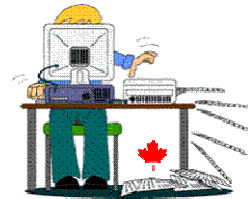


## Media Watch...

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

Compiled & Annotated by Barry R. Ashpole

Key differences between rural and urban palliative care: Scroll down to [Specialist Publications](#) and 'Be known, be available, be mutual: A qualitative ethical analysis of social values in rural palliative care' (p.8), published in *BMC Medical Ethics*.

## Canada

### Legal and ethical issues in end of life care

#### **Baby Joseph takes last breath at home**

ONTARIO | CBC News (Windsor) – 28 September 2011 – Joseph Maraachli, the terminally ill baby at the centre of a legal and ethical battle, has died at his Windsor home. Baby Joseph ... suffered from a degenerative brain disease. He was 20 months old when he died late Tuesday afternoon. <http://www.cbc.ca/news/canada/windsor/story/2011/09/28/wdr-baby-joseph.html>

From Media Watch dated 25 April 2011:

- ONTARIO | CBC News (Windsor) – 21 April 2011 – '**Baby Joseph returns to Canada.**' Joseph Maraachli, the terminally ill baby at the centre of a legal and ethical battle that led to his care in a U.S. hospital, returned to Canada. Canadian doctors had refused to perform a tracheotomy to prolong his life. <http://www.cbc.ca/news/health/story/2011/04/21/wdr-maraachli-returns-to-windsor.html>

### Statistics Canada

#### **Life expectancy rises slightly in Canada**

CBC NEWS | Online report – 27 September 2011 – A baby born in 2006 can expect to live to an average age of 80.9.<sup>1</sup> Three provinces showed life expectancy at birth that were above the national average: British Columbia at 81.4 years; Ontario at 81.3 years; and, Quebec at 81.0 years. Men generally have a lower life expectancy than women, but the gap has narrowed in the past decade. <http://www.cbc.ca/news/health/story/2011/09/27/life-expectancy-canada.html>

1. 'Canada's population estimates: Age and sex,' Statistics Canada, September 2011. <http://www.statcan.gc.ca/daily-quotidien/110928/dq110928a-eng.htm>

Cont.

Of related interest:

- CBC NEWS | Online report – 29 September 2011 – **'Aging Canada will boost budget pain, watchdog says.'** Canada's aging population and other factors mean the country's finances are not sustainable over the long term, according to a report released by Parliament's budget watchdog. <http://www.cbc.ca/news/politics/story/2011/09/29/pol-budget-officer-report.html>

### Non-profits unite over end-of-life care

NOVA SCOTIA | *Metro Halifax* – 27 September 2011 – A group of 16 not-for-profit organizations joined forces ... to form the Quality End of Life Care Coalition of Nova Scotia in an attempt to help shape public policy and to raise awareness concerning end-of-life care in the [maritime] province. <http://www.metronews.ca/halifax/local/article/980703--non-profits-unite-over-end-of-life-care>

### Four tiers of administration before home care funding reaches front lines

ONTARIO HEALTH COALITION | Online report – 26 September 2011 – The Ontario Health Coalition (OHC) today reiterated its findings from a home care report released in April this year.<sup>1</sup> The report includes figures from Ontario's Auditor General, showing cost of home care administration through the Community Care Access Centres.<sup>2</sup> In addition to the Auditor General's figures, the coalition notes home care funding in Ontario goes through ... four tiers of administration before funding reaches front-line care. The coalition has been calling for reform of home care to create a public non-profit system which would redirect funding and staff to front line care. <http://www.web.net/~ohc/homecare2011finalreport.pdf>

1. *Still Waiting: An assessment of Ontario's Home Care System After Two Decades of Restructuring*, Ontario Health Coalition, April 2011. <http://www.web.net/ohc/homecare2011finalreport.pdf> (Noted in Media Watch dated 11 April 2011)
2. *Ontario Auditor General 2010 Annual Report*, December 2010 (Chapter 3; Section 3.04, pp.113-131). [http://www.auditor.on.ca/en/reports\\_en/en10/2010ar\\_en.pdf](http://www.auditor.on.ca/en/reports_en/en10/2010ar_en.pdf) (Noted in Media Watch dated 11 April 2011)

#### [Specialist Publications](#)

Of particular interest:

**'Emergency department use among end-of-life home care clients'** (p.11), published in the *Journal of Palliative Care*.

