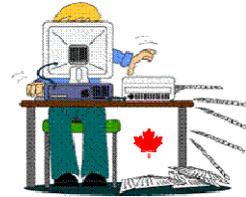


## Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Expressions of loss and separation: Scroll down to [Specialist Publications](#) and 'Does the Internet change how we die and mourn?' (p.11), published in *OMEGA – Journal of Death & Dying*.

## Canada

### Compassionate care in Canada

GLOBAL NEWS | Online report – 29 February 2012 – It's an issue many Canadians are affected by, but few ever discuss. An estimated 4-5 million Canadians are caring for an ill loved one. However, the stress can be immense – both emotionally and financially. Most caregivers are women, many of who are low-income. In 2004, the Liberal government created the Compassionate Care Benefit. A Global News investigation found many families who need the money aren't able to access it. A parliamentary report<sup>1</sup> ... called for an overhaul of the system, but so far there has been no action. In a three-part

series, Global took a look at compassionate care in Canada. Who is caring for a sick relative? What kind of help are they getting? And how much more do they deserve?  
<http://www.globalnews.ca/compassionate+care/6442590034/story.html>

### Caring for a loved one in the U.S.

'Care work in America: Expected but not respected' (p.6), published in *The Hill*, Washington DC.

1. *Not to be Forgotten: Care of Vulnerable Canadians*, Ad Hoc (All Party) Parliamentary Committee on Palliative & Compassionate Care, 17 November 2011 (noted in Media Watch dated 21 November 2011). <http://pcpcc-cpspsc.com/wp-content/uploads/2011/11/ReportEN.pdf>

From Media Watch dated 19 September 2011:

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online article – 15 September 2011 – 'Family caregivers' ideal expectations of Canada's Compassionate Care Benefit.'  
<http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2011.01028.x/abstract>

From Media Watch dated 23 May 2011:

- *BMC PUBLIC HEALTH* | Online article – 18 May 2011 – 'Canada's Compassionate Care Benefit: Is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care?' <http://www.biomedcentral.com/content/pdf/1471-2458-11-335.pdf>

## Government accepts recommendations of Health Quality Council report

ALBERTA | *Edmonton Journal* – 28 February 2012 – The Alberta government says it has accepted and will immediately start work on the 21 recommendations from the Health Quality Council of Alberta's review of health-care issues released last week.<sup>1</sup> It will also set up two task forces, including one to examine the governance of the health system and the "role clarity with respect to the [Alberta] College of Physicians & Surgeons." The second task force will involve [the Council's] review of emergency medical services. <http://www.edmontonjournal.com/health/Government+accepts+recommendations+Health+Quality+Council+report/6223603/story.html>

From Media Watch dated 27 February 2012:

- ALBERTA | *Calgary Herald* (OpEd) – 23 February 2012 – **'Health report revelations thump you right in heart.'** One shocker was the ... revelation [in the report] that palliative care patients, when rushed to hospital in crisis, have been left to die on emergency ward gurneys. <http://www.calgaryherald.com/opinion/columnists/Braid+Health+report+revelations+thump+right+heart/6194550/story.html>

### Extract from Health Quality Council of Alberta report (i.e., required actions)

Alberta Health Services...

...standardize across all healthcare sectors its palliative care terminology, such as "goals of care" and "allow natural death," and dissuade the use of descriptors such as "do not resuscitate."

...strive to support palliative patients who have sudden, unexpected symptom crisis so these patients have options for immediate care at home that can obviate the need to go to an emergency department, and support the patient and family's decision to remain at home.

...explore options to admit patients with symptom crises directly to an intensive palliative care unit or medical unit, depending on their needs, rather than to the emergency department.

