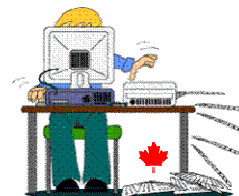


## Media Watch...

is intended as an advocacy and research tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in hospice and palliative care, and in the quality of end-of-life care in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

8 July 2013 Edition | Issue #313



Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013 ©

Compiled & Annotated by Barry R. Ashpole

With this issue of Media Watch, the weekly report begins its 7<sup>th</sup> year of publication.

## Canada

### Ontario home care more hazardous than families

ONTARIO | *The Toronto Star* (OpEd) – 7 July 2013 – For 30 years, politicians and health-care officials ... have touted the benefits of home care. It's convenient, allows seniors to live independently and saves the medical system billions of dollars. A hospital bed costs an average of \$842 a day. Home care costs an average of \$42 a visit. But there's something missing from this rosy narrative. There are no safety standards for home care. What goes on in patients' houses or apartments does not have to be documented or disclosed. A study by the Canadian Patient Safety Institute lifts the veil.<sup>1</sup> The lead researchers, Dr. Diane Doran of the University of Toronto and Dr. Régis Blais of the Université de Montréal, show how hazardous home care can be and outlines what needs to be done to make it safer. The researchers found 10-13% of home-care patients experience an "adverse event" – a serious fall, medication error or preventable infection – every year. (The comparable rate for hospitals is 3.3-5% annually.) The researchers combed the records of home-care organizations across the country and filled in the gaps with statistical extrapolation. Their ... findings substantiate what many families have been saying for years: hospitals discharge frail, elderly patients without proper planning or adequate support. [http://www.thestar.com/opinion/commentary/2013/07/05/ontario\\_home\\_care\\_more\\_hazardous\\_than\\_families\\_told\\_goar.html](http://www.thestar.com/opinion/commentary/2013/07/05/ontario_home_care_more_hazardous_than_families_told_goar.html)

1. *Safety at Home: Pan-Canadian Home Care Safety Study*, Canadian Patient Safety, July 2013. <http://www.patientsafetyinstitute.ca/English/research/commissionedResearch/SafetyatHome/Documents/Safety%20at%20Home%20Care.pdf>

### Media Watch: Reach & Frequency

The weekly report is currently distributed to 1,200+ academics and researchers; administrators, educators and policy makers in the fields of bio-medical ethics, health care, and social services – and, to frontline health care providers. Approximately 30-35% of recipients reside in North American (Canada and the U.S.); 20% in Central and South America; 20-25% in Eastern, Western & Northern Europe; 10% in Africa; 15% in Australia and New Zealand; and, 5% in Asia. An informal survey in 2012 indicated that, on average, 3-5 people read or review each issue.

### Media Watch Online

Media Watch (or a link to the weekly report) is posted on several websites that serve the hospice and palliative care communities-at-large (see p.12 for listing).

## Let's speak less of death and more about care

ONTARIO | *The Toronto Star* (OpEd) – 2 July 2013 – "End of life" is the polite code for "ending life," either through the withdrawal of life-prolonging treatment or physician-assisted (or directed) termination. It is not about the compassion required for chronic cases ... but about creating a structure that permits those cases to be inexpensively and safely ended. That, of course, would be good news for the government, whose funding of care centres, nursing homes, home support and hospice and palliative care services is lamentably inadequate. We know this from the waiting lists for skilled-nursing facilities and the failure of hospices like Perram House, which closed earlier this year because of funding problems. The province expects hospices to raise operating capital as a charity rather than be fully funded by the government. Perram House couldn't do that. "The end of life is messy," New Democratic Party health critic France Gélinas said in her support of [Ontario Premier Kathleen] Wynne's call for a discussion. It's not, however. The end of life is pretty clear and very simple: the heart stops beating and respiration ceases. Life for the fragile, however, is a different matter. It involves a range of issues, an array of specialities and sometimes also special facilities. The result will not bring a person back to health ... but will give them the best possible life they can live. This isn't about age, however. While most frame these discussions in talk of seniors, the issue of fragile life versus a quickened death is not age restricted. [http://www.thestar.com/opinion/commentary/2013/07/02/lets\\_speak\\_less\\_of\\_death\\_and\\_more\\_about\\_care.html](http://www.thestar.com/opinion/commentary/2013/07/02/lets_speak_less_of_death_and_more_about_care.html)

