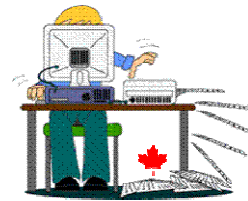


## Media Watch...

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.

23 May 2011 Edition | Issue #202



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Compiled & Annotated by Barry R. Ashpole

**Efficacy of palliative care interventions: Scroll down to [Specialist Publications](#) and 'Does palliative care improve outcomes for patients with incurable illness? A review of the evidence' (p.10), published in the *Journal of Supportive Oncology*.**

## Canada

### Ontario creates registry to oversee home care workers

ONTARIO | *Toronto Star* – 19 May 2011 – Seniors and families will now have a way to check out personal support workers caring for them in their homes, the province has announced. The electronic registry will detail the work experience, education and contact information of personal support workers who provide intimate care in homes of ill seniors, people with disabilities, or chronic medical problems. <http://www.thestar.com/news/article/994284--ontario-creates-registry-to-oversee-home-care-workers>

### Specialist Publications

Of particular interest:

**'Canada's Compassionate Care Benefit: Is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care?'** (p.10), published online at *BMC Public Health*.

### Comparison between the U.S. & Ontario

### End-of-life care changes called for

ONTARIO | CBC News – 18 May 2011 – End-of-life care falls short of what the average person wants, says a study that compares palliative care in the U.S. and Ontario.<sup>1</sup> While most patients prefer supportive measures that avoid a hospital death, U.S. patients received more chemotherapy. Ontario patients have more days in hospital, have more use of emergency rooms, and were much more likely to die in hospital. An editorial about the study concludes the rates of inpatient deaths are too high in the U.S. and much too high in Ontario.<sup>2</sup> The study was done by the [U.S.] National Cancer Institute and specifically compared end-of-life care for lung cancer patients. <http://www.cbc.ca/news/health/story/2011/05/18/palliative-care-lung-cancer-comparison-study.html>

Cont.

1. 'End-of-life care for lung cancer patients in the U.S. and Ontario,' *Journal of the National Cancer Institute*, published online 18 May 2011.  
<http://jnci.oxfordjournals.org/content/early/2011/05/18/jnci.djr145.abstract>
2. 'End-of-life cancer care in Ontario and the U.S.: Quality by accident or quality by design?' *Journal of the National Cancer Institute*, published online 13 May 2011.  
<http://jnci.oxfordjournals.org/content/early/2011/05/13/jnci.djr161.full>

### The black art of delivering bad news to patients

CBC RADIO | 'White Coat, Black Art' – 17 May 2011 – The moment doctors refer patients to a palliative care team may be the first that a patient realizes that death is near. It's one of the most difficult conversations a physician and patient can ever have.  
<http://www.cbc.ca/whitecoat/blog/2011/05/17/the-black-art-of-delivering-bad-news-to-patients/>

### Specialist Publications

Of particular interest:

**'Voice analysis during bad news discussion in oncology: Reduced pitch, decreased speaking rate, and nonverbal communication of empathy'** (p.11), published in *Supportive Care in Cancer*.

### Ontario appeal court to hear case about who decides when to remove life support

ONTARIO | Canadian Press – 17 May 2011 – Doctors at a Toronto hospital are taking their fight to remove a patient from life support against his family's wishes to Ontario's highest court in a case that could change how decisions are made about withdrawing life-saving treatment in the province. Hassan Rasouli's doctors at Sunnybrook Health Sciences Centre believe he is in a persistent vegetative state and are appealing a Superior Court ruling last month<sup>1</sup> that said if they can't get permission from Rasouli's family to remove him from a ventilator, they must seek consent from Ontario's Consent & Capacity Board. If the court rules in favour of the doctors, it's unlikely other end-of-life cases would go

before the Board, says a lawyer involved with the case. "The underlying issue is whether or not doctors have the right to withdraw treatment that they view to be of no benefit to the patient, or in other words, at end of life, futile," said Mark Handelman, who spent a decade adjudicating on the Board.  
<http://www.google.com/hostednews/canadianpress/article/ALeqM5gVR3jeMVS0u5K8xrifp8p4lpWTaq?docId=6877046>

### Extract from Canadian Press report:

Ontario is the only province [in Canada] with a Consent & Capacity Board, which usually hears a case and issues a ruling in about a week.

