## Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in hospice, palliative care and end-of-life issues — to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry.

## 1 August 2011 Edition | Issue #212



Compilation of Media Watch 2008, 2009, 2010, 2011 ©

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Seamless care: Scroll down to **Specialist Publications** and 'Navigation and palliative care' (p.8), published in *Cancer*.

## Canada

Compassionate Care Benefit

## Service Canada putting programs to 'secret shopper' test

CTV NEWS | Online report - 30 July 2011 -A pilot mystery shopper program ran between 2007 and 2009. A report on that pilot project found most face-to-face dealings with Service Canada staff were generally pleasant. But not always, as one secret shopper found while looking for information on employment insurance [EI] compassionate care benefits. "The queue line was very small and everyone was forced to stand uncomfortably close to each other in order to fit within the line-up area. I waited in this crowded line-up before it was my turn to speak with the receptionist who seemed to be working at a snail's pace," the shopper reported. "I walked up to the booth and the receptionist looked up at me blankly, waiting for me to speak. I told her that I might need to leave work to take care of my grandmother who was ill. She asked, very bluntly, if my grandmother was going to die. When I said 'Yes,' she told me, in a monotone voice, that I could apply for EI compassionate care. She handed me photocopies of forms which she told me a doctor needed to sign, and told me to look

up compassionate care on the web. "I left the office feeling sad that information on EI compassionate care could not have been provided with a more compassionate attitude." <a href="http://ottawa.ctv.ca/servlet/an/local/CTVNews/20110730/secret-shoppers-rate-government-services-110730/20110730/?hub=OttawaHome">http://ottawa.ctv.ca/servlet/an/local/CTVNews/20110730/secret-shoppers-rate-government-services-110730/20110730/?hub=OttawaHome</a>

**N.B.** Employment Insurance Compassionate Care Benefits website (last updated 22 June 2011): <a href="http://www.servicecanada.gc.ca/eng/ei/types/compassionate\_care.shtml">http://www.servicecanada.gc.ca/eng/ei/types/compassionate\_care.shtml</a>

## Reports pending on end-of-life care in Canada

Parliamentary Committee on Palliative & Compassionate Care: <a href="http://www.pcpcccpspsc.ca/index\_files/Page300.htm">http://www.pcpcccpspsc.ca/index\_files/Page300.htm</a>

Royal Society of Canada Expert Panel on End-of-Life Decision Making: <a href="http://www.rsc-src.ca/documents/WorkingTOR">http://www.rsc-src.ca/documents/WorkingTOR</a> EndofLifePanel</a> Feb24 10 000.pdf

Quebec Select Committee on Dying with Dignity: http://www.assnat.qc.ca/en/actualites-sallepresse/nouvelle/Actualite-21205.html

#### Freedom from pain

## Al-Jazeera to air University of British Columbia student documentary

BRITISH COLUMBIA | CBC News – 20 July 2011 – A documentary made by journalism students from the University of British Columbia [UBC] about the difficulty of getting morphine in the developing world is to air ... on Al-Jazeera. Nine students from the UBC international reporting program partnered with Al-Jazeera English to produce the documentary 'Freedom from Pain' ... [which] ... took the group to India, <sup>1</sup> Ukraine <sup>2</sup> and Uganda <sup>3</sup> to investigate how countries around the world deal with patients suffering pain from cancer, injuries and other conditions involving chronic pain. http://www.cbc.ca/news/arts/story/2011/07/20/freedom-from-pain.html

