The concerns and fears encompassed in this question can overwhelm caregivers as they put vast amounts of energy into trying to protect children/youth from the suffering and pain that awaits them. Perhaps the hardest lesson these caregivers must learn is that they cannot protect their child/youth from the death any more than they can stop the death from happening. [http://www.supportiveoncology.net/index.php?id=7178&cHash=071010&tx\\_ttnews\[tt\\_news\]=61188](http://www.supportiveoncology.net/index.php?id=7178&cHash=071010&tx_ttnews[tt_news]=61188)

## 'Life Before Death'

*LANCET ONCOLOGY*, 2011;2(8):733-734. Genesis of the 'Life Before Death' project lay in remarks from WHO [World Health organization] ... that 600 million people worldwide were going to suffer in their lifetime from untreated pain due to a lack of access to medicinal opiates, explains Australian documentary maker Sue Collins. "We found that a very alarming statistic," she added. Here are three more alarming statistics: more than 5 billion people worldwide have no access to essential pain medicines; this year 3-6 million people will die with untreated severe pain from cancer and AIDS; and 99·9% of these deaths will be in low-income and middle-income countries. [http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(11\)70211-X/fulltext](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(11)70211-X/fulltext)

**N.B.** the 'Life Before Death' project was highlighted in Media Watch dated 8 August 2011 (p.4).

From Media Watch dated 6 June 2011:

- HUMAN RIGHTS WATCH | Press release – 2 June 2011 – '**Global: Tens of millions face death in agony.**' Tens of millions of people worldwide are denied access to inexpensive medications for severe pain, Human Rights Watch said in a [new] report. The report details the failure of many governments to take even basic steps to ensure that people with severe pain due to cancer, HIV, and other serious illnesses have access to palliative care, a health service that seeks to improve quality of life. <http://www.hrw.org/en/news/2011/06/02/global-tens-millions-face-death-agony>

## Advance care planning in terminally ill and frail older persons

*PATIENT EDUCATION & COUNSELING* | Online article – 2 August 2011 – The majority of [study] participants were willing to talk about dying. In some elderly, however, non-acceptance of their nearing death made ACP [advance care planning] conversations impossible. Most ... wanted to plan those issues of end-of-life care related to personal experiences and fears. They were less interested in planning other end-of-life situations being outside of their power of imagination. <http://www.sciencedirect.com/science/article/pii/S0738399111003752>

### 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.



## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *HEALTH LAW IN CANADA*, 2011;31(4):81-148. 'A perfection of means, and confusion of aims": Finding the essence of autonomy in assisted death laws.' This article explores whether the principles of autonomy and self-determination are indeed at the root of the assisted death laws currently in place in a number of jurisdictions. It is written to appeal to a very broad audience and to those who wish to become better informed about the legal aspects of the assisted death debate. <http://robsonhall.ca/june2011/assisted/index.html>

## Worth Repeating

### Feeling like a burden to others: A systematic review focusing on the end of life

*PALLIATIVE MEDICINE*, 2007;21(2):115-128. Research into the burden of illness has focused predominantly on family caregivers, with little consideration of the other side of the caregiving relationship-care recipients perspectives on having become a 'burden to others.' However, there is now a small but growing body of evidence to suggest that worry about creating burden to others is a common and troubling concern for people who are nearing the end of their lives. This concern is referred to as 'self-perceived burden.' The present study provides a systematic review of the literature, addressing self-perceived burden at the end of life. Literature was searched for relevant studies in palliative care and related fields. The review revealed that self-perceived burden is reported as a significant problem by 19-65% of terminally ill patients. It is correlated with loss of dignity, suffering, and a 'bad death.' Self-perceived burden has also been identified as a relevant factor in death-hastening acts among patients with life-threatening illness, as well as in clinical decisions, such as the choice of place of care at the end of life, advance directives, and acceptance of treatment. <http://pmj.sagepub.com/content/21/2/115.abstract>

### Media Watch Online

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

#### **Canada**

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

Ontario | HPC Consultation Services: <http://www.hpconnection.ca/newsletter/inthenews.html>

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

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

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

#### **International**

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

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

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

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