1. 'Court rules that withdrawal of life support is a plan of treatment requiring consent,' *Canadian Medical Association Journal*, published online 8 April 2011 (and noted in Media Watch dated 11 April 2011). [http://www.cmaj.ca/earlyreleases/8april11\\_court-rules-that-withdrawal-of-life-support-is-a-plan-of-treatment-requiring-consent.dtl](http://www.cmaj.ca/earlyreleases/8april11_court-rules-that-withdrawal-of-life-support-is-a-plan-of-treatment-requiring-consent.dtl)
- ONTARIO | *Toronto Star* – 19 May 2011 – **'Family goes to court to keep dad alive: He talks to us with his eyes.'** Lying unconscious at Sunnybrook Health Sciences Centre with tough odds of recovery ... [Hassan Rasouli] ... can nevertheless communicate silently with them, hear and understand their voices and somehow make them understand his wish for a chance at life, they insist. <http://www.thestar.com/news/crime/article/993710--family-goes-to-court-to-keep-dad-alive-he-talks-to-us-with-his-eyes?bn=1>
  - ONTARIO | *Globe & Mail* – 18 May 2011 – **'Consent for ending life support would undermine MDs' authority, court hears.'** Forcing doctors to seek consent before terminating life-support for patients they deem irreversibly comatose would hamstring them when it comes to prescribing any treatment. <http://www.theglobeandmail.com/news/national/ontario/consent-for-ending-life-support-would-undermine-mds-authority-court-hears/article2027062/>

## Music can be medicine for the dying

ONTARIO | *Toronto Star* – 16 May 2011 – Sandi Curtis has played some tough gigs with her guitar – a duet for an opera singer in the final stages of lung cancer, Beatles classics for a man just days away from dying. "The wonderful thing about music is that it's so powerful," says Curtis. It also has the ability to ease pain, reduce anxiety and lift moods, according to a new study of so-called "music therapy" and its positive impact on palliative care patients. It didn't hurt that some of the musicians playing at the deathbeds of the 371 patients in the study were violinists, violists and cellists from the Windsor Symphony Orchestra. In fact, the musical encounters had such a profound impact on so many of the patients and families, some asked the musicians to play at their loved ones' funerals, says Curtis ... whose study is featured in the journal *Music & Medicine*.<sup>1</sup> The research project is the largest of its kind done in Canada on music therapy. <http://www.healthzone.ca/health/newsfeatures/article/991360--music-can-be-medicine-for-the-dying>

1. 'Music therapy and the symphony: A university-community collaborative project in palliative care,' *Music & Medicine*, 2011;3(1):20-26. <http://mmd.sagepub.com/content/3/1/20.abstract>

From Media Watch dated 17 January 2011:

- *MUSIC & MEDICINE*, 2011;3(1):9-14. '**Mapping the cultural landscape in palliative care and music therapy.**' This paper maps the discussion of cultural issues in palliative care and music therapy. <http://mmd.sagepub.com/content/3/1/9.abstract>

**N.B.** This issue of *Music & Medicine* focuses on music therapy and supportive cancer care. Contents page: <http://mmd.sagepub.com/content/3/1.toc>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC | Inside Politics – 17 May 2011 – '**Euthanasia, the people's choice.**' There simply isn't any other issue on which the public and the politicians are so out of sync with each other. The discrepancy was picked up by Vote Compass, an online survey of national issues ... during the recent [federal] election campaign, according to director of analytics Peter Loewen. "The Vote Compass data help us identify issues in which the views of our respondents match up with none of the parties. Euthanasia is the most startling case," Loewen said. This is how the Vote Compass question was worded: "If they so wish, should terminally ill patients be able to end their own lives with medical assistance?" Almost all Vote Compass respondents were supportive of the option, regardless of political stripe. Only a small hump of Conservative supporters strongly disagreed with the notion. Vote Compass is not a scientific poll, meaning it's not a strictly representative sample, because the people who answered the questions are self selecting. Nonetheless, this is data gleaned from well over a million people; in fact, Loewen adds, there are thousands of people who answered in each constituency alone. <http://www.cbc.ca/news/politics/inside-politics-blog/2011/05/euthanasia-the-peoples-choice.html>



### 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>

## U.S.A.

### **For-profit hospice industry raises worries**

UNITED PRESS INTERNATIONAL | Online report – 19 May 2011 – End-of-life hospice care is being dominated by investor-owned chains that cherry-pick patients and cut labor costs to maximize profits, U.S. researchers say. Dr. Robert Stone, an emergency medicine physician in Bloomington, Indiana., and Joshua Perry of Indiana University say end-of-life hospice care was once the province of charitable organizations, but 52% of hospices are now part of the for-profit sector. For-profit hospice industry grew by 128% from 2001 to 2008, while the non-profit sector grew by only 1%. During the same period, government-sponsored hospices increased by 25%.

"Research shows that for-profit hospices, and especially publicly traded chain providers, generate higher revenues than their non-profit counterparts," Stone says. "They do this in part ... by selectively recruiting longer-term patients, most of whom do not have cancer, thereby gaming the Medicare payment system." Medicare currently pays hospice providers a fixed *per diem* payment throughout a patient's stay, regardless of whether services are provided on any given day, Stone says. "Hospice patients' use of services are greatest on the first day, when services are set up, and in the last few days of life. Hospices that recruit longer-term patients will be overpaid and will

drain funds that should be going to patient care. Typically, the for-profit companies also pay lower salaries and benefits to a less-skilled staff, and employ fewer registered nurses. This raises quality concerns."