- INDIAN EXPRESS (New Delhi) 6 April 2011 'Hospitals told to use morphine as pain-killer for cancer patients.' Waking up to the need for morphine in pain management of terminally ill cancer patients, the Union Ministry of Health & Family Welfare has decided to promote the use of the drug.
   http://www.indianexpress.com/news/hospitals-told-to-use-morphine-as-painkiller-for-cancer-patients/772364/1
- ASSOCIATED PRESS 12 May 2011 'Ukrainian cancer patients denied pain relief.' Hundreds of thousands of Ukrainians who suffer from terminal illnesses are denied proper pain relief, Human Rights Watch said in a report, urging Ukrainian authorities to adopt international guidelines for pain management (noted in Media Watch dated 16 May 2011). <a href="http://www.seattlepi.com/news/article/Ukrainian-cancer-patients-denied-pain-relief-1376503.php">http://www.seattlepi.com/news/article/Ukrainian-cancer-patients-denied-pain-relief-1376503.php</a>
- THE MONITOR (Kampala) 1 June 2011 'Hospice begins making pain killers.' Hospice Uganda is now reconstituting opium imported from Scotland ... to make oral morphine ... [which is used in palliative care for cancer and HIV/Aids patients] (noted in Media Watch dated 6 June 2011). http://allafrica.com/stories/201105311294.html

## U.S.A.

#### **Expressions of grief**

## An open letter to Norway... Don't make the mistake we made

HUFFINGTON POST | Online posting – 29 July 2011 – Mourning is a very complicated process. Grief compounded by violence, all the more complex. You have a long road ahead of you. Please, I urge you, as you go through your mourning, do not make the same mistake we made. Not all of us. But most of us. We only consciously grieved the events of the actual day of 9/11. We didn't understand that when people experience grief in the present... it opens up all the grief they have not yet grieved from the past, even the grief that is no longer conscious. We didn't understand that if a person doesn't discern which grief is from the current day and which grief is from the past, and if a person doesn't tease the here-and-now grief away from the grief-of-long-ago, and if a person doesn't work through the grief at its origins... none of the grief will ever end. http://www.huffingtonpost.com/judith-barr/an-open-letter-to-norway- b 911739.html

## Of related interest:

■ DIGITAL JOURNAL | Online report – 26
July 2011 – 'Grieving a soulmate, over
24,000 views on YouTube and
counting.' Can soulmate grief be
captured on YouTube? Can a video
trailer capture the devastating grief
associated with the death of a lover?
According to Robert Orfali, YouTube can
be a powerful medium for discussing
grief.http://www.digitaljournal.com/pr/37
2618

## **Specialist Publications**

Of particular interest:

'Parental Bereavement Act of 2011 introduced in U.S. Senate' (p.8), published in HR & Employment Law News

## Hospice helps dying for dementia patients

UNITED PRESS INTERNATIONAL | Online report – 29 July 2011 – People whose loved ones received hospice care reported an improved quality of care and that the quality of dying was improved, U.S. researchers say. Lead author Dr. Joan Teno, a Brown University gerontologist, and colleagues analyzed 538 survey responses of family members of nursing home patients who died of dementia – 260 received hospice care and 278 did not. Family members of hospice recipients were 51% less likely to report unmet needs and concerns with quality of care and were 49% less likely to report an unmet need for management of pain, the study says. They were 50% less likely to have wanted more emotional support before their loved one's death and they rated the peacefulness of dying and the quality of dying more positively than families whose loved ones did not receive hospice care, Teno says. The survey indicates those who felt their loved one received hospice care "too late" had stronger concerns about care and support in almost every one of the survey's many measures and they felt worse off than people who had no hospice care at all. <a href="http://www.upi.com/Health News/2011/07/29/Hospice-helps-dying-for-dementia-patients/UPI-13801311994224/?spt=hs&or=hn">http://www.upi.com/Health News/2011/07/29/Hospice-helps-dying-for-dementia-patients/UPI-13801311994224/?spt=hs&or=hn</a>

 'Does hospice improve quality of care for persons dying from dementia?' Journal of the American Geriatrics Society, published online 28 July 2011. <a href="http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2011.03505.x/abstract">http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2011.03505.x/abstract</a>

#### A family caregiver's perspective

## Pros and cons of using feeding tubes

FLORIDA | Hernando Today (Tampa) – 28 July 2011 – One of the toughest decisions a family may have to make as their loved one's health deteriorates is whether to go the route of having a feeding tube inserted. When the time came for me to make the decision for my father, I elected not to have the procedure performed. I knew my father had already suffered enough, for at that point he was barely recognizable. But believe me, this was an arduous choice. If at all possible, it shouldn't be laid on any one person's shoulders. Holding back nourishment is such an unnatural act. As a rule, caregivers spend a great deal of time and energy attempting to hold back the inevitable tide of muscle and weight loss, which ultimately leads not only to physical weakness but mental as well. And once the body begins to actually reject food, sadly, death becomes imminent. <a href="http://www2.hernandotoday.com/content/2011/jul/28/HBNEWSO3-pros-and-cons-of-using-feeding-tubes/">http://www2.hernandotoday.com/content/2011/jul/28/HBNEWSO3-pros-and-cons-of-using-feeding-tubes/</a>