Of related interest:

- ONTARIO | *Toronto Star* (OpEd) – 27 September 2011 – **'What became of the plan for aging at home?'** In his first term as Ontario premier, Dalton McGuinty made a firm commitment to seniors: "If you require care, want it in your home and that care costs less than sending you to a hospital or nursing home, we will make sure you get it." <http://www.thestar.com/news/article/1060622>

**New Link**

#### [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>

## U.S.A.

### Art of living from sheer presence

#### **Documentary explores unique subculture of hospice volunteers**

*THE ATLANTIC* | Online article – 28 September 2011 – 'Lessons for the Living' is a poignant documentary ... exploring the unique subculture of hospice volunteers as they contemplate their own philosophies of life and death. This grounding excerpt from the film follows Kathleen, who is both a hospice volunteer and a hospice patient. She has been preparing for her own death for over a decade, but has managed to master that art of living from sheer presence – a powerful lesson, indeed, for the rest of us. <http://www.theatlantic.com/life/archive/2011/09/documentary-explores-unique-subculture-of-hospice-volunteers/245817/>

#### **Palliative care comes to the emergency department**

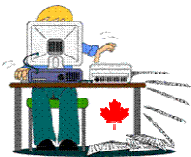
PENNSYLVANIA | *Inquirer* (Philadelphia) – 28 September 2011 – When Joseph Morelli's medical history popped up on her computer screen early one Sunday this month, Meg Greene, a nurse case manager in Bryn Mawr Hospital's emergency department, immediately recognized that he might benefit from her specialty: palliative care. Greene is part of a small but growing group of medical providers who say many patients in emergency departments are not appropriate for the all-out rescue medicine these units are designed to deliver. Instead, they are suffering from the pain and inexorable decline of cancer and chronic illness or old age, and may be better served by care aimed at comfort, not cure. [http://www.philly.com/philly/health\\_and\\_science/130678858.html](http://www.philly.com/philly/health_and_science/130678858.html)

From Media Watch dated 12 September 2011:

- *SOCIAL SCIENCE & MEDICINE* | Online article – 1 September 2011 – '**Caring for the dying in emergency departments.**' The authors examine the spaces of dying and death, which are created in a place designed to save life, and not necessarily to provide supportive and palliative care. <http://www.sciencedirect.com/science/article/pii/S0277953611005132>

From Media Watch dated 8 August 2011:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article – 30 July 2011 – '**Does palliative care have a future in the emergency department?**' Providers acknowledged many benefits of palliative care presence in the emergency department, including provision of a specialized skill set, time to discuss goals of care, and an opportunity to intervene for seriously ill or injured patients. <http://www.sciencedirect.com/science/article/pii/S0885392411002727>



#### **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>

## "They're going to unplug grandma"

### **End-of-life directives do not hasten death, study finds**

*U.S.A. TODAY & WORLD REPORT* | Online report – 28 September 2011 – New research suggests that sick people who talk about advance directives don't die earlier than their counterparts who don't have those discussions about end-of-life care.<sup>1</sup> The study only looked at patients who were mildly or moderately ill, not those who were expected to die soon. And the study doesn't definitively prove that the discussions don't affect death rates. Still, the findings suggest that "having a discussion or completing a directive doesn't lead to harm." [Study author Dr. Stacy Fischer an assistant professor at the University of Colorado School of Medicine] and her colleagues launched their study in the wake of the 2009 health care debate, after a provision that allowed funding for advance directive discussions under the Medicare program came under scrutiny. Although this provision had been in place during the George W. Bush administration, the Obama administration removed the provision from the Affordable Care Act so that the issue could not cloud the larger debate about affordable health care, the study said. The controversy also introduced the term "death panels" to the public. Media reports say no such panels – alleged to allow doctors to make decisions about who lives or dies – actually existed in President Obama's health care reform proposal. <http://health.usnews.com/health-news/managing-your-healthcare/healthcare/articles/2011/09/28/end-of-life-directives-do-not-hasten-death-study-finds>

1. "They're going to unplug grandma": Advance directive discussions and documentation do not decrease survival in patients at baseline lower risk of death,' *Journal of Hospital Medicine*, published online 29 September 2011. <http://onlinelibrary.wiley.com/doi/10.1002/jhm.930/abstract>

### **Americans favor investment in community and home-based health care**

*CALIFORNIA | Sacramento Bee* – 27 September 2011 – [In poll about federal spending priorities for health care] nearly four out of five Americans (79%) said the federal government should strengthen patients' access to home medical equipment and services, according to the online survey. Most Americans (61%) said they favor investment in community- or home-based care to improve cost-effective health care. <http://www.sacbee.com/2011/09/27/3942765/americans-favor-investment-in.html>