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

#### **Hospice care more common in wealthier areas, study finds**

U.S. NEWS & WORLD REPORT | Online report – 16 May 2011 – The availability of hospice care in the U.S. is strongly associated with a local area's average household income, a new study says.<sup>1</sup> Dr. Maria Silveira, of the Veterans Affairs Ann Arbor Healthcare System and an assistant professor in the department of internal medicine at the University of Michigan and her colleagues found that for every \$1,000 increase in median household income in a county, there was a 3% increase in the supply of hospice services.

<http://health.usnews.com/health-news/managing-your-healthcare/economics/articles/2011/05/16/hospice-care-more-common--in-wealthier-areas-study-finds>

1. 'Community supply of hospice: Does wealth play a role?' *Journal of Pain & Symptom Management*, online article posted 24 March 2011. [http://www.jpmsjournal.com/article/S0885-3924\(11\)00019-4/abstract](http://www.jpmsjournal.com/article/S0885-3924(11)00019-4/abstract)

1. 'In the business of dying: Questioning the commercialization of hospice,' *Journal of Law, Medicine & Ethics*, 2011;39(2):224-234. <http://onlinelibrary.wiley.com/doi/10.1111/j.1748-720X.2011.00591.x/abstract>

From Media Watch dated 7 February 2011:

- CALIFORNIA | *Los Angeles Times* – 1 February 2011 – **'For-profit hospices may choose cheaper-to-treat patients, study finds.'** Research findings report that for-profit hospice services may be selecting patients who are less expensive to treat – leaving the pricier patients to non-profit agencies.<sup>1</sup> [http://www.latimes.com/health/boostershots/la-heb-for-profit-hospice-20110201\\_0\\_5630476.story](http://www.latimes.com/health/boostershots/la-heb-for-profit-hospice-20110201_0_5630476.story)

1. 'Association of hospice agency profit status with patient diagnosis, location of care, and length of stay,' *Journal of the American Medical Association*, 2011;305(5):472-479. <http://jama.ama-assn.org/content/305/5/472.abstract>

Cont.

Of related interest:

- CONNECTICUT | *The Middletown Press* – 16 May 2011 – '**Experts at odds over proposed changes in Connecticut hospice care rules.**' In the state where hospice care first arrived in America, the bar has been set high for those who care for dying patients and help them toward a peaceful, pain-free end. Now, 28 hospice providers are hoping the state will update its rules so that more of them can create freestanding hospices. Officials at Connecticut Hospice, however, say new rules would allow only a weak imitation of the care that the first hospice in the nation has provided. <http://middletownpress.com/articles/2011/05/16/news/doc4dd13a6da77a7476238595.txt>

From Media Watch dated 2 May 2011:

- *CONNECTICUT POST* (Bridgeport) | Online report – 26 April 2011 – '**New hospice regulations improve end-of-life care.**' The state Department of Public Health has proposed new regulations for hospice facilities. <http://www.ctpost.com/default/article/New-hospice-regulations-improve-end-of-life-care-1353404.php>

### **West Virginia slow to create electronic system for end-of-life care wishes**

WEST VIRGINIA | *Charleston News* – 18 May 2011 – West Virginia is leading the nation in incorporating patient wishes for end-of-life care into their medical history, according to a new American Association for Retired Persons study.<sup>1</sup> About 85% state residents in hospice settings have a filled out a Physician Orders for Scope of Treatment [POLST] form that translates patients' wishes into medical orders, from their wish for aggressive treatment, limited intervention or comfort care, according to the study. "The good news is that West Virginia is by and large one of the national leaders and we are doing almost everything recommended in the report," said Dr. Alvin Moss, director of the West Virginia Center for End-of-Life Care. "But there is one key thing that they strongly recommend that we are not doing." The state has been slow to add POST and other end-of-life care materials to an electronic health record system, Moss said. The center is working to launch an e-Directive Registry as part of the West Virginia Health Information Network, which would create a secure database to inform paramedics and doctors how a patient wants to be treated in an emergency, Moss said. <http://sundaygazette.com/News/201105180882>

1. *Improving Advanced Illness Care: The Evolution of State POLST Programs*, American Association for Retired Persons, April 2011. <http://assets.aarp.org/rgcenter/ppi/cons-prot/POLST-Report-04-11.pdf>

### **Hospice care doesn't hasten death: Study**

REUTERS | Online report – 17 May 2011 – Terminally ill patients who opt to receive hospice care won't die any faster as a result of that choice, according to Korean researchers.<sup>1</sup> Their findings add to a recent U.S. debate over hospices, which some fear might accelerate the decline of very sick people. Few studies have looked at what the different types of care mean for survival. <http://www.reuters.com/article/2011/05/17/us-hospice-study-idUSTRE74G6VR20110517>

1. 'Impact of awareness of terminal illness and use of palliative care or intensive care unit on the survival of terminally ill patients with cancer: Prospective cohort study.' *Journal of Clinical Oncology*, online article posted 16 May 2011. <http://jco.ascopubs.org/content/early/2011/05/16/JCO.2010.30.1184.abstract>