#### Even in death, paperwork rules

TEXAS | EMS.com – 28 July 2011 – Back in 2008, paramedics stopped resuscitation efforts on an out-of-hospital cardiac arrest after locating what appeared to be a valid "living will." Unfortunately, the family may not have realized that the patient had expressed his views on resuscitation, and it created conflict on scene and long afterwards. The crew was cleared on any wrongdoing, and it appears that since then several steps were taken to more formally recognize and implement a do not resuscitate order [DNR]. Like most other states, Texas does have processes in place for its EMS [Emergency Medical Service] providers to follow in DNR situations. Being only on the receiving end, however, puts us at a disadvantage when family and friends are not advised of the legal ramifications associated with violating what is in fact a physician's order. It is incumbent upon the primary care providers to work closely with the patient and the family to make sure all members are clear about what should happen when the end of life process begins. <a href="http://www.ems1.com/ems-management/articles/1085947-Even-in-death-paperwork-rules/">http://www.ems1.com/ems-management/articles/1085947-Even-in-death-paperwork-rules/</a>

#### Required caregiver training

## New stipend program for caregivers of veterans disperses first payments

FORBES | Online article – 26 July 2011 – Family members caring for veterans received their first payments from the U.S. Department of Veterans Affairs' new Family Caregiver Program. The program ... provides a monthly stipend to family members who care for veterans that were seriously injured in the line of duty after 1 September 2001. Nearly 200 family caregivers of veterans completed the program's required caregiver training program in time to receive a stipend in July. <a href="http://blogs.forbes.com/bernardkrooks/2011/07/25/new-stipend-program-for-caregivers-of-veterans-disperses-first-payments/">http://blogs.forbes.com/bernardkrooks/2011/07/25/new-stipend-program-for-caregivers-of-veterans-disperses-first-payments/</a>

## Hospitals make palliative care a priority to improve patients' quality of life

WASHINGTON POST | Online article – 25 July 2011 – In the controlled chaos of an hospital emergency department, ensuring that patients are pain-free and can make informed choices about their care often takes a back seat to assessing and stabilizing them and moving them through the system as fast as possible. But now some experts say that providing palliative care – which focuses on patients' quality-of-life issues – can and should be a priority in emergency departments, and they're putting together a program to help hospitals better address those issues. "A decade ago, we thought of the emergency department as a way station," says Tammie Quest, an associate professor of emergency medicine at Emory University School of Medicine who is also board-certified in hospice and palliative medicine. "Now we're recognizing what can be done to identify patient needs there, and help to initiate what can be done in the hospital or once the patient leaves the hospital." <a href="http://www.washingtonpost.com/national/health-science/hospitals-make-palliative-care-a-priority-to-improve-patients-quality-of-life/2011/07/14/glQAsg1AZI\_story.html">http://www.washingtonpost.com/national/health-science/hospitals-make-palliative-care-a-priority-to-improve-patients-quality-of-life/2011/07/14/glQAsg1AZI\_story.html</a>

From Media Watch dated 25 July 2011:

■ JOURNAL OF PALLIATIVE MEDICINE | Online article – 18 July 2011 – 'The palliative care model for emergency department patients with advanced illness.' Although some data on pilot programs are available, optimal models of delivery of emergency department-based palliative care have not been rigorously studied. <a href="http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0011">http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0011</a>

From Media Watch dated 4 April 2011:

- JOURNAL OF INTENSIVE CARE MEDICINE | Online article 24 March 2011 'End of life care in ICU: A practical guide.' The purpose of this manuscript is to provide a practical guide to end of management for all bedside practitioners. The manuscript outlines not all but some fundamentally important ethical concepts and provides helpful rules and steps on end-of-life management... <a href="http://jic.sagepub.com/content/early/2011/02/13/0885066610392697.abstract">http://jic.sagepub.com/content/early/2011/02/13/0885066610392697.abstract</a>
  - N.B. Additional articles on the palliative care in the intensive care unit are noted in this issue of Media Watch.