Noted in Media Watch, 1 July 2013, #312 (p.1):

- ONTARIO | *The Toronto Star* (OpEd) – 24 June 2013 – **'Rare agreement in Ontario on need for end-of-life discussions.'** The complex issues behind end-of-life care are resonating with enough Ontarians, normally divisive members of parliament agree it's time to act. [http://www.thestar.com/opinion/editorials/2013/06/24/rare\\_agreement\\_in\\_ontario\\_on\\_need\\_for\\_endoflife\\_discussions\\_editorial.html](http://www.thestar.com/opinion/editorials/2013/06/24/rare_agreement_in_ontario_on_need_for_endoflife_discussions_editorial.html)

### Specialist Publications

'Quebec's end-of-life bill makes palliative care more transparent' (p.8), in *Canadian Medical Association Journal*.

Noted in Media Watch, 15 April 2013, #301 (p.2):

- ONTARIO | *The Toronto Star* – 10 April 2013 – **'Perram House hospice closing – staff got two days' notice.'** Perram House – one of the few hospices in the city providing end-of-life care to marginalized, homeless and drug-addicted people – will close on Wednesday. [http://www.thestar.com/life/health\\_wellness/2013/04/10/perram\\_house\\_hospice\\_closing\\_wednesday\\_staff\\_got\\_two\\_days\\_notice.html](http://www.thestar.com/life/health_wellness/2013/04/10/perram_house_hospice_closing_wednesday_staff_got_two_days_notice.html)

## U.S.A.

### The rapid rise of the male caregiver

*FORBES* | Online – 2 July 2013 – In 2009 ... men accounted for 34% of the nearly 65 million family caregivers in the U.S.<sup>1</sup> But more recent surveys show the number of men in this traditionally female role has risen rapidly, driven by a combination of factors, including the recession, changing gender expectations, and longer life expectancies. A 2012 analysis ... finds that men may now represent as many as 45% of all family caregivers.<sup>2</sup> And a new study ... reports that between 1996 and 2011, the percentage of men among adults caring for a family member with Alzheimer's disease or dementia almost doubled, to 40% from 19%.<sup>3</sup> This shift is most likely due to demographics. Among people over 65, Alzheimer's and dementia are more prevalent among women than men. More than 3.9 million cases of Alzheimer's disease have been diagnosed in women over 65, compared with only 1.8 million diagnoses for men in the same age group. <http://www.forbes.com/sites/nextavenue/2013/07/02/the-rapid-rise-of-the-male-caregiver/>

Cont.

1. *Caregiving in the U.S.*, National Alliance for Caregiving & American Association for Retired Persons, 2009. <http://www.caregiving.org/pdf/research/CaregivingUSAllAgesExecSum.pdf>
2. *Family Caregivers Online*, Pew Research Center's Internet & American Life Project, 2012. [http://www.pewinternet.org/~media/Files/Reports/2012/PIP\\_Family\\_Caregivers\\_Online.pdf](http://www.pewinternet.org/~media/Files/Reports/2012/PIP_Family_Caregivers_Online.pdf)
3. *2013 Alzheimer's disease facts and figures*, *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 2013;9(2):208-245. [Noted in Media Watch, 6 May 2013, #304; (p.7)] [http://www.alzheimersanddementia.com/article/S1552-5260\(13\)00076-9/fulltext#abstract](http://www.alzheimersanddementia.com/article/S1552-5260(13)00076-9/fulltext#abstract)

Of related interest:

- **FORBES** | Online – 8 July 2013 – **'Are we underestimating how much help aging parents need at home.'** We all just got a reality check in a report from the Congressional Budget Office about how many hours of daily assistance an aging person is likely to need.<sup>1</sup> It tells us about our aging parents who have trouble functioning independently in their activities of daily living, which include bathing, dressing, eating, toileting, walking, and transferring from bed to chair. <http://www.forbes.com/sites/carolynrosenblatt/2013/07/08/are-we-underestimating-how-much-help-aging-parents-need-at-home/>

1. *Rising Demand for Long-Term Services and Supports for Elderly People*, June 2013. <http://www.cbo.gov/sites/default/files/cbofiles/attachments/44363-LTC.pdf>

### The language of end-of-life care

#### **Common end-of-life medical terms**

CABLE NEWS NETWORK | Online – 1 July 2013 – At the end of life or in critical care situations, it's common for doctors to use terms that may sound vague to friends and family members. Former South African President Nelson Mandela, 94, remained in critical but stable condition Monday, suffering from a recurrent lung infection. He's been hospitalized since 8 June in Pretoria, South Africa. His condition worsened last week, according to family members who described his health as "delicate" and said "anything is imminent." His daughter Zindzi Mandela told ITV, however, that her father is alert and recognizes when a new person enters his room. Here are some terms likely

to be used in such situations – as defined by Dr. Darlene Nelson, a pulmonary and critical care specialist at the Mayo Clinic. [http://www.cnn.com/2013/07/01/health/end-of-life/?hpt=he\\_c2](http://www.cnn.com/2013/07/01/health/end-of-life/?hpt=he_c2)

#### Specialist Publications

**'Effectiveness of the ACA (Availability, Current issues & Anticipation) training programme on GP-patient communication in palliative care: A controlled trial'** (p.8), in *BMC Family Practice*.

#### **Why is the way physicians want to die so different from the rest of us?**

CALIFORNIA | *Pacific Standard* (Santa Barbara) – 1 July 2013 – When you ask people how they'd like to die, most will say that they want to die quickly, painlessly, and peacefully – preferably in their sleep. But if you ask them whether they would want various types of interventions were they on the cusp of death and already living a low-quality of life, they typically say "yes" and "can I have some more please." Blood transfusions, feeding tubes, invasive testing, chemotherapy, dialysis, ventilation, and chest pumping CPR. Most people say "yes." But not physicians. Doctors, it turns out, overwhelmingly say "no." The only intervention that doctors overwhelmingly want is pain medication. In no other case do even 20% of the physicians say "yes." First, few non-physicians actually understand how terrible undergoing these interventions can be. A second reason why physicians and non-physicians may offer such different answers has to do with the *perceived effectiveness* of these interventions. <http://www.psmag.com/health/why-is-the-way-physicians-want-to-die-so-different-from-the-rest-of-us-61206/>

Cont.

Noted in Media Watch, 4 March 2013, #295 (p.11):

- CANADA | *The Medical Post* – 26 February 2013 – '**Doctors aren't like others at the end of life.**' Researchers found that when doctors were asked about their treatment preferences in the hypothetical event of an irreversible brain injury, 90% said they would decline CPR, more than 85% reported they would say no to ventilation and dialysis, and around 80% would opt out of surgery and a feeding tube. The only treatment most wanted: pain medication. <http://www.canadianhealthcarenetwork.ca/physicians/news/doctors-arent-like-others-at-the-end-of-life-26828>

Noted in Media Watch, 12 March 2012, #244 (p.3):

- *FORBES* | Online – 7 March 2012 – '**How to die like a doctor.**' When doctors choose how to treat their terminal illness, they take prognosis into account. If prognosis is not good, most opt for comfort care and conservative treatment. Ideally, a death well prepared for is a more comfortable death, and this is what doctors choose. So what can you do to die like a doctor? <http://www.forbes.com/sites/carolynmclanahan/2012/03/07/how-to-die-like-a-doctor/>

**N.B.** Several articles on doctor's personal preferences in the context of their own end-of-life care are noted in this issue of Media Watch.