#### **[Media Watch posted on Palliative Care Network-e Website](#)**

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/world/world/>

## International

### Survey seeks rethink on hospital for terminally ill

AUSTRALIA (WESTERN AUSTRALIA) | *Sydney Morning Herald* – 23 May 2011 – Increased hospital admissions in the last three months of life could be of little benefit to dying people and are in contrast to the wishes of many, two new surveys show. People who have conditions known to be terminal, and who therefore should qualify for palliative care in the community, are admitted to hospital an average of eight times during their last year for an average six days on each occasion, the first Australian study on the subject has found.<sup>1</sup> Three months before they died an exponential increase began in the time people spent in hospital, and nearly two-thirds of the 1071 people in the West Australian survey died away from their home. The results, which are expected to be similar across Australia, confirmed "there is extensive use of inpatient services in the last year of life by people whose deaths are clinically expected", wrote lead researcher Lorna Rosenwax. In a separate national survey of 1000 people, two-thirds said they had firm preferences about where they wanted to die, but fewer than half had discussed their wishes with family. Of those who said they did have a preference, three-quarters wished to die at home, versus only 8% who wanted to die in hospital. <http://www.smh.com.au/national/survey-seeks-rethink-on-hospital-for-terminally-ill-20110522-1ez1t.html>

1. 'Hospital and emergency department use in the last year of life: a baseline for future modifications to end-of-life care,' *Medical Journal of Australia*, published online 23 May 2011. [http://www.mja.com.au/public/issues/194\\_11\\_060611/ros11093\\_fm.html](http://www.mja.com.au/public/issues/194_11_060611/ros11093_fm.html)

#### The death whisperers

AUSTRALIA | *The Australian* – 21 May 2011 – What happens during the days and nights before the dying take their last breath? How do patients endure the loneliness, the white-knuckled fear of the unknown, the psychological trauma of letting go? Nurses, doctors, chaplains and those who care for the dying brim with mysterious coincidences, patient premonitions, visions, auras or, as Helen Walker, of Melbourne's Cabrini palliative care unit, puts it, "the amazing energy" often felt in the room as a person dies. These phenomena are different to the "near-death" sensations of bright lights and tunnels reported by those who recover from trauma or cardiac arrest. There is fierce debate between sceptics, who dismiss them as hallucinations, drug-induced imagery or the effect of oxygen deprivation, and researchers, including medical professionals, who are intrigued by new evidence of their prevalence and significance. It is a field rich with controversy, but those who dwell close to the dying embrace the inexplicable as part of a day's work. <http://www.theaustralian.com.au/news/features/the-death-whisperers/story-e6fmg8h6-1226059721591>

Of related interest:

1. AUSTRALIA (VICTORIA) | *Western Australia Today* – 22 May 2011 – "**Thousands' missing palliative care.**" A report released by the state government revealed about 7,500 Victorians who die from chronic illnesses each year miss out on palliative care. It said Aborigines and other people from non-English-speaking backgrounds may also be going without help because statistics showed only 7% of palliative care services were being provided to people who spoke a language other than English. <http://www.watoday.com.au/victoria/thousands-missing-palliative-care-20110522-1eyxa.html>

**N.B.** Australia was rated 2nd in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. [http://graphics.eiu.com/upload/QOD\\_main\\_final\\_edition\\_Jul12\\_toprint.pdf](http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf)

Cont.



## Health Minister refutes criticism of palliative care

PORTUGAL | *The Portugal News* – 21 May 2011 – Refusing to comment on accusations from the Portuguese Palliative Care Association (APCP), which claimed that up to ninety percent of the thousands of people requiring such care in this country went without, Minister Ana Jorge said "Our system for treating patients and providing palliative care is supported by the WHO and is an example to other countries." She refused to address the figures put forward by Isabel Neto, president of the APCP. "I have no knowledge of that percentage, ninety percent, of patients who do not have access to palliative care, and therefore I am not going to comment on those numbers", she said, adding: "What I can say is that our system is the most adequate because we give priority to proximity, in other words, to patients being able to have their treatments

the closest possible to their place of residence, whether they are terminally ill or not, and on the other hand, they are kept within their social context and close to their families." In Mrs. Neto's opinion, the fact that palliative care is integrated within the continuous care network makes the process "too bureaucratic, with referral times that are too slow, that do not benefit patients' needs." <http://www.theportugalnews.com/cgi-bin/article.pl?id=1113-19>

European Association for Palliative Care Task Force on the Development of Palliative Care in Europe report on Portugal posted August 2006. <http://www.eapcnet.org/download/forPolicy/CountriesRep/Portugal.pdf>

**N.B.** Portugal was rated 31st in *The Quality of Death: Ranking End-of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. [http://graphics.eiu.com/upload/QOD\\_main\\_final\\_edition\\_Jul12\\_toprint.pdf](http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf)