## 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: <a href="http://www.ipcrc.net/barry-r-ashpole.php">http://www.ipcrc.net/barry-r-ashpole.php</a>

#### Trends: For-profit hospices

## Medicare hospices that focus on nursing facility residents

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES | Office of Inspector General – 18 July 2011 – 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. Compared to hospices nationwide, these high-percentage hospices received more Medicare payments and served beneficiaries who spent more time in care. High percentage hospices typically enrolled beneficiaries whose diagnoses required less complex care and who already lived in nursing facilities before they elected hospice care. Medicare currently pays hospices the same rate for care provided in nursing facilities as it does for care provided in other settings, such as private homes. Unlike private homes, nursing facilities are staffed with professional caregivers and are often paid by third party payers, such as Medicaid. These facilities are required to provide personal care services, which are similar to hospice aide services that are paid for under the hospice benefit. Some hospices may be seeking beneficiaries with particular characteristics, including those with conditions associated with longer but less complex care. Such beneficiaries are often found in nursing facilities. By serving these beneficiaries for longer periods, the hospices receive more Medicare payments, which can contribute to larger profits. http://oig.hhs.gov/oei/reports/oei-02-10-00070.asp

From Media Watch dated 25 July 2011:

CALIFORNIA | San Francisco Chronicle – 22 July 2011 – 'Preparing Americans for death lets for-profit hospices neglect end of life.'

http://www.sfgate.com/cgibin/article.cgi?f=/g/a/2011/07/22/bloomberg1376-LOPPSE1A74E901-3G83F78B9VT0I642MF1U1GBMDE.DTL

From Media Watch dated 4 July 2011:

NEW YORK TIMES | Online article – 27 June 2011 – 'Concerns about costs rise with hospices' use.'

http://www.nytimes.com/2011/06/28/health/28hospice.html? r=1&ref=hospicecare

From Media Watch dated 23 May 2011:

UNITED PRESS INTERNATIONAL | Online report – 19 May 2011 – 'For-profit hospice industry raises worries.'

http://www.upi.com/Health\_News/2011/05/19/For-profit-hospice-industry-raises-worries/UPI-78121305782622/

JOURNAL OF LAW, MEDICINE & ETHICS, 2011;39(2): 224-234. 'In the business of dying: Questioning the commercialization of hospice.'http://onlinelibrary.wiley.com/doi/10.111 1/j.1748-720X.2011.00591.x/abstract

 Medicare Hospices that Focus on Nursing Facility Residents, July 2011. <a href="http://oig.hhs.gov/oei/reports/oei-02-10-00070.pdf">http://oig.hhs.gov/oei/reports/oei-02-10-00070.pdf</a>

### Of related interest:

LONG-TERM CARE NEWS & ASSISTED LIVING | Online report – 1 August 2011 – 'Hospices to receive 2.5% bump for Medicare patients.' Hospices treating Medicare beneficiaries will see a 2.5% increase in payments for fiscal year 2012, according to a final rule released ... by the Centers for Medicare & Medicaid Services. They must also begin reporting on the quality of care. http://www.mcknights.com/hospices-to-receive-25-bump-for-medicare-patients/article/208702/

## 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. <a href="http://www.pcn-e.com/community/pg/file/world/world/">http://www.pcn-e.com/community/pg/file/world/</a>

## International

#### Funding should follow the patient

#### 'Make funds fair'

U.K. | Gazette (Hemel Hempstead) – 29 July 2011 – A hospice boss has challenged the government to improve funding for a service that allows terminally ill patients to die in their own homes. Iain Rennie Grove House Hospice Care (IRGH) says its nurses help 60% of the 1,700 patients in their area to die in their own homes. Nationwide, just 20% of the terminally ill usually get that chance. Its bosses say that the IRGH service is cheaper than hospital care and a preference of patients – but that it only gets 10% of total National health Services funding. <a href="http://www.hemeltoday.co.uk/news/business/local-business/make\_funds\_fair\_1\_2911830">http://www.hemeltoday.co.uk/news/business/local-business/make\_funds\_fair\_1\_2911830</a>