1. 'Review of the Quality of Care and Safety of Patients Requiring Access to Emergency Department Care and Cancer Surgery and the Role and Process of Physician Advocacy,' Health Quality Council of Alberta, February 2012. <http://www.hqca.ca/assets/files/FINAL%20REPORT.pdf>

## U.S.A.

### Doctors do die differently – how we make certain

*FORBES* | Online article – 2 March 2012 – Recently, there was a great post by Dr. Ken Murray titled, 'Why Doctors Die Differently.'<sup>1</sup> Dr. Murray eloquently discusses the decisions physicians make for themselves at the end of life, and our hesitation in bestowing "our views on the vulnerable." He ends with a story of his non-physician cousin choosing the non-aggressive path after a cancer diagnosis, illustrating that more people can make this choice. In the Twittersphere, there has been much discussion about this article. Matthew Herper, a wonderful journalist for *Forbes* and a man who likes his data, has stated, "I still want to see real data on whether doctors actually do die differently than everybody else." The original post by Dr. Murray didn't have reference to data... <http://www.forbes.com/sites/carolynmclanahan/2012/03/02/doctors-do-die-differently-how-we-make-certain/>

1. 'Why doctors die differently,' *Wall Street Journal*, 25 February 2012. <http://online.wsj.com/article/SB10001424052970203918304577243321242833962.html>

**N.B.** Several articles in recent months have focused on physicians and their personal choices in terms of end of life care. See Media Watch dated 27 February 2012 ('Why MOST doctors like me would rather DIE than endure the pain of treatment we inflict on others for terminal diseases: Insider smashes medicine's big taboo' and 'How doctors choose to die,' p.8); dated 23 January 2012 ('What doctors know – and we can learn – about dying,' p.2)

## Advance directives

### "Twenty-two days and two blinks of an eye"

FORBES | Online article – 2 March 2012 – An article from a recent edition of the *Journal of the American Geriatrics Society*<sup>1</sup> ... suggests that you might not have control of your care at the end of your life, even if you are conscious. The article, written by three physicians from the Division of Geriatric Medicine & Gerontology, Johns Hopkins School of Medicine, discusses the shortcomings of advance healthcare directives ("living will" or power of attorney for health). When there is conflict between the patient's wishes as expressed in the document, and those of family, guess who gets to decide your fate? If you are conscious, even if you can't talk, the decision should be up to you and you

alone, not anyone else. In this story, an elder was maintained for 22 days on life support, despite her wishes to the contrary. <http://www.forbes.com/sites/carolynrosenblatt/2012/03/02/twenty-two-days-and-two-blinks-of-an-eye/>

#### Specialist Publications

Of particular interest:

**'An assessment of social diffusion in the Respecting Choices® Advance Care Planning Program'** (p.9), published in *Death Studies*.

1. 'When doctors and daughters disagree: Twenty-two days and two blinks of an eye,' *Journal of the American Geriatrics Society*, published online 8 November 2012 (noted in Media Watch dated 24 November 2012). <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2011.03700.x/abstract>

Of related interest:

- ASSOCIATED PRESS | Online report – 27 February 2012 – **'Medical tattoos with vital information replacing bracelets for some.'** An increasing number of Americans are turning to medical tattoos to warn emergency responders about important medical conditions. "Bracelets are nice, but something as strong as a tattoo ... that is a strong statement," said Dr. Ed Friedlander, a Kansas City pathologist who has "No CPR" tattooed in the center of his chest, so a paramedic would see it. [http://www.cbsnews.com/8301-504763\\_162-57386101-10391704/medical-tattoos-with-vital-information-replacing-bracelets-for-some/](http://www.cbsnews.com/8301-504763_162-57386101-10391704/medical-tattoos-with-vital-information-replacing-bracelets-for-some/)

### Meaning-based therapy may aid terminal patients

NEW YORK | Reuters – 2 March 2012 – Psychotherapy focused on spirituality and finding meaning may help improve quality of life and well-being in terminally ill cancer patients, suggests a new study from a large cancer treatment center.<sup>1</sup> The talk therapy sessions only seemed to provide a short-term benefit – though researchers said that was reasonable given that many of the study participants were near the end of their lives, with progressively worsening disease. The study's lead author said that while hospice and palliative care doctors and nurses are well-versed in treating pain and nausea, for example, there hasn't been definitive evidence on the treatment of non-physical symptoms in very ill patients. "What palliative care clinicians have not had up until now are interventions that have shown some effectiveness in dealing with issues like loss of meaning, feeling demoralized (and) a loss of sense of spiritual well-being," said Dr. William Breitbart, from New York's Memorial Sloan-Kettering Cancer Center. "This is a new tool," he told Reuters Health. "It gives more structure to what people are already attempting to do." Breitbart said that many hospitals and hospices offer terminal patients access to a clergyman or chaplain, but meaning-centered discussions with a psychotherapist could be an option for patients who don't relate to a religious figure. <http://www.reuters.com/article/2012/03/03/us-based-therapy-idUSTRE82204220120303>