### Accuracy of death certificates

#### **Making the right call, even in death**

*THE NEW YORK TIMES* | Online – 1 July 2013 – It is one of a doctor's most important final acts in caring for a patient, even though the patient is no longer around to appreciate it ... filling out the death certificate, a document that has myriad benefits for the living: establishing a legal basis for life insurance and estate settlements; providing critical information to survivors and descendants in an era of burgeoning advances in genetics; advancing knowledge about diseases, accidents and other causes of death; and much else. For all these reasons, the accuracy of the certificates should be a paramount concern for public health, both nationally and internationally. And that is why two recent studies of doctors in New York City teaching hospitals are so unsettling.<sup>1,2</sup> The studies ... support what researchers have long suspected: that heart disease is over reported as a cause of death, while diseases like pneumonia and cancer tend to be underreported. Equally disturbing, one of the studies suggests that the health system is far too cavalier about the accuracy of death certificates. [http://www.nytimes.com/2013/07/02/health/making-the-right-call-even-in-death.html?ref=health&\\_r=0](http://www.nytimes.com/2013/07/02/health/making-the-right-call-even-in-death.html?ref=health&_r=0)

1. 'Impact of a hospital-level intervention to reduce heart disease over reporting on leading causes of death,' *Preventing Chronic Disease*, 2013;10:120210. A hospital-level intervention to ... led to substantial changes to other leading causes of death, changing the leading cause of premature death. Heart disease over reporting is likely obscuring the true levels of cause-specific mortality. [http://www.cdc.gov/pcd/issues/2013/12\\_0210.htm](http://www.cdc.gov/pcd/issues/2013/12_0210.htm)
2. 'Survey of New York City resident physicians on cause-of-death reporting,' *Preventing Chronic Disease*, 2010,' 2013;10:120288. Most resident physicians believed the current cause-of-death reporting system is inaccurate, often knowingly documenting incorrect causes. [http://www.cdc.gov/pcd/issues/2013/12\\_0288.htm](http://www.cdc.gov/pcd/issues/2013/12_0288.htm)

Noted in Media Watch, 28 January 2013, #290 (p.8):

- *AMERICAN MEDICAL NEWS* | Online – 21 January 2013 – '**Death certificates present final medical complication.**' Signing a death certificate is not always a straightforward process. Physicians often face uncertainties about an individual's cause of death or how to answer the portions of certificates they are responsible for. Although the basic format has changed little in the last few decades, doctors face difficulties as some states attempt to convert from paper to eCertificates. <http://www.ama-assn.org/amednews/2013/01/21/prsa0121.htm>

## International

### End-of-life care in Taiwan

#### Government looks into "futile care"

TAIWAN | *The Taipei Times* – 8 July 2013 – With a rapidly aging population and a cash-strapped National Health Insurance [NHI] system, the government is paying more attention to the issue of "futile medical care," treatment applied only to prolong life without a foreseeable cure or positive outcome, and the prospect of hospice care. "Of the NT\$570 billion [US\$18.9 billion] healthcare expenditure paid by the NHI, about NT\$170 billion is spent on futile medical treatment," [National Taiwan University Hospital Jinshan Branch Superintendent] Huang [Sheng-Jean] said. <http://www.taipeitimes.com/News/taiwan/archives/2013/07/08/2003566617>

### The Liverpool Care Pathway

#### Inquiry into policy that "kills off" patients

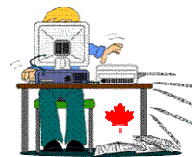
U.K. | *The Independent* – 7 July 2013 – The Liverpool Care Pathway [LCP] ... has never been properly tested. Concern over the fact that the LCP has never been subjected to a randomised clinical trial to test claims that it is the best way to treat the terminally ill has prompted the Health Secretary, Jeremy Hunt, to order a full inquiry... The LCP is used in hospitals across the U.K. despite complaints from hundreds of families that their relatives have died unnecessarily and before their time because of the policy which they say "kills off" patients. The revelation that it has been widely adopted throughout the U.K. as well [as] 21 other countries will fuel public disquiet at its use. The first thorough clinical study of the treatment, which typically involves heavy sedation and the withdrawal of life-sustaining treatment, including tubes providing fluids and nutrition, is currently being prepared in Belgium. <http://www.independent.co.uk/life-style/health-and-families/health-news/inquiry-into-policy-that-kills-off-patients-8692592.html>