## Palliative care outsourced to voluntary sector at two trusts

U.K. | Guardian – 26 July 2011 – The wholesale transfer of end-of-life care to charities at two health trusts puts them at the vanguard of the government's National Health Service (NHS) reform plans. Although the voluntary sector provides much end-of-life care locally across the U.K., this is the first time that it has been given responsibility for an area's entire palliative services. <a href="http://www.guardian.co.uk/society/2011/jul/26/palliative-care-outsourced-voluntary-sector">http://www.guardian.co.uk/society/2011/jul/26/palliative-care-outsourced-voluntary-sector</a>

#### Assisted (or facilitated) death

Representative sample of recent news media coverage:

RADIO NETHERLANDS WORLDWIDE | Online report – 29 July 2011 – 'Third of Dutch doctors reject euthanasia.' A third of Dutch family doctors have refused to honour a euthanasia request over the past five years, a recent poll suggests. <a href="http://www.rnw.nl/english/bulletin/third-dutch-doctors-reject-euthanasia">http://www.rnw.nl/english/bulletin/third-dutch-doctors-reject-euthanasia</a>

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

#### A study on caregiver burden: Stressors, challenges, and possible solutions

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE CARE | Online article – 22 July 2011 – The majority of caregivers [i.e., study participants] reported experiencing role conflict and inadequate stress management. Caregivers who worked outside the home, those who cared for two parents concurrently, those with the least amount of outside assistance, and caregivers who spent a longer period of time caregiving reported the highest levels of health problems and overall burden. Caregivers stated a need for more support from hospice agencies, more education on caregiver training, and more public education about hospice services. Faith played a positive role in alleviating caregiver burden. Early identification, intervention, education and coordination of services may help to alleviate caregiver burden, which will improve quality of life for both patient and caregiver. http://ajh.sagepub.com/content/early/2011/07/22/1049909111416494.abstract

#### Of related interest:

JOURNAL OF HEALTH PSYCHOLOGY | Online article – 25 July 2011 – 'The reluctance to burden others as a value in end-of-life decision making: A source of inaccuracy in substituted judgment.' The authors investigated the reluctance to burden others (RBO), a commonly cited patient value, as a possible source of proxy inaccuracy. Although RBO predicted treatment preferences for both elders and proxies, elders rated RBO significantly more important than did proxies. <a href="http://hpq.sagepub.com/content/early/2011/07/22/1359105311414956.abstract">http://hpq.sagepub.com/content/early/2011/07/22/1359105311414956.abstract</a>

## Unrelieved pain and suffering in patients with advanced cancer

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE CARE | Online article – 22 July 2011 – A multi-dimensional approach with knowledge of the risk factors for poor pain control is important to prevent, detect, and manage risk factors for intractable pain, including psychosocial distress, addictive behavior, and delirium in patients with terminal cancer. The authors present 3 cases of patients with advanced cancer with intractable bone pain whose hospital courses were complicated by severe psychosocial distress and delirium. They also propose an algorithm of multidimensional approach to unrelieved pain and suffering in patients with advanced cancer. http://ajh.sagepub.com/content/early/2011/07/10/1049909111415511.abstract

## An empirical evaluation of predictive tools for mortality

ARCHIVES OF INTERNAL MEDICINE | Online article – 25 July 2011 – The authors aimed to evaluate the discriminating performance of predictive tools for death and the variability in this performance across different clinical conditions and studies. Most tools designed to predict mortality have only modest accuracy, and there is large variability across various diseases and populations. http://archinte.ama-assn.org/cgi/content/short/archinternmed.2011.334