#### **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/owner/MediaWatch>

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>

## International

### **Public urged to support palliative care**

*BORNEO POST* | Online report – 3 October 2011 – Palliative Care has been recognised as an urgent humanitarian aid worldwide, with the development of its services steadily growing over the past decade, particularly in less developed and developing nations. In Miri [a city in northern Sarawak, Malaysia, on the island of Borneo], it consists of doctors and nurses from Miri Hospital and volunteers and provides physical, psychological and spiritual support not only to patients but also to their families. <http://www.theborneopost.com/2011/10/03/public-urged-to-support-palliative-care/>



### **Many will age but few will bear the cost**

*THE AUSTRALIAN* | Online report – 1 October 2011 – Older Australians generally want to remain independent and in control of how and where they live; to stay connected to their families and communities; and be able to exercise some measure of choice over their care. These are the opening words in the Productivity Commission's report 'Caring for Older Australians,' released in August. How and where we spend the last years and months of our lives is becoming one of the most fraught and pressing questions of the age. And no less difficult is the related question of how we negotiate our very final days, amid renewed Greens-led political discussion on legalising euthanasia and the increasing use of "living wills," recording a person's opposition to specific medical interventions. At first blush the aspirations ascribed to us by the Productivity Commission - control and connectedness - seem modest. But set against the backdrop of the looming population crunch, there is much left to do in

public policy and private enterprise to realise them. <http://www.theaustralian.com.au/national-affairs/many-will-age-but-few-will-bear-the-cost/story-fn59niix-1226153985821>

#### Engaging in 'death talk'

#### **Build confidence to match competence**

*AUSTRALIAN AGEING AGENDA* | Online article – 29 September 2011 – The key to providing better end-of-life care in Australia is to boost the confidence, not the competence of residential aged care staff, an international palliative care expert said. Head of the U.K.'s national end-of-life care program, Les Storey, believes that education and training – specific to making aged care staff feel more comfortable engaging in 'death talk' – must be more widespread throughout the sector if a high standard of end-of-life care is to ever be provided well, across the board. <http://www.australianageingagenda.com.au/2011/09/29/article/Build-confidence-to-match-competence/LIOSUARXBG>

From Media Watch dated 12 September 2011:

- *AUSTRALIAN AGEING AGENDA* | Online report – 6 September 2011 – '**Choice and control over life and death.**' The Productivity Commission [PC] has taken up the palliative care cause, recommending that the aged care system "should aim to be consumer-directed, allowing older Australians to have choice and control over their lives and to die well." Behind those words – "to die well" – is a much greater emphasis placed on palliative care in the final version of the PC's report.<sup>1</sup> <http://www.australianageingagenda.com.au/2011/08/16/article/Choice-and-control-over-life-and-death/PCZVWNMNLJ.html>

1. Caring for Older Australians. Productivity Commission, 2011. <http://pc.gov.au/projects/inquiry/aged-care/report>

## Landmark judgement

### **Judge rejects family's right to die case**

U.K. | *Daily Telegraph* – 28 September 2011 – In the first case of its kind in this country, Mr. Justice Baker said that preservation of life was a fundamental principal of law. The woman's mother and sister had urged him to allow her to die, describing her "pointless existence" and saying she would not have wanted to live in such a state. But the judge found that the woman, identified only as "M," did have "some positive experiences" and crucially there was a "reasonable prospect" that those experiences could be extended. In a landmark 43,000 word judgment, he acknowledged that prior to her illness, "M" had told her family that she would not want to be kept alive in such circumstances, but said that such statements were "informal" and therefore not legally binding. The judge added: "The factor which does carry substantial weight, in my judgment, is the preservation of life. Although not an absolute rule, the law regards the preservation of life as a fundamental principle." Ruling that it would not be in the M's best interests to

withdraw artificial nutrition and hydration, he expressed sympathy for M's family, who have endured "years of anguish" and had demonstrated a deep devotion to M. But he said that they should now work together with M's doctors and carers on a revised care plan. <http://www.telegraph.co.uk/health/healthnews/8794013/Judge-rejects-family-right-to-die-case.html>