1. 'Pilot randomized controlled trial of individual meaning-centered psychotherapy for patients with advanced cancer,' *Journal of Clinical Oncology*, 27 February 2012. <http://jco.ascopubs.org/content/early/2012/02/27/JCO.2011.36.2517.abstract?sid=cacf19a6-45f8-4455-89df-59230a4da366>

## Innovative prison hospice volunteer conference to bring training to inmate volunteers

LOUISIANA-MISSISSIPPI HOSPICE & PALLIATIVE CARE ORGANIZATION | Online posting – 29 February 2012 – With the approval of the Louisiana Department of Public Safety & Corrections and Warden Burl Cain, the Louisiana-Mississippi Hospice & Palliative Care Organization will present a four-day prison hospice volunteer conference at Louisiana State Penitentiary at Angola, Louisiana, from 13-16 March 2012. The hospice program at Louisiana State Penitentiary at Angola is one of the leading programs in the nation that serves as a model for others. The prison hospice volunteer conference will allow additional prison hospice programs to learn the skills and processes that have been carefully devel-

oped at Angola. Louisiana currently has inmate hospice volunteer programs operating within five correctional facilities ... and one inmate hospice volunteer program operating at Mississippi State Prison in Parchman. <http://www.marketwatch.com/story/innovative-prison-hospice-volunteer-conference-to-bring-training-to-inmate-volunteers-2012-02-29-153000>

The Hospice Education Network will film the conference and distribute the recorded conference sessions to hospice prison programs across the country.

**N.B.** Media Watch, as a general rule, does not note upcoming events. It is beyond the scope of the weekly report. An exception was drawn in the case of this conference given its unique focus.

### International, multi-centre study

#### End-of-life care is about much more than pain control

CALIFORNIA | *Los Angeles Times* – 28 February 2012 – A great deal of thought and effort has been placed into improving the final days of life for people with terminal illness in the last two decades. While pain control is a huge part of that, a [recent] study<sup>1</sup> ... demonstrates the significance of a range of caregiving measures, aside from medications, that can improve the patient's quality of life. The study showed taking care of the patient's body, paying attention to the environment, and personalizing care was highly valued. In a commentary in *PLoS Medicine*,<sup>2</sup> the journal's editors called the exhaustive study a significant contribution to improving end-of-life care. <http://www.latimes.com/health/boostershots/la-heb-end-of-life-20120228,0,4708265.story>

1. 'Complexity in non-pharmacological caregiving activities at the end of life: An international qualitative study,' *PloS Medicine*, 2012;9(2):1-10 (noted in Media Watch dated 20 February 2012). <http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001173>
2. 'Beyond the numbers: Describing care at the end of life,' *PloS Medicine*, 28 February 2012. <http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001181>

#### What culture teaches us about grief

HUFFINGTON POST | Online article – 28 February 2012 – Are death and our reactions to it that culturally different? If death is a universal, shouldn't we assume that grief should be as well? After all, since every culture experiences death, should we not expect that every culture should grieve and mourn in similar ways? Studies on grief have taught us that the answer to that question is far more complex than we once believed. In fact, the only universal statement we can really affirm is that each culture has developed ways to respond to loss. Beyond that, there is little common ground. [http://www.huffingtonpost.com/kenneth-j-doka/whitney-houston-death\\_b\\_1300060.html](http://www.huffingtonpost.com/kenneth-j-doka/whitney-houston-death_b_1300060.html)

**N.B.** Scroll own to [Specialist Publications](#) and 'Does the Internet change how we die and mourn?' published in *OMEGA – Journal of Death & Dying*, and 'Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients,' published in the *Journal of Palliative Medicine* (p.11).