## Palliative care study launched at hospital

U.K. | *Yorkshire Post* – 17 May 2011 – A ... project to assess the best way of providing palliative care to in-patients with a life-limiting illness started in Northallerton. It builds on the good practice established by the team for in-reach services at the Friarage over many years. However, it includes a number of new elements, to ensure a more integrated approach both on the ward and once patients are discharged into the community. [http://www.yorkshirepost.co.uk/news/around-yorkshire/local-stories/palliative\\_care\\_study\\_launched\\_at\\_hospital\\_1\\_3386403](http://www.yorkshirepost.co.uk/news/around-yorkshire/local-stories/palliative_care_study_launched_at_hospital_1_3386403)

## Protecting health and human rights at all stages of life

EUROPE | *The Financial* – 16 May 2011 – Do we have the right to decide whether to start, continue or end medical treatment, and what might be the uses, benefits and limitations of living wills, with a view to better protection of health and human rights at all stages of life? These questions will be the central themes of a hearing ... organised by the Social Affairs Committee of the Parliamentary Assembly of the Council of Europe, at which parliamentarians and experts from France, Switzerland, Spain and Ukraine will review the situation in Council of Europe member states. [http://finchannel.com/Main\\_News/Politics/87098\\_Protecting\\_health\\_and\\_human\\_rights\\_at\\_all\\_stages\\_of\\_life/](http://finchannel.com/Main_News/Politics/87098_Protecting_health_and_human_rights_at_all_stages_of_life/)

Of related interest:

- EUROPE | BBC News – 17 May 2011 – **'Elderly care costs could treble says OECD.'** The cost of caring for the elderly could treble by 2050, according to the Organisation for Economic Cooperation & Development [OECD].<sup>1</sup> <http://www.bbc.co.uk/news/health-13437528>
- 1. *Help Wanted? Providing and Paying for Long-Term Care*, OECD May 2011. [http://www.oecd.org/document/23/0,3746,en\\_2649\\_34629\\_47659479\\_1\\_1\\_1\\_1,00.html](http://www.oecd.org/document/23/0,3746,en_2649_34629_47659479_1_1_1_1,00.html)

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (SCOTLAND) | *The Herald* (Glasgow) – 17 May 2011 – **'MacDonald to resume assisted suicide fight.'** A new bid to make assisted suicide legal in Scotland is planned by Member of the Scottish Parliament Margo MacDonald who claimed she has a mandate to introduce the legislation at Holyrood [the Scottish parliament]. <http://www.heraldsotland.com/news/politics/macdonald-to-resume-assisted-suicide-fight-1.1101785>

From Media Watch dated 6 December 2011:

- U.K. (SCOTLAND) | BBC News – 1 December 2010 – **'Margo MacDonald's End of Life Assistance Bill rejected.'** The Scottish Parliament has rejected plans to give terminally ill people the right to choose when to die, despite claims they were widely backed. <http://www.bbc.co.uk/news/uk-scotland-11876821>
- SWITZERLAND | BBC News (from Geneva) – 16 May 2011 – **'Making the difficult decision to die.'** Voters in [the canton of] Zurich may have rejected proposals to ban assisted suicide and "suicide tourism," but the journey towards making the decision to die remains as difficult as ever. [http://news.bbc.co.uk/2/hi/programmes/from\\_our\\_own\\_correspondent/9485413.stm](http://news.bbc.co.uk/2/hi/programmes/from_our_own_correspondent/9485413.stm)

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

### Palliative care in Bulgarian general practice

*ADVANCES IN PALLIATIVE MEDICINE*, 2011;10(1):17-22. Bulgaria has no national guidelines, recommendations, standards or policy concerning palliative care. On the background of the demographic situation – increase in the relative portion of elderly people – as well as the raised incidence level of severe chronic diseases, there is an urgent need of palliative care services. Within the framework of their general obligations towards the patients that have chosen them, GPs perform activities characteristic of palliative care – identification, co-ordination, control of symptoms and home care. The investigation of these activities and the analysis of the

results can serve as a first step in formation of structured palliative care in our country. <http://www.advpm.eu/>

**N.B.** Scroll down contents page to 'Palliative care in Bulgarian general practice' for a link to a pdf copy of this article.

European Association for Palliative Care Task Force on the Development of Palliative Care in Europe report on Bulgaria posted August 2006. <http://www.eapcnet.org/download/forPolicy/CountriesRep/Bulgaria.pdf>

### Assault as treatment: Mythology of CPR in end-of-life dementia care

*ANNALS OF LONG-TERM CARE: CLINICAL CARE & AGING*, 2011;19(5):31-32. Many people have come to view cardiopulmonary resuscitation (CPR) as a routine intervention following cardiac arrest, and they insist on CPR for their loved ones even when the physician explains its likely futility. Physicians who refuse a family member's request to perform unwarranted CPR risk becoming the center of media, legal, and disciplinary scrutiny. Although CPR is largely perceived as a benign life-saving intervention, it inflicts indignity and possibly pain on a dying patient, and should not be used when it is unlikely to succeed or to benefit the patient if successful. <http://www.annalsoflongtermcare.com/article/assault-treatment-mythology-cpr-end-life-dementia-care>

Cont.