#### **Judges to hear applications to withdraw life-sustaining treatment in public**

*SOLICITORS JOURNAL* | Online report – 29 September 2011 – Cases concerned with the withdrawing of life-sustaining treatment from patients in a minimally conscious or vegetative state should all be heard by the Court of Protection and ... in public, a senior judge ruled. [http://www.solicitorsjournal.com/story.asp?sectioncode=2&storycode=18981&c=3&eclipse\\_action=getsession&eclipse\\_action=getsession](http://www.solicitorsjournal.com/story.asp?sectioncode=2&storycode=18981&c=3&eclipse_action=getsession&eclipse_action=getsession)

### **Cancer patients die waiting for hospital letters**

AUSTRALIA (NEW SOUTH WALES) | *The Daily Telegraph* (Sydney) – 27 September 2011 – Cancer patients have been kept waiting so long to receive follow-up letters from their specialists that some have died before the advice arrived at their GPs. A backlog of correspondence needing to be typed up at Westmead Hospital means about 700 people have waited up to three years for the letters to be sent. In one case, a Sydney doctor received a letter from Westmead about a female patient with advanced skin cancer that had been dictated by a specialist on 21 August 2009, but was not typed up until 16 September 2011. By the time it reached Dr. Adrian Sheen the woman had been dead for a year. <http://www.dailytelegraph.com.au/news/sydney-nsw/cancer-patients-die-waiting-for-hospital-letters/story-e6freuzi-1226147316230>

### **Children's hospice opens in Dublin**

IRELAND | Raidió Teilifís Éireann News (Dublin) – 27 September 2011 – Ireland's first children's hospice has been officially opened in Dublin. It cares for children from birth to 18 years and their families. The hospice has eight bedrooms, each with an ensuite facility. There are over 1,400 children living with life-limiting or threatening conditions in Ireland. Around 350 children die each year from one of these conditions. In the Dublin, Mid-Leinster and Northeast regions alone, over 400 children will need a

palliative care environment this year. <http://www.rte.ie/news/2011/0927/hospice.html>

#### **Specialist Publications**

Of particular interest:

**'New frontiers in palliative care'** (p.10), published in the *Irish Medical Times*.

Cont.

From Media Watch dated 21 March 2011:

- IRELAND | *Irish Times* – 15 March 2011 – **'Making dying 'a little bit easier.'** The Irish Hospice Foundation [IHF] has a plan to put in place eight outreach nurses throughout the State who will be available to help families cope when their child has a life-limiting illness. As part of its Hospice Homecare for Children Programme, the IHF is offering training in palliative care for children to public health nurses and other healthcare professionals. A database of all children with palliative care needs throughout the State is planned [and] Ireland's first Paediatric Palliative Care consultant is to be appointed. <http://www.irishtimes.com/newspaper/health/2011/0315/1224292151112.html>

### Dying cancer patients should not be given 'futile' drugs

U.K. | *Daily Telegraph* – 26 September 2011 – After a year-long investigation, a panel of leading academics said that the cost of treating cancer to western societies is spiralling out of control, as the ageing population means that increasing numbers of people are growing tumours. Hi-tech treatments are being developed at a rapid pace while new medicines are coming on the market with little evidence to show they will help patients, it was claimed. Doctors are said to be recommending new treatments with no thought to their cost or effectiveness because they don't want to disappoint patients, leaving them with "false hope" as some drugs will only lengthen sufferers' lives by a few weeks. A detailed report, published in *The Lancet Oncology*,<sup>1</sup> said that in some cases it may be better for terminally ill patients to "forgo" these treatments in favour of better end-of-life

care. <http://www.telegraph.co.uk/health/healthnews/8790468/Dying-cancer-patients-should-not-be-given-futile-drugs.html>

1. 'Delivering affordable cancer care in high-income countries,' *The Lancet Oncology*, 2011;12(10):933-980. [http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(11\)70141-3/abstract](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(11)70141-3/abstract)

#### Extract from *The Lancet Oncology* article:

In developed countries, cancer treatment is becoming a culture of excess. We over diagnose, over treat, and over promise. This extends from use of complex technology, surgery, and drugs to events related to the acceptance of treatment side-effects.