## Nobody declared brain dead ever wakes up feeling pretty good

*THE ATLANTIC* | Online article – 27 February 2012 – A day rarely goes by that I don't read a few sensational headlines: 'Man declared dead feels 'pretty good' or 'Husband celebrates miracle as 'brain dead' wife wakes up in hospital.' I recently read an article that seemed to describe a man on death row in Huntsville, Texas. It attempted to shock its readers with the claim that a college student had been declared brain dead and "just hours before he was slated to be killed and his organs given to another patient," he miraculously recovered. That's right, they said "killed." As a neurologist who specializes in brain injury, I have cared for many brain-injured patients and there were times when they did better than I anticipated, but sensational articles like these only confuse the public. <http://www.theatlantic.com/health/archive/2012/02/nobody-declared-brain-dead-ever-wakes-up-feeling-pretty-good/253315/>

## The Joint Commission awards first advanced certifications for palliative care

THE JOINT COMMISSION | Online posting – 27 February 2012 – Regions Hospital in St. Paul, Minnesota, Strong Memorial Hospital in Rochester, New York, Mt. Sinai Medical Center, New York City, St. Joseph Mercy Oakland, Pontiac, Michigan, and The Connecticut Hospice, Inc. in Branford, Connecticut, have become the first hospitals across the country to receive Advanced Certification for Palliative Care from The Joint Commission. "Seriously ill patients will benefit from the decision by these five leading hospitals to follow national standards and evidence-based guidelines that emphasize the need for expert caregivers to work together as teams with patients and their families," says Michele Sacco, executive director, Advanced Certification for Palliative Care, The Joint Commission. "Certification signifies that these hospitals are committed to patient and family-centered care to optimize the quality of life for patients with serious illnesses. It is the best signal to the community that the quality of care these organizations provide is effectively managed to meet

the unique and specialized needs of patients." [http://www.jointcommission.org/the\\_joint\\_commission\\_awards\\_first\\_advanced\\_certifications\\_for\\_palliative\\_care/](http://www.jointcommission.org/the_joint_commission_awards_first_advanced_certifications_for_palliative_care/)

### The Joint Commission Advanced Palliative Care Certification standards emphasize:

A formal, organized palliative care program led by an interdisciplinary team whose members possess the requisite expertise in palliative care;

Leadership endorsement and support of the program's goals for providing care, treatment and services;

A special focus on patient and family engagement;

Processes which support the coordination of care and communication among all care settings and providers; and

The use of evidence-based national guidelines or expert consensus to guide patient care.

**N.B.** An independent, not-for-profit organization, The Joint Commission accredits and certifies more than 19,000 health care organizations and programs in the U.S.



### 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>

## **In health care debate, where are the doctors?**

MINNESOTA | *Minnesota Daily* (St. Paul) – 27 February 2012 – We have heard the politicians' viewpoints on the Patient Protection & Affordable Care Act [PPACA]; it's either too expensive and contributes to the deterioration of capitalism as we know it, or it doesn't go far enough in helping the 46 million Americans living without health insurance. We have heard smatterings of public backlash to PPACA, or as it is colloquially known, "Obamacare." The "death panel" myth – which was somehow extrapolated from a section of the bill that would pay physicians to provide voluntary counseling to Medicare patients about end-of-life care options – was probably the most famous and embarrassingly ridiculous example of public misinformation. I want to hear from the people responsible for providing health care: the doctors themselves. As they come across plenty of uninsured patients or patients whose insurance won't cover the care they desperately need, their opinion and advice is more than warranted in public discussion of health care reform. <http://www.mndaily.com/2012/02/27/health-care-debate-where-are-doctors>

## **Care work in America: Expected but not respected**

WASHINGTON DC | *The Hill* – 27 February 2012 – Last month the Bureau of Labor Statistics reported that home care is the fastest-growing occupation in the U.S. More jobs will be created in home care than in any other occupation through 2020. But this positive news is tempered by the negative realities facing many workers in the industry. Home care work is too often "expected but not respected," in the words of worker Tracy Dudzinski, dismissed as neither skilled nor demanding enough to qualify as a real job. That may explain the surprising fact that home care workers are denied federal minimum wage, overtime, and other protections under the Fair Labor Standards Act (FLSA), a law that was passed over 70 years ago. Reform is long overdue, but it may be finally taking root. <http://thehill.com/blogs/congress-blog/healthcare/212811-care-work-in-america-expected-but-not-respected>