Of related interest:

- *ANNALS OF LONG-TERM CARE: CLINICAL CARE & AGING*, 2011;19(5):11. **'Should late-stage dementia patients receive feeding tubes near the end of life?'** Older adults with dementia often develop problems with chewing and swallowing in the final stages of the disease, which can result in aspiration pneumonia. While feeding tube insertion can be a solution to these problems in some patients, research indicates that this method does not extend life or improve the quality of life for patients with advanced dementia. <http://www.annalsoflongtermcare.com/article/should-late-stage-dementia-patients-receive-feeding-tubes-near-end-life>

### **Withdrawal of life-support in paediatric intensive care – a study of time intervals between discussion, decision and death**

*BMC PEDIATRICS* | Online article – 21 May 2011 – Scant information exists about the time-course of events during withdrawal of life-sustaining treatment. The authors investigated the time required for end-of-life decisions, subsequent withdrawal of life-sustaining treatment and the time to death. Wide case-by-case variation in timeframes occurs at every step of the process of withdrawal of life-sustaining treatment until death. This knowledge may facilitate medical management, clinical leadership, guidance of parents and inform organ procurement after cardiac death. <http://www.biomedcentral.com/content/pdf/1471-2431-11-39.pdf>

Of related interest:

- *BRITISH MEDICAL BULLETIN* | Online article – 19 May 2011 – **'Guidance for withdrawal and withholding of intensive care as part of neonatal end-of-life care.'** The child's 'best interests' take precedent and clinical guidance has been published to support the joint decision-making partnership of clinicians and families. Withholding and withdrawing intensive care should be part of an overall end-of-life care plan incorporating the principles and standards of palliative care. <http://bmb.oxfordjournals.org/content/early/2011/05/18/bmb.lbr016.abstract>

### **Assessment of depression when patients desire a hastened death**

*END OF LIFE JOURNAL* | Online article – Accessed 19 May 2011 – Patients' mental health status is an important element of palliative and end-of-life care. However, depression is often under-recognised in terminally ill cancer patients. That is because symptoms of depression can mimic those of advanced cancer and clinicians often think that patients' low mood is an understandable reaction to terminal illness. Depression has been associated with patients desiring a hastened death or requesting assisted suicide. Nurses are often the health professional with whom patients discuss thoughts about dying. However, nurses do not always know how best to respond to patients when they say that they want to die. When faced with desire for hastened death (DHD), it is essential that nurses assess patients for symptoms that may be indicative of depression. This article provides an overview of the main signs and symptoms of depression. <http://endoflifejournal.stchristophers.org.uk/clinical-review/assessment-of-depression-when-patients-desire-a-hastened-death>

Of related interest:

- *MEDSCAPE* | Online interview – 10 May 2011 – **'Palliative care psychiatry: What is it and does it work?'** Because patients with advanced life-threatening illnesses can have complex psychiatric issues and are often referred to palliative care teams, these teams need access to psychiatry and psychiatrists as consultants to provide exquisite interdisciplinary palliative care that addresses the complexities of this burden of suffering. <http://www.medscape.com/viewarticle/741903>

#### [Quotable Quotes](#)

*If you realize that all things change, there is nothing you will try to hold on to.  
If you are not afraid of dying, there is nothing you cannot achieve. Lao Tzu*

## Family caregivers and palliative care: Current status and agenda for the future

*JOURNAL OF PALLIATIVE MEDICINE* | Online article – 20 May 2011 – The quality of life of the person confronting the end stages of their life may be severely compromised without the support of family caregivers. Indeed, most people requiring palliative care would not be able to fulfill their preferences, such as care at home, without significant family caregiver input. As a consequence, health services are mandated to support the family alongside the person diagnosed with a life-threatening illness. In short, palliative care is supposed to be family centred. However, the quality and type of support made available to family caregivers has been questioned. The purpose of this review is to outline a succinct and empirically informed account of family caregiving within the context of palliative care and to propose an agenda for the future. The appraisal is underpinned by several systematic reviews,

and other seminal publications from the last decade. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0413>

### **Canada's Compassionate Care Benefit: Is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care?**

*BMC PUBLIC HEALTH* | Online article – 18 May 2011 – The Compassionate Care Benefit (CCB) is not living up to its full potential in sustaining informal palliative/end-of-life caregivers. Effort is required to transform the CCB so that it may fulfill the potential it holds for serving as one public health response to caregiver burden that forms part of a healthy public policy that addresses the determinants of this burden. <http://www.biomedcentral.com/content/pdf/1471-2458-11-335.pdf>