- U.K. | *The Independent* (OpEd) – 28 September 2011 – **'Drugs: The doctor's dilemma.'** When treating terminally ill patients, should medics prescribe expensive drugs that offer a few more weeks – or help them enjoy what time they have left, free from invasive treatments? <http://www.independent.co.uk/life-style/health-and-families/features/drugs-the-doctors-dilemma-2361871.html>

### End of Life Care Strategy: 3rd Annual Report

U.K. (ENGLAND | Department of Health – 26 September 2011 – The Department of Health has published the third annual report of the national End of Life Care Strategy for England. [http://www.endoflifecareforadults.nhs.uk/assets/downloads/dh\\_130253.pdf](http://www.endoflifecareforadults.nhs.uk/assets/downloads/dh_130253.pdf)

#### Digital immortality

#### Difference engine: Facebook for the dead

U.K. | *The Economist* – 23 September 2011 – Clearly, multimedia and the internet can be harnessed to enhance the way people ... communicate about the dead via inscriptions, obituaries, memorials, requiems or *memento mori*. Indeed, the earliest applications of multimedia for remembrance were the post-mortem daguerreotypes [the first commercially successful photographic process] used by grieving Victorians as mementos of their dear departed. Today, tributes set up on websites by families and friends of a deceased have become commonplace. <http://www.economist.com/blogs/babbage/2011/09/digital-immortality>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Guardian* – 30 September 2011 – '**Assisted suicide law around the world.**' Around the world the trend in legislation suggests a gradual shift towards decriminalisation. Switzerland, Luxembourg, Belgium, the Netherlands and the U.S. states of Oregon, Montana and Washington have all legislated to allow assisted suicide in clearly defined situations. The European court of human rights ruled that while an individual has a right to decide how and when to die, the state is not obliged to provide the means to do so. <http://www.guardian.co.uk/society/2011/sep/30/assisted-suicide-law-around-the-world?newsfeed=true>
- ARGENTINA | *Global Post* – 28 September 2011 – '**Argentina mulls allowing euthanasia.**' The case of a 2-year-old girl in a vegetative state has drawn attention to the issue of euthanasia in Argentina. Her parents have asked that their daughter be allowed a "dignified death." In response to the case, the Argentine Senate and the Buenos Aires legislature began individual hearings on whether to legalize euthanasia. <http://www.globalpost.com/dispatches/globalpost-blogs/que-pasa/argentina-mulls-allowing-euthanasia>
- U.K. (ISLE OF MAN) | *Isle of Man Newspapers* – 28 September 2011 – '**Suicide policy same as U.K.**' New policy guidelines on assisted suicide are being applied in the Isle of Man, in line with those adopted in the U.K. Director of public prosecutions Stuart Neale said it was the Isle of Man's policy to follow UK guidelines on such matters. "We aim for consistency within the British Isles. It is a policy decision," he said. "We follow guidelines issued by the Crown Prosecution Service in the UK." [http://www.iomtoday.co.im/news/isle-of-man-news/suicide\\_policy\\_same\\_as\\_uk\\_1\\_3814031](http://www.iomtoday.co.im/news/isle-of-man-news/suicide_policy_same_as_uk_1_3814031)
- AUSTRALIA (SOUTH AUSTRALIA) | *The Advertiser* (Adelaide) – 27 September 2011 – '**Thirty doctors support euthanasia bill.**' More than 30 doctors across Australia have backed a proposed law which would give doctors a defence to provide treatment that shortens a person's life. The state branch of the Australian Medical Association and the Law Society last week issued a joint statement condemning the Bill. <http://www.adelaidenow.com.au/news/south-australia/thirty-doctors-support-euthanasia-bill/story-e6frea83-1226147294701>
- SOUTH AFRICA | *Eye Witness News* (Cape Town) – 27 September 2011 – '**Debate on euthanasia intensifies.**' University of Western Cape academic, Sean Davidson, launched the Dignity South Africa Campaign. He is due to stand trial in his home country New Zealand for assisting his chronically ill mother to end her life. The debate around euthanasia has become vociferous as the one relating to abortion. <http://www.eyewitnessnews.co.za/Story.aspx?id=74790>

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

### **Be known, be available, be mutual: A qualitative ethical analysis of social values in rural palliative care**

*BMC MEDICAL ETHICS* | Online article – 28 September 2011 – The values identified in this study offer the opportunity to better understand common ethical tensions that arise in rural healthcare and key differences between rural and urban palliative care. In particular, these values shed light on problematic health system and health policy changes. When initiatives violate deeply held values and hard won rural capacity to address the needs of their dying members is undermined, there are long lasting negative consequences. The social fabric of rural life is frayed. These findings offer one way to re-conceptualize healthcare decision making through consideration of critical values in order to support ethically good palliative care in rural settings. <http://www.biomedcentral.com/content/pdf/1472-6939-12-19.pdf>