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

Representative sample of recent news media coverage:

- GEORGIA PUBLIC BROADCASTING | Online report – 28 February 2012 – **'Assisted suicide bill moves forward.'** A state House committee passed a bill that would make it a felony to help someone commit suicide. The bill follows a recent Georgia Supreme Court decision that struck down an existing assisted suicide law. <http://www.gpb.org/news/2012/02/28/assisted-suicide-bill-moves-forward>

## **International**

### **Palliative care in India**

#### **Huge demand for home-based palliative care in district**

INDIA | *The Hindu* – 5 March 2012 – A huge demand for pain and palliative care service remains unmet as is revealed under the ongoing programme of Pain & Palliative Care Service by the District Panchayat [assembly]. The programme has technical support of the National Rural Health Mission [NRHM] and the District Health. The programme is on in 37 out of the 84 panchayats and the numbers of patients registered is about 6,000. Of these, about 3,000 patients need at least a weekly follow-up programme and about 800 are patients with urine catheters. Of those registered under the programme, about 30% are paraplegics and another 30% are elderly people who are dependent on another person for meeting their daily needs. There are about 20-30% people who are terminally ill cancer patients; others include mentally and physically challenged persons. <http://www.thehindu.com/news/cities/Kochi/article2963007.ece>

## Dignity in Care report calls for shake-up in staff selection and appraisal

U.K. | *The Guardian* – 29 February 2012 – Nurses, doctors and care workers should be recruited as much for their compassion as for their exam results, according to an inquiry into improving the dignity of treatment of elderly people in hospitals and care homes. A shake-up of the criteria used for selecting and appraising staff should give the same emphasis to their assessed values and capacity to engage with older people as to their formal qualifications, the inquiry recommends. But it stops short of backing any lowering of academic entry bars. The call is among a raft of proposals by a commission set up jointly by bodies representing National Health Service organisations and local

councils together with a leading charity for older people, following a series of reports and investigations exposing poor care in hospitals and care homes.

<http://www.guardian.co.uk/society/2012/feb/29/dignity-in-care-report-staff-selection>

### Extract from 'Delivering Dignity...'

Providing end-of-life care tailored to the wishes and needs of each individual is central to dignified care in all care homes. Residents should be allowed to die in their own care home if that is their wish.

1. 'Delivering Dignity. Securing dignity in care for older people in hospitals and care homes. A report for consultation,' National Health Service Confederation, Local Government Group and Age UK, February 2012. <http://www.nhsconfed.org/Documents/dignity.pdf>

## Taking care of the vegetative state

ITALY | *West (Welfare Society Territory)* – 28 February 2012 – In Italy, the results of the national project 'Functioning and Disability in Vegetative and Minimally Conscious State' are now available.<sup>1</sup> The initiative, financed by the Ministry of Health, through the Comitato Collaborazione Medica, and coordinated by the Institute of Research & Treatment, Carlo Besta Neurological Institute of Milan, has also carefully analyzed the needs, the emotional reactions, the psychosocial aspects of the caregivers and the families of patients with disturbance of consciousness and the work-related stress of health operators of the sector. <http://www.west-info.eu/taking-care-of-the-vegetative-state-disability-minimally-conscious-state-disturbance-of-consciousness/>

1. Executive summary (in Italian): <http://www.west-info.eu/files/risultati-progetto-disabilita-stati-vegetativi-minima-coscienza.pdf>

### Specialist Publications

Of particular interest:

**'Withdrawal of artificial nutrition and hydration for patients in a permanent vegetate state: Changing Tack'** (p.8), published in *Bioethics*.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE NETHERLANDS | Radio Netherlands Worldwide – 29 February 2012 – **'Nine myths about euthanasia in The Netherlands.'** The Dutch law allowing euthanasia under certain sharply-defined circumstances often raises eyebrows abroad. And it gives rise to countless unfounded allegations. <http://www.rnw.nl/english/article/nine-myths-about-euthanasia-netherlands>