## **Does palliative care improve outcomes for patients with incurable illness? A review of the evidence**

*JOURNAL OF SUPPORTIVE ONCOLOGY*, 2011;9(3):87-94. In this article, the authors review the efficacy of various palliative care interventions to improve patients' quality of life, physical and psychological symptoms, satisfaction with care, family caregiver outcomes, health-service utilization, and quality of end-of-life care. They identified 22 randomized studies that evaluate the efficacy of various palliative care interventions. Palliative care research has been hampered by methodological challenges related to attrition and missing data due to progressive illness and death. In addition, interventions to date have varied widely in the focus and extent of services, with only eight studies entailing direct clinical care by palliative care specialists, making comparisons across trials challenging. Despite these limitations, accumulating evidence shows that palliative care interventions do improve patients' quality of life, satisfaction with care, and end-of-life outcomes. <http://www.sciencedirect.com/science?ob=ArticleURL&udi=B6KMD-52TW1FP-9&user=10&coverDate=06%2F30%2F2011&rdoc=1&fmt=high&orig=gateway&origin=gateway&sort=d&docanch or=&view=c&acct=C000050221&version=1&urlVersion=0&userid=10&md5=dbdcaddb64f446bc4bebe3724c563b32&searchtype=a>

Of related interest:

- *BMC PALLIATIVE CARE* | Online article – 12 May 2011 – '**Palliative care making a difference in rural Uganda, Kenya and Malawi.**' Patients valued being treated with dignity and respect. Being supported at home reduced physical, emotional and financial burden of travel to and care at health facilities. Practical support and instruction in feeding and bathing patients facilitated good deaths at home. In each country, mobile phones enabled rapid access to clinical and social support networks. Staff and volunteers generally reported that caring for the dying in the face of poverty was stressful, but also rewarding, with resilience fostered by having effective analgesia, and community support networks. <http://www.biomedcentral.com/content/pdf/1472-684x-10-8.pdf>

**N.B.** Uganda was rated 39th in *The Quality of Death: Ranking End-of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. [http://graphics.eiu.com/upload/QOD\\_main\\_final\\_edition\\_Jul12\\_toprint.pdf](http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf)

## [New York's] Palliative Care Information Act in real life

*NEW ENGLAND JOURNAL OF MEDICINE*, 2011;364(2):1885-1887. Admittedly, physicians have too often left patients with advanced incurable illness unaware of the reality of their condition. The solution, however, is to focus on the real obstacles to respectful conversation about the limits of medical efforts to extend life and about the alternatives to disease-directed treatments; a legalistic solution is likely to prompt a merely legalistic response, such as a new checklist requirement for physicians and an additional page in the hefty pile of papers foisted on patients. We all want physicians to speak about these matters with patients and their families openly, patiently, empathetically, and collaboratively. That means physicians need to feel comfortable communicating their own values and experiences and providing non-authoritarian guidance and support while expressing interest in and respect for the experiences and values of patients and their families. <http://www.nejm.org/doi/full/10.1056/NEJMp1102392>

Of related interest:

- *THE CLINICAL TEACHER*, 2011;8(2):138-139. **'Dealing with death.'** Twenty-one new doctors from 17 different medical schools in Great Britain were interviewed, in which the emphasis of the interviews includes their learning from medical school, palliative care experiences, and how they learn to care for dying patients. The survey revealed that the participants described death as a taboo subject. <http://onlinelibrary.wiley.com/doi/10.1111/j.1743-498X.2011.00451.2.x/abstract>
- *MEDICAL NEWS TODAY* | Online report – 17 May 2011 – **'Clinicians' attention lacking in discussions of end-of-life care.'** Clinicians consistently fall short in discussing end-of-life care with patients with chronic obstructive pulmonary disorder, according to a study completed by researchers in Washington [presented at the recent annual conference of the American Thoracic Society]. <http://www.medicalnewstoday.com/releases/225543.php>

## Voice analysis during bad news discussion in oncology: Reduced pitch, decreased speaking rate, and nonverbal communication of empathy

*SUPPORTIVE CARE IN CANCER* | Online article – 14 May 2011 – All but one [oncology health care] provider [i.e., study participant] reduced speaking rate, the majority also reduced pitch in ... [discussing] ... bad news. Listeners perceived a significant difference between the nonverbal characteristics of the providers' voice when performing the two tasks [i.e., discussing bad news versus discussing neutral topics] and rated speech produced with the reduced rate and lower pitch as more caring and sympathetic. These results suggest that simultaneous assessment of verbal content and multi-parameter prosodic analysis of speech is necessary for a more thorough understanding of the expression and perception of empathy. This information has the potential to contribute to the enhancement of communication training design and of oncologists' communication effectiveness. <http://www.springerlink.com/content/j826u2752402538w/>