## Non-response in a survey of physicians on end-of-life care for the elderly

*BMC RESEARCH NOTES* | Online article – 26 September 2011 – The aim of the study is to reflect methodological aspects regarding survey conduction and to analyse factors that cause physicians to take part in a study on delivering end-of-life care for the elderly. The response rate to the questionnaire on end-of-life care for the elderly was 40%. Of the non-responders to the questionnaire, 12.8% stated the reasons for non-participation. Overall, the response rate to the questionnaire varied with specialty and location of the practice: radiotherapists answered significantly more frequently than other categories of physician (e.g., general practitioners) and physicians in rural areas significantly more frequently than their colleagues in urban areas. The reasons most frequently given for non-participation were "not concerned with the subject" and "no time." <http://www.biomedcentral.com/content/pdf/1756-0500-4-367.pdf>

## Dying well with dementia: Qualitative examination of end-of-life care

*BRITISH JOURNAL OF PSYCHIATRY* | Online article – 22 September 2011 – People with dementia often die badly, receiving end-of-life care of poorer quality than that given to those who are cognitively intact. The data [from in-depth interviews with bereaved family carers and care health professionals] highlighted the challenge and imperative of 'dementia-proofing' end-of-life care for people with dementia. This requires using dementia expertise to meet physical care needs, going beyond task-focused care and prioritising planning and communication with families. <http://bjp.rcpsych.org/content/early/2011/09/03/bjp.bp.111.093989.abstract>

Representative list of recent articles on dementia and end of life care:

- *International Journal of Geriatric Psychiatry* | Online article – 22 August 2011 – '**Care at the end of life for people with dementia living in a care home: A qualitative study of staff experience and attitudes.**' <http://onlinelibrary.wiley.com/doi/10.1002/gps.2772/full> (Noted in Media Watch dated 29 August 2011.)
- U.K. | National Council for Palliative Care & Dying Matters Coalition online posting – 12 July 2011 – '**New calls to discuss end of life care with people with dementia.**' <http://www.ncpc.org.uk/news/60> (Noted in Media Watch dated 18 July 2011.)
- *American Journal of Hospice & Palliative Medicine* | Online article – 10 June 2011 – '**End-of-life issues in caring for patients with dementia: The case for palliative care in management of terminal dementia.**' <http://ajh.sagepub.com/content/early/2011/06/03/1049909111410306.abstract> (Noted in Media Watch dated 13 June 2011.)
- *Australian Ageing Agenda* | Online reports – 3 May 2011 – '**Planning for the End of Life for People with Dementia**, A two-part report for Alzheimer's Australia by Prof. Colleen Cartwright. Part 1 (March 2011): [http://www.alzheimers.org.au/common/files/NAT/20110404\\_Nat\\_Paper\\_23EoLP1.pdf](http://www.alzheimers.org.au/common/files/NAT/20110404_Nat_Paper_23EoLP1.pdf) Part 2 (May 2011): [http://www.alzheimers.org.au/common/files/NAT/20110503\\_Nat\\_Paper\\_EoLP2.pdf](http://www.alzheimers.org.au/common/files/NAT/20110503_Nat_Paper_EoLP2.pdf). (Noted in Media Watch dated 9 May 2011.)
- *Current Oncology Reports* | Online article – 19 April 2011 – '**The challenges of providing palliative care for older people with dementia.**' <http://www.springerlink.com/content/e68776uw8p78704m/> (Noted in Media Watch dated 2 May 2011.)
- *National Post* (Toronto, Canada) | Online report – 5 January 2010 – '**Preparing for a deluge of dementia.**' <http://network.nationalpost.com/np/blogs/fullcomment/archive/2010/01/05/national-post-editorial-board-preparing-for-a-deluge-of-dementia.aspx> (Noted in Media Watch dated 11 January 2010.)

### End-of-life transitions among nursing home residents with cognitive issues

*NEW ENGLAND JOURNAL OF MEDICINE*, 2011;365(13):1212-1221. Among 474,829 [Medicare] nursing home decedents [examined], 19.0% had at least one burdensome transition. Blacks, Hispanics, and those without an advance directive were at increased risk. Nursing home residents in regions in the highest quintile of burdensome transitions (as compared with those in the lowest quintile) were significantly more likely to have a feeding tube, have spent time in an ICU in the last month of life, have a stage IV decubitus ulcer, or have had a late enrollment in hospice. Burdensome transitions are common, vary according to state, and are associated with markers of poor quality in end-of-life care. <http://www.nejm.org/doi/full/10.1056/NEJMsa1100347>