From Media Watch dated 27 February 2012:

- *INTERNATIONAL BUSINESS TIMES* | Online report – 20 February 2012 – **'Rick Santorum's 'involuntary euthanasia' claim outrages Dutch.'** Rick Santorum's claim that The Netherlands advocates mass murder through involuntary euthanasia has prompted a furious backlash from the Western European country, with local news sources calling the Republican a "crazy extreme" candidate making up facts to stir up his political base. <http://www.ibtimes.com/articles/301702/20120220/rick-santorum-euthanasia-netherlands-dutch-backlash.htm>

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

### **CPR vs. DNR in the context of palliative care**

*ADVANCES IN PALLIATIVE MEDICINE*, 2011;10(3-4):89-94. Medical advances have significantly improved the chances of survival for many patients with life-threatening illnesses. Simultaneously, complex ethical dilemmas have arisen. While limiting and/or forgoing a particular treatment in some situations at the end of life is now commonly accepted, many patients still die after heroic, extraordinary means were applied to postpone their inevitable death. This paper considers some of the issues surrounding the use of cardiopulmonary resuscitation and arranging "do not resuscitate" orders for palliative care patients. <http://www.advpm.eu/>

### **Withdrawal of artificial nutrition and hydration for patients in a permanent vegetative state: Changing Tack**

*BIOETHICS*, 2012;26(3):157-163. In the U.S., the decision of whether to withdraw or continue to provide artificial nutrition and hydration (ANH) for patients in a permanent vegetative state (PVS) is placed largely in the hands of surrogate decision-makers, such as spouses and immediate family members. This practice would seem to be consistent with a strong national emphasis on autonomy and patient-centered healthcare. When there is ambiguity as to the patient's advanced wishes, the presumption has been that decisions should weigh in favor of maintaining life, and therefore, that it is the withdrawal rather than the continuation of ANH that requires particular justification. <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2010.01841.x/abstract>

Of related interest:

- *JOURNAL OF MEDICAL ETHICS* | Online article – 28 February 2012 – **'How family caregivers' medical and moral assumptions influence decision making for patients in the vegetative state: A qualitative interview study.'** Whether or not prior treatment wishes of patients in a vegetative state are respected depends on their applicability, and also on the medical assumptions and moral attitudes of the surrogates. The authors recommend repeated communication, support for the caregivers and advance care planning. <http://jme.bmj.com/content/early/2012/02/27/medethics-2011-100373.abstract>

### **Barriers to providing end-of-life care for people with dementia: A whole-system qualitative study**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online article – 29 February 2012 – Five areas were identified [in this study] as barriers to providing good end-of-life care: impact of hospitalisation, care pathways, advance care planning, impact on carers, staff skills and training. A wide range of health and social professionals provided end-of-life care to people with dementia but with little coordination or knowledge of each other's activity or remit. Care was fragmented and *ad hoc* leading to crises and inappropriate hospital admissions. Staff lacked confidence and requested more training. Many of the identified barriers were underpinned by feelings of uncertainty regarding disease trajectory and the perceived futility of interventions. Areas of good practice were specialist nurse support to family carers and 'in reach' to nursing homes. Qualitative methods of service evaluation facilitated a broader and deeper understanding of a range of perspectives, which, with other components of rapid participatory appraisal, generated potential solutions to improve care. <http://spcare.bmj.com/content/early/2012/02/29/bmjspcare-2011-000178.abstract>

From Media Watch dated 6 February 2012:

- *ANNALS OF INTERNAL MEDICINE*, 2012;156(1):45-51. **'Advanced dementia: State of the art and priorities for the next decade.'** Research over the past 25 years ... has delineated abundant opportunities for improvement, including greater recognition of advanced dementia as a terminal illness... [http://www.annals.org/content/156/1\\_Part\\_1/45.abstract?sid=2e111ab3-a1df-4f14-bf66-315a8d86cbba](http://www.annals.org/content/156/1_Part_1/45.abstract?sid=2e111ab3-a1df-4f14-bf66-315a8d86cbba)