Of related interest:

- U.K. | *The Daily Mail* – 5 July 2013 – '**Hospital care pathway won't be banned... but it could get a new name: Inquiry set to back end-of-life plan, despite public fears.**' The controversial Liverpool Care Pathway is to stay in use in hospitals – but its name may change. Complaints by hundreds of families to the Health Service Ombudsman have failed to persuade an official inquiry to ban the Pathway, which is meant to ease the last hours of the dying. <http://www.dailymail.co.uk/news/article-2357195/Hospital-care-pathway-wont-banned-new-Inquiry-set-end-life-plan-despite-public-fears.html?ito=feeds-newsxml>
- U.K. | *The Daily Telegraph* – 2 July 2013 – '**Investigation into Liverpool Care Pathway death.**' The death of an elderly woman on the controversial LCP is to be officially investigated after a man claimed doctors had attempted to "murder" his mother. Mrs. [Jean] Tulloch's case is thought to be the first individual death to be officially investigated in the U.K. <http://www.telegraph.co.uk/health/10153414/Investigation-into-Liverpool-Care-Pathway-death.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>



## Reforms to meet the needs of bereaved families

### **Major overhaul of coroner services in England and Wales**

U.K. (ENGLAND & WALES) | Ministry of Justice – 4 July 2013 – The needs of bereaved families will be put at the heart of a reformed coroner system by a new national code. The new legal framework will ensure all 96 coroners in England & Wales will work to the same standards, ending the past inconsistencies which led to criticisms of a postcode lottery – with bereaved people in some areas facing long waits for inquests. Coroner services ... will be locally delivered within national standards designed to lead to a more efficient system of investigations and inquests. <https://www.gov.uk/government/news/major-overhaul-of-coroner-services-in-england-and-wales>

Noted in Media Watch, 20 January 2011, #183 (pp.7,8):

- U.K. | BBC News – 3 January 2011 – **'Post-mortem rates in England & Wales 'should be cut.'** The number of post-mortem examinations in England & Wales could be cut by 60% if the system in Scotland was used.<sup>1</sup> Scotland's autopsy rate is 6% compared to 22% in England & Wales. <http://www.bbc.co.uk/news/uk-12109847>

1. *Journal of the Royal Society of Medicine*, 2011;104(1):19-24. **'How can we reduce the number of coroner autopsies? Lessons from Scotland and the Dundee initiative.'** In the authors' view external examinations are not only cost-effective but also a necessary element in any death investigative system which wishes to strike an appropriate balance between intrusion by the state and the rights of the bereaved. <http://jrsm.rsmjournals.com/cgi/content/abstract/104/1/19>

## Elder care in the U.K.

### **Woefully inadequate homecare presents a massive challenge**

U.K. | *The Guardian* – 3 July 2013 – The timing was accidental – but striking. On the day the government was hosting a summit to drive improvements in the way some of the most vulnerable members of society are cared for at home, the BBC released TV footage showing the human impact of failings in the system.<sup>1</sup> The scenes showing an 83-year-old woman becoming upset as her carer failed to turn up on time were a stark reminder that some of the care provided to people in their own homes is woefully inadequate. As care and support minister Norman Lamb put it: "The report ... was not an isolated experience – we know there are lots of examples, along with the very good care we also see. We have all got a responsibility to address the fact there are some very vulnerable people at risk in their own homes. Behind your own front door you are

particularly vulnerable because no one can see what's happening." Speaking at the high-level summit to launch the government's homecare innovation challenge, Lamb said that, amid the squeeze on budgets and increasing demographic pressures, there could be no doubt as to the scale of the task to improve a system which currently could "incentivise poor care, low wages and neglect." <http://www.guardian.co.uk/social-care-network/2013/jul/03/inadequate-homecare-massive-challenge>