## **Confronting suffering and death at the end of life: The impact of religiosity, psychosocial factors, and life regret among hospice patients**

*DEATH STUDIES*, 2011;35(9):777-800. Although the role of spiritual, psychological, and social factors is receiving increasing attention in the end of life (EOL) context, we know far less than we need to about how these factors shape attitudes toward life and death in the face of looming loss. The present study begins to remedy these limitations by examining the relative impact of demographic characteristics, religious and psychosocial factors, and life regret on death attitudes and psychological well-being for a diverse group of 153 hospice patients. In general, results showed that factors assessed in this investigation were significantly correlated with death attitudes and emotional health. When study factors were examined simultaneously, gender, ethnicity, intrinsic religiosity, social support, and future-related regret each were shown to have a unique impact on various aspects of EOL adjustment and distress. The article concludes by offering direction to researchers interested in integrating and extending the empirical study of the attitudes of adults facing serious illness, and underscoring the clinical implications of these findings for professionals offering psychosocial and spiritual care at the end of life.  
<http://www.tandfonline.com/doi/abs/10.1080/07481187.2011.583200>

### **Patient-focus conferences**

#### **New frontiers in palliative care**

*IRISH MEDICAL TIMES* | Online OpEd – 30 September 2011 – Has it ever struck you how few conferences there are for patients? In particular, how infrequently patient conferences are run with professional ones? With international experts gathered together for the main event, you would think organisers and sponsors would run a patient-focused event in parallel. I've only ever been to one such event in Ireland. Focusing on liver disease and hepatitis, it was instructive to follow speakers from the professional forum to the patient one. The really skilled presenters spoke on the same topic using completely different but accessible language at the patient event, compared with the scientific lingo being sprayed around the professional forum next door. Impressive stuff. <http://www.imt.ie/opinion/2011/09/new-frontiers-in-palliative-care.html>

Of related interest:

- **CANCER** | Online article – 22 September 2011 – **'Is public communication about end-of-life care helping to inform all? Cancer news coverage in African American versus mainstream media.'** This study of news reporting compared "mainstream" (general market) media with African American media, which serves the largest minority group. The specific goal of this study was to determine whether these news media communicate differently about cure-directed cancer treatment and end-of-life alternatives. <http://onlinelibrary.wiley.com/doi/10.1002/cncr.26499/full>

### **Cultural challenges**

#### **Traditional expectations versus U.S. realities: First- and second-generation Asian Indian perspectives on end-of-life care**

*JOURNAL OF GENERAL INTERNAL MEDICINE* | Online article – 24 September 2011 – The authors examined the perspectives of first- and second-generation South Asians living in the U.S. regarding end-of-life care. Traditional cultural values, such as duty to family, greatly influenced end-of-life care preferences and retained importance across generations. Clinicians caring for Asian Indian patients may be better able to assess care preferences after exploring the complex interplay between traditional expectations and specific social realities for each patient. Attention should be given attitudes toward death and suffering, family duty, and preferences for information disclosure and decision making. <http://www.springerlink.com/content/c31q0504304367tu/>

## Who should make decisions about treatment limitation for young children with life-threatening or life-limiting conditions?

*JOURNAL OF PAEDIATRICS & CHILD HEALTH*, 2011;47(9):594-598. It is now ethical orthodoxy that parents should be involved in the decision-making about their children's health care. This extends to decisions about whether to continue or to limit life-sustaining medical treatment for a child with a life-limiting or life-threatening condition. What remains contested and uncertain is the extent and nature of parental involvement, especially in this emotionally charged situation. In particular, should it be the parents, who are the ultimate decision-makers, taking final responsibility, should it be a shared decision, or should it be a medical decision that parents are simply asked to consent to? One approach to this issue is to consider the in-principle ethical arguments and weigh their merits. The two key principles here are parental rights and authority, and the best interests of child, and the contested issue is what to do if these appear to clash. Another approach is to consider the principles in the practical clinical context. <http://onlinelibrary.wiley.com/doi/10.1111/j.1440-1754.2011.02177.x/abstract>

From Media Watch dated 23 May 2011:

- *BMC PEDIATRICS* | Online article – 21 May 2011 – **'Withdrawal of life-support in paediatric intensive care – a study of time intervals between discussion, decision and death.'** The authors investigated the time required for end-of-life decisions, subsequent withdrawal of life-sustaining treatment and the time to death. <http://www.biomedcentral.com/content/pdf/1471-2431-11-39.pdf>