#### Of related interest:

■ JOURNAL OF PALLIATIVE MEDICINE | Online article – 27 July 2011 – 'Being aware of the prognosis: How does it relate to palliative care patients' anxiety and communication difficulty with family members in the Hong Kong Chinese context?' Patients whose family members were less aware of the prognosis were more likely to experience difficulty communicating with family members. This study further suggests that awareness of prognosis may not harm Chinese patients. <a href="http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0099">http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0099</a>

## Primary palliative care: Facing twin challenges

AUSTRALIAN FAMILY PHYSICIAN, 2011; 40(7):517-518. There are many systemic barriers to the routine provision of this type of care in Australia. These need to be identified and solutions to account for them devised. There is currently a randomised controlled trial underway looking at whether a toolkit to help assess caregiver needs (supported by specific information for GPs) is effective in helping carers of patients with advanced cancer, and is practical within the Australian system. We need to know that whatever systems are implemented work and are feasible in general practice, not foisted upon us. This type of research will help address part of this first research challenge of primary palliative care for the future. The challenge is magnified by the fact that 25% of the Australian general

practice workforce chooses not to administer palliative care. A picture of such a group is shown below. The features that distinguish these practitioners are the very features of Australia's future general practice workforce. <a href="http://www.racgp.org.au/afp/201107/201107">http://www.racgp.org.au/afp/201107/201107</a> mitchell.pdf

## Reasons for not providing palliative care

- Do not do home visits 75%
- Feel like there is inadequate support 70%
- Family or personal commitments 70%
- Lack of knowledge 48%
- Lack of interest 30%
- Emotional burden of care 16%

#### Of related interest:

NORTH CAROLINA MEDICAL JOURNAL, 2011;72(3):229-231. 'Palliative care and the search for value in health reform.' Improving value in health care is of paramount importance, and doing so will require focus on both the costs and benefits of care. Palliative care addresses symptoms of disease regardless of prognosis, helps patients clarify their goals or care, and is key in improving value in the health care system. <a href="http://www.ncmedicaljournal.com/wp-content/uploads/2011/05/72315-web1.pdf">http://www.ncmedicaljournal.com/wp-content/uploads/2011/05/72315-web1.pdf</a>

#### Seamless care

## Navigation and palliative care

CANCER, 2011;117(15 Suppl):3583-3589. This article defines palliative and hospice care and describes some of the current challenges of integrating palliative care into other forms of care. It also considers outcomes that navigation might be expected to improve for patients receiving palliative care or enrolled in hospice. These outcomes include symptom relief; communication efficacy; transitions of care; and access to palliative care, hospice, and bereavement care for families. Although these outcomes may not have been specifically assessed in patients in cancer navigation programs, they represent important outcomes for patients receiving palliative care and their families. It is recognized that the types of outcomes that are important to track for patients and families receiving palliative care should be consistent with outcomes at other stages of illness. <a href="http://onlinelibrary.wiley.com/doi/10.1002/cncr.26266/full">http://onlinelibrary.wiley.com/doi/10.1002/cncr.26266/full</a>

#### Of related interest:

CANCER, 2011;117(15 Suppl):3590-3600. 'Patients, family caregivers, and patient navigators.'
 Navigation services may be strengthened by establishing a partnership between the patient, family/caregiver, and the navigator. http://onlinelibrary.wiley.com/doi/10.1002/cncr.26263/full

#### Parental Bereavement Act of 2011 introduced in U.S. Senate

HR & EMPLOYMENT LAW NEWS | Online report – 26 July 2011 – A bill that would allow parents grieving from the death of their child to receive up to 12 weeks of job-protected time-off under the Family Medical Leave Act has been introduced by Senator Jon Tester of Montana. Parents are currently eligible for extended, unpaid time-off to care for newborn babies, adopted children, and family members with serious health conditions. Tester's 'Parental Bereavement Act of 2011' would ensure that the death of a child is treated like other life-altering events, allowing parents time to grieve. <a href="http://hr.blr.com/HR-news/Benefits-Leave/FMLA-Leave-of-Absence/Parental-Bereavement-Act-of-2011-Bill-Introduced-i/">http://hr.blr.com/HR-news/Benefits-Leave/FMLA-Leave-of-Absence/Parental-Bereavement-Act-of-2011-Bill-Introduced-i/</a>