Of related interest

- *PATIENT EDUCATION & COUNSELING* | Online article – 14 May 2011 – **'Teaching and evaluating breaking bad news: A pre-post evaluation study of a teaching intervention for medical students and a comparative analysis of different measurement instruments and raters.'** This study serves as a stimulus for further research on the training of specific elements of breaking bad news [bbn] and different approaches of evaluating competency. In light of the different facets of bbn competency, it is important to set priorities regarding the teaching aims and to provide a consistent approach. [http://www.sciencedirect.com/science?\\_ob=ArticleURL&\\_udi=B6TBC-52VP37H-4&\\_user=10&\\_coverDate=05%2F14%2F2011&\\_rdoc=8&\\_fmt=high&\\_orig=browse&\\_origin=browse&\\_zone=rsllist\\_item&\\_srch=doc-info\(%23toc%235139%239999%23999999999%2399999%23FLA%23display%23Articles\)&\\_cdi=5139&\\_sort=&\\_docanchor=&\\_ct=218&\\_acct=C000050221&\\_version=1&\\_urlVersion=0&\\_userid=10&md5=16e2be9bf91304d57a883b5485e53dee&searchtype=a](http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6TBC-52VP37H-4&_user=10&_coverDate=05%2F14%2F2011&_rdoc=8&_fmt=high&_orig=browse&_origin=browse&_zone=rsllist_item&_srch=doc-info(%23toc%235139%239999%23999999999%2399999%23FLA%23display%23Articles)&_cdi=5139&_sort=&_docanchor=&_ct=218&_acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=16e2be9bf91304d57a883b5485e53dee&searchtype=a)

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article – 16 May 2011 – '**Process and outcomes of euthanasia requests under the Belgian act on euthanasia: A nationwide survey.**' The incidence of euthanasia in Belgium has been studied, but the process and outcomes of euthanasia requests have not been investigated. Under the Belgian Act on Euthanasia, about half of the requests are granted. [http://www.jpmsjournal.com/article/S0885-3924\(11\)00154-0/abstract](http://www.jpmsjournal.com/article/S0885-3924(11)00154-0/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.

### Links to Sources

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

### Something Missed or Overlooked?

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

### 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?media\\_watch=1](http://www.mhpcn.ca/Physicians/resources.htm?media_watch=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/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>

## Worth Repeating

### **Negotiating palliative care expertise in the medical world**

*SOCIAL SCIENCE & MEDICINE*, 2003; 57(2):277-288. This paper explores the relationship between palliative medicine and the wider medical world. It draws on data from a focus group study in which doctors from a range of specialties talked about developing palliative care for patients with heart failure. In outlining views of the organisation of care, participants engaged in a process of negotiation about the roles and expertise of their own, and other, specialties. The authors' analysis considers the expertise of palliative medicine with reference to its technical and indeterminate components. It shows how these are used to promote and challenge boundaries between medical specialties and with nursing. The boundaries constructed on palliative medicine's technical contribution to care are regarded as particularly coherent within orthodox medicine. In contrast, its indeterminate expertise, represented by the 'holistic' and 'psychosocial' agendas, is potentially compromising in a medical world that prizes science and rationality. The authors show how the coherence of both kinds of expertise is contested by moves to extend palliative care beyond its traditional temporal (end-of-life) and pathological

(cancer) fields of practice.

[http://www.sciencedirect.com/science?\\_ob=ArticleURL&\\_udi=B6VBF-47HBTFF-4&\\_user=10&\\_coverDate=07%2F31%2F2003&\\_alid=1753565454&\\_rdoc=5&\\_fmt=high&\\_orig=search&\\_origin=search&\\_zone=rslt\\_list\\_item&\\_cdi=5925&\\_sort=r&\\_st=13&\\_docanchor=&\\_view=c&\\_ct=426&\\_acct=C000050221&\\_version=1&\\_urlVersion=0&\\_userid=10&md5=c91b5b19aaac85d86b5b126e91bd97d9&searchtype=a](http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6VBF-47HBTFF-4&_user=10&_coverDate=07%2F31%2F2003&_alid=1753565454&_rdoc=5&_fmt=high&_orig=search&_origin=search&_zone=rslt_list_item&_cdi=5925&_sort=r&_st=13&_docanchor=&_view=c&_ct=426&_acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=c91b5b19aaac85d86b5b126e91bd97d9&searchtype=a)

#### **Hospice and palliative care**

*INTERNATIONAL ENCYCLOPEDIA OF PUBLIC HEALTH*, 2008:460-469. Each year 58 million people die around the world, 60% due to chronic diseases. Each death involves five other people in caregiving and grieving. Hospice and palliative care has developed effective responses to the needs of populations with life-threatening diseases, by making the lives of individuals toward the end of life pain-free and dignified, and by supporting their families. By 2030 there will be 74 million deaths per year and 17% of the world will be aged 60 and over.

[http://www.sciencedirect.com/science?\\_ob=ArticleURL&\\_udi=B98GG-4T7XCGF-G9&\\_user=10&\\_origUdi=B6VBF-47HBTFF-4&\\_fmt=high&\\_coverDate=03%2F03%2F2009&\\_rdoc=1&\\_orig=article&\\_origin=article&\\_zone=related\\_ref&\\_acct=C000050221&\\_version=1&\\_urlVersion=0&\\_userid=10&md5=fa213ed8762b76f9c5e74ef0b6033bfa](http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B98GG-4T7XCGF-G9&_user=10&_origUdi=B6VBF-47HBTFF-4&_fmt=high&_coverDate=03%2F03%2F2009&_rdoc=1&_orig=article&_origin=article&_zone=related_ref&_acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=fa213ed8762b76f9c5e74ef0b6033bfa)

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