From Media Watch dated 4 April 2011:

- *PAEDIATRICS & CHILD HEALTH*, 2011; 16(4):241-244. **'Withholding and withdrawing artificial nutrition and hydration.'** ...guidance for Canadian paediatric health care practitioners regarding when withholding or withdrawing artificial nutrition and hydration may be an ethically permissible option as part of a palliative care plan and to briefly address some pragmatic considerations. <http://www.pulsus.com/journals/abstract.jsp?sCurrPg=abstract&jnlKy=5&atlKy=10034&isuKy=972&isArt=t&fromfold=Current Issue>

## Emergency department use among end-of-life home care clients

*JOURNAL OF PALLIATIVE CARE*, 2011;27(3):224-8. Emergency department (ED) use is a quality-of-care indicator for community-based end-of-life (EOL) care. This study examined ED use by EOL home care clients. The sample included all EOL home care clients who received care from one community care access centre in Ontario, Canada. Results showed that 35% of clients used the ED within 45 days of assessment. Multivariate analysis identified two determinants of ED use: excessive weight loss and previous hospitalization. Managing terminal illness is often a difficult task, and comprehensive, ongoing assessment of clients' changing status is critical. Client care and service planning for clients who have lost excessive amounts of weight or who have been recently hospitalized need to be monitored closely to prevent any future avoidable ED use. <http://www.ncbi.nlm.nih.gov/pubmed/21957800>

## Ukraine failing to provide evidence-based palliative care

*THE LANCET*, 2011;378(9797):1130. Ukraine has a ready supply of morphine yet government policies have left tens of thousands of patients who need the drug either completely without access, or with inadequate access, according to a new report by Human Rights Watch. Ukraine has enacted strict laws aimed at combating drug abuse. But it seems that some of these regulations are impeding the medical use of opioid analgesic drugs. Earlier this year the World Health Organization examined worldwide consumption of opioid drugs for medical purposes and found that consumption in Ukraine was "virtually non-existent." There are several contributory factors. [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)61493-1/fulltext#](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)61493-1/fulltext#)

Cont.

From Media Watch dated 16 May 2011:

- UKRAINE | 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.<sup>1</sup> <http://www.seattlepi.com/news/article/Ukrainian-cancer-patients-denied-pain-relief-1376503.php>
- 1. *Uncontrolled Pain: Ukraine's Obligation to Ensure Evidence-Based Palliative Care*, Human Rights Watch, 12 May 2011. <http://www.hrw.org/en/reports/2011/05/12/uncontrolled-pain-0>

### **Assisted (or facilitated) death**

Representative sample of recent articles, etc:

- *JOURNAL OF MEDICAL ETHICS* | Online article – 27 September 2011 – **'Senior doctors' opinions of rational suicide.'** Most senior doctors in England & Wales [i.e., respondents to a postal survey] feel that rational suicide is possible. There was no association with specialty. Strong religious belief was associated with disagreement, although levels of agreement were still high in people reporting the strongest religious belief. Most doctors who were opposed to physician assisted suicide believed that rational suicide was possible, suggesting that some medical opposition is best explained by other factors such as concerns of assessment and protection of vulnerable patients. <http://jme.bmj.com/content/early/2011/09/27/medethics-2011-100116.abstract>

#### **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.

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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.

## Worth Repeating

### **Making sense of dying: A review of narratives written since 1950 by people facing death from cancer and other diseases**

*PALLIATIVE MEDICINE*, 2006;20(3):183-195. This article reviews a sample of narratives written since 1950 by people knowingly facing death as a result of cancer and other diseases, in order to compare experiences and show how these relate to wider changes in practice in end of life care. A ... search of libraries, archives, journals and internet sources located English spoken literature, including books, poems, newspapers, journal articles, diaries, and internet postings of writings by people facing terminal disease. The initial search located a wide range of published and unpublished narratives ... yielding 148 narratives by different authors. A purposive sub-sample of 63 of these narratives was reviewed. Over the last half century there have been changes in both the volume of available literature and patterns of writing about end of life experience. Therapeutic benefits of writing are reported as a way of making sense of dying combined with a strong sense of purpose in sharing the story. There is a clear awareness of social needs when dying, along with issues of communication with medical staff, symptom control, realities of suffering, and spiritual aspects of dying. Differences are found in the nature and style of writing about cancer in comparison to other illnesses. <http://pmj.sagepub.com/content/20/3/183.abstract>

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