#### **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.hpcconnection.ca/newsletter/inthenews.html

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

#### USA

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

#### International

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

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

## End of life enhanced by dignity therapy

IRISH MEDICAL TIMES | Online report – 28 July 2011 – Individualised psychotherapy should be made widely available to all individuals nearing the end of their lives, researchers have found. Known as dignity therapy, the approach can enhance the end-of-life experience for cancer patients. Dignity therapy, delivered by a psychologist, psychiatrist or palliative care nurse, was found to be of more benefit to cancer patients than standard palliative care and client-centred care, the randomised trial of over 400 patients found. There were no significant differences in levels of distress between the three patient groups, but dignity therapy significantly improved quality of life and enhanced the dignity of patients and assisted their families, the researchers found. http://www.imt.ie/clinical/2011/07/end-of-life-enhanced-by-dignity-therapy.html

1. 'Dignity therapy for patients who are terminally ill,' *Lancet Oncology*, 2011;12(8):712-713. http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(11)70185-1/fulltext

**N.B.** Noted in Media Watch dated 11 July 2011, titled 'Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: A randomised controlled trial.'

## Does this patient have medical decision-making capacity?

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2011;306(4):420-427. Evaluation of the capacity of a patient to make medical decisions should occur in the context of specific medical decisions when incapacity is considered. Incapacity is common and often not recognized. The MMSE [Mini-Mental State Examination] is useful only at extreme scores. The ACE [Aid to Capacity Evaluation] is the best available instrument to assist physicians in making assessments of medical decision-making capacity. http://jama.ama-assn.org/content/306/4/420.abstract

# Establishing an analytical framework in law and bioethics for nurses engaged in the provision of palliative sedation

JOURNAL OF NURSING LAW, 2011;14(2):58-67. This article addresses the legal and ethical issues that nurses need to understand when they are involved in the provision of palliative sedation in the U.S. Presenting a series of cases that reflect the full range of palliative care options, the discussion draws analogies and distinctions between these measures and other interventions that affirmatively cause death such as euthanasia and physician-assisted death, thus enabling nurses to develop a framework within which to analyze the various circumstances in which ethically challenging palliative interventions may present themselves. The authors ... propose ... guidelines designed to limit the application of palliative interventions in a manner that comports with the law and bioethical norms, thereby shielding nurses from the risk of engaging in palliative care interventions that arguably exceed the bounds of accepted professional behavior. http://www.ingentaconnect.com/content/springer/nlaw/2011/00000014/00000002/art00003

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

• MORTALITY, 2011;16(3):223-241. 'Joining a right-to-die society: Motivation, beliefs and experiences.' This paper reports a survey of the membership of a UK right-to-die society Friends at the End (FATE). A questionnaire answered by 41% (162) of the members of this society provided insight into motives and experiences that had led to a decision to join. Members were more likely to be female, older and of higher social standing than the general population. A high proportion were religious and found no conflict between this and their membership, and a high proportion had backgrounds in health and social care. Motives for membership included the desire for practical assistance with dying, past involvement with deaths that involved high levels of dependency and distress, and commitment to 'right' to die ideology. The concerns of members about the distress of dying mirror what is known about the reasons why people approaching death request an assisted death. <a href="http://www.tandfonline.com/doi/abs/10.1080/13576275.2011.586123">http://www.tandfonline.com/doi/abs/10.1080/13576275.2011.586123</a>

## **Worth Repeating**

## The last 2 years of life: Functional trajectories of frail older people

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY, 2003;51(4):492-498. Patients with advanced frailty [i.e., study participants], with or without cognitive impairment, have an end-of-life functional course marked by slowly progressive functional deterioration, with only a slight acceleration in the trajectory of functional loss as death approaches. Patients with cognitive impairment have particularly high rates of functional impairment at the time of death. These results suggest that end-of-life care systems that are targeted toward patients with functional trajectories clearly suggesting impending death ... are poorly suited to older people dying with progressive frailty. http://onlinelibrary.wiley.com/doi/10.1046/j.1532-5415.2003.51157.x/abstract

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## **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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