## **An assessment of social diffusion in the Respecting Choices® Advance Care Planning Program**

*DEATH STUDIES*, 2012;36(4):301-322. This study examines the potential social diffusion effects of the Respecting Choices® advance care planning program administered in La Crosse, Wisconsin, since 1991. The program produces educational materials for patients, trains facilitators to help patients prepare for end of life, and ensures that advance directives are connected to patients' medical records. The authors found that participants [in the study] who were living in the La Crosse area were significantly less likely than their peers living elsewhere to have executed a living will or appointed a health care power of attorney. This pattern may reflect psychological reactance, where individuals reject a message or lesson when they perceive compliance as a threat to their autonomy. There was no evidence of social diffusion effects; participants who lived in the La Crosse region themselves or who had social network members residing in the area were no more likely than those with no known ties to the region to have engaged in advance care planning. <http://www.tandfonline.com/doi/abs/10.1080/07481187.2011.584016>

### **Media Watch Online**

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

#### **Canada**

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx> (Click on 'Current Issue' under 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://www.hpconnection.ca/newsletter/inthenews.html>

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

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

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

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

#### **Europe**

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

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

#### **International**

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

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

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

### **Media Watch 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>

## Electronic palliative care system for GPs may be 'within a year'

*IRISH MEDICAL TIMES* | Online report – 1 March 2012 – Dr. Paul Gregan, a Consultant in Palliative Medicine and a GP based in Deansgrange, Dublin, is working with colleagues to fast-track the delivery of the system, which would allow GPs to easily and effectively share palliative care information with out-of-hours staff. The system would mirror a similar set-up in Scotland utilised by approximately one-third of GPs there. "There's a tool called an Electronic Palliative Care Summary, and in other countries GPs would have a summary sheet included in their software, most of which is pre-populated by the computer," Dr. Gregan told the *Irish Medical Times*. "The GP fills out the rest with relevant, up-to-date information on an individual patient who they might be worried about, for example if they were finishing up on a Friday evening or going away somewhere." The information would then be emailed to an after-hours service in the event they were required to attend a palliative care patient at short notice... <http://www.imt.ie/news/general-practice/2012/03/electronic-palliative-care-system-for-gps-may-be-within-a-year.html>

From Media Watch dated 20 February 2012:

- *FAMILY PRACTICE* | Online article – 15 February 2012 – '**Introducing an electronic Palliative Care Summary (ePCS) in Scotland: Patient, carer and professional perspectives.**' <http://fampra.oxfordjournals.org/content/early/2012/02/14/fampra.cms011.abstract>

## Guidance to 'transform' hospital end of life care

*NURSING TIMES* (U.K.) | Online report – 28 February 2012 – Good communication between nurses and other staff is at the centre of guidance intended to "transform" end of life care in acute hospitals. The document<sup>1</sup> ... recommends that [National Health Service] trusts develop an overarching plan to raise awareness of end of life issues across all wards, backed by a rapid discharge process for patients who choose to die at home. <http://www.nursingtimes.net/nursing-practice/clinical-specialisms/end-of-life-and-palliative-care/guidance-to-transform-hospital-end-of-life-care/5041893.article>

1. 'Transforming end of life care in acute hospitals: The route to success 'how to' guide,' National End of Life Care Programme, National Health Service, February 2012. <http://www.endoflifecareforadults.nhs.uk/publications/acute-rtis-howtoguide>

**N.B.** This guide builds upon 'The route to success in end of life care – achieving quality in acute hospitals,' published in 2010. <http://www.endoflifecareforadults.nhs.uk/publications/route-to-success-acute-hospitals>

Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online article – 29 February 2012 – '**Socioeconomic position and place of death of cancer patients.**' The found socioeconomic differences in whether death occurred at home or at institutions indicate that age, income and social class must be taken into account when palliative care services engage in fulfilling preferences of dying at home. This may lead to more equality in the possibility of dying at home, despite differences in socioeconomic level. <http://spcare.bmj.com/content/early/2012/02/29/bmjspcare-2011-000116.abstract>

### Essential practices in palliative care

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE (IAHPC) | Online posting – Accessed 27 February 2012 – *IAHPC List of Essential Practices in Palliative Care: Project Description* describes a consensus based process of palliative care workers, other clinical specialists, primary care workers and general practitioners to identify those practices needed to identify, evaluate and treat the suffering still endured by so many. It is hoped that teachers and tutors – doctors, nurses, clinical psychologists – will in the light of this information and guidance, review their own skills and practice, their teaching and their priorities in this realm of palliative care in the primary care setting. [http://hospicecare.com/uploads/2012/2/IAHPC%20List%20of%20Essential%20Practices%20in%20Palliative%20Care\\_FINAL.pdf](http://hospicecare.com/uploads/2012/2/IAHPC%20List%20of%20Essential%20Practices%20in%20Palliative%20Care_FINAL.pdf)

## Overview and analysis

### **Does the Internet change how we die and mourn?**

OMEGA – JOURNAL OF DEATH & DYING, 2012;64(4):275-302. The article outlines the issues that the internet presents to death studies. Part 1 describes a range of online practices that may affect dying, the funeral, grief and memorialization, inheritance and archaeology; it also summarizes the kinds of research that have been done in these fields. Part 2 argues that these new online practices have implications for, and may be illuminated by, key concepts in death studies: the sequestration (or separation from everyday life) of death and dying, disenfranchisement of grief, private grief, social death, illness and grief narratives, continuing bonds with the dead, and the presence of the dead in society. In particular, social network sites can bring dying and grieving out of both the private and public realms and into the everyday life of social networks beyond the immediate family, and provide an audience for once private communications with the dead. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,1,6;journal,1,255;linkingpublicationresults,1:300329,1>

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 2 March 2012 – '**Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients.**' The guidelines were developed for multidisciplinary health care professionals and clinical services commonly involved in caring for adult patients receiving palliative care in a variety of care sites throughout Australia. These consensus-based guidelines have been endorsed key Australian and international organizations. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0466>

### **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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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:

- *JOURNAL OF MEDICAL ETHICS* | Online article – 28 February 2012 – '**Mahātmā Gandhi's view on euthanasia and assisted suicide.**' To many in India and elsewhere, the life and thoughts of Mohandas Karamchand Gandhi are a source of inspiration. The idea of non-violence was pivotal in his thinking. In this context, Gandhi reflected upon the possibility of what is now called 'euthanasia' and 'assisted suicide.' So far, his views on these practices have not been properly studied. In his reflections on euthanasia and assisted suicide, Gandhi shows himself to be a contextually flexible thinker. In spite of being a staunch defender of non-violence, Gandhi was aware that violence may sometimes be unavoidable. Under certain conditions, killing a living being could even be an expression of non-violence. He argued that in a few rare cases it may be better to kill people who are suffering unbearably at the end of life. In this way, he seems to support euthanasia and assisted suicide. Yet, Gandhi also thought that as long as care can be extended to a dying patient, his or her suffering could be relieved. Since in most cases relief was thus possible, euthanasia and assisted suicide were in fact redundant. By stressing the importance of care and nursing as an alternative to euthanasia and assisted suicide, Gandhi unconsciously made himself an early advocate of palliative care in India. This observation could be used to strengthen and promote the further development of palliative care in India. <http://jme.bmj.com/content/early/2012/02/27/medethics-2011-100268.abstract>

## Worth Repeating

### The shadow side of hospice care

*ILLNESS, CRISIS & LOSS*, 2007;15(3):245-259. The subject of this article is the dark or 'shadow' side of working with dying and bereaved people in hospice and palliative care services, and the interplay of complex personal, professional, and organizational issues that can influence both the quality of patient care and the well-being of staff. Examples of how support needs have been identified and managed are drawn from the author's experience as a social worker, educator and consultant. Current understandings of staff stress lack insight into the dark side of hospice care and fail to appreciate the depth of emotional anguish repeated exposure to human suffering can bring. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=searcharticlesresults,8,15>;

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