#### **Specialist Publications**

**'Care of the dying patient in the community'**  
(p.8), in *British Medical Journal*.

1. 'CCTV footage reveals domestic care neglect,' BBC, 13 June 2013. The BBC has obtained footage showing multiple failings in the home care provided by a company to one woman – as ministers warn the next abuse scandal may come in the sector. <http://www.bbc.co.uk/news/uk-22885514>

## Self-reporting approach to quality of care

### **Durham hospice releases report into quality of care**

U.K. (ENGLAND) | *The Northern Echo* (Darlington) – 2 July 2013 – St. Cuthbert's Hospice ... has released the findings of its Quality Account, spelling out what the hospice achieved during the year 2012-2013. Chief Executive Paul Marriott, said: "Organisations are used to publishing financial accounts that set out how money is spent. However, all organisations funded by the NHS [National Health Service] are now required to publish an account of their approach to quality." The report shows that during the year, 225 patients used the hospice's in-patient facilities, around 75% of them after a cancer diagnosis. The number of patients in the day hospice increased from 109 in the previous year to 118, while the number of face-to-face counselling sessions with a qualified member staff rose from 118 to 956 over the same period. The report also identifies eight aspirations for improvement over the coming years, ranging from improving the nutritional value of the food provided by the hospice to improvements to the buildings and surroundings. [http://www.thenorthernecho.co.uk/news/local/northdurham/durham/10520951.Durham\\_hospice\\_produces\\_report\\_into\\_quality\\_of\\_care/](http://www.thenorthernecho.co.uk/news/local/northdurham/durham/10520951.Durham_hospice_produces_report_into_quality_of_care/)

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

Representative sample of recent news media coverage:

- FRANCE | TVNZ News (New Zealand) – 2 July 2013 – **'France aims to allow euthanasia despite ethics doubt.'** French President François Hollande has reaffirmed his aim to legalise voluntary euthanasia after a majority of the country's national ethics committee advised him not to let doctors help the terminally ill take their lives. Hollande said France would hold a national debate on the issue ... and his government would submit a bill in parliament by year's end that would go beyond the current law that bars doctors from providing assisted suicide. <http://tvnz.co.nz/world-news/france-aims-allow-euthanasia-despite-ethics-doubts-5484055>

#### **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 and research tool.

#### **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.

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

### **Effectiveness of the ACA (Availability, Current issues & Anticipation) training programme on GP-patient communication in palliative care: A controlled trial**

*BMC FAMILY PRACTICE* | Online – 2 July 2013 – The authors hypothesized that GPs exposed to a new training programme in GP-patient communication in palliative care focusing on availability of the GP for the patient, current issues the GP should discuss with the patient, and anticipation by the GP of various scenarios, would discuss more issues and become more skilled in their communication with palliative care patients. Sixty-two GPs were assigned to the intervention and 64 to the control group. The authors found no effect of the ACA training programme on how the GPs communicated with the patient or on the number of issues discussed by GPs with the patient. <http://www.biomedcentral.com/content/pdf/1471-2296-14-93.pdf>

### **Care of the dying patient in the community**

*BRITISH MEDICAL JOURNAL* | Online – 3 July 2013 – The consensus from international studies of patient preferences is that, given adequate support, most people would prefer to die at home. However, more than half of all deaths in the U.K. occur in hospital, with only 18% of people dying in their own home. Suggested reasons for this include a lack of anticipatory care planning, poor coordination between healthcare agencies, and insufficient community resources. National and local policies now focus on facilitating home deaths, and recently there has been a small increase in the proportion and absolute number of people dying at home. The demographics of deaths across Europe are changing with the ageing population, with deaths from dementia, cancer, and chronic diseases becoming more common. Caring for such patients in hospital will probably become unsustainable in terms of capacity, cost, and patient satisfaction. The focus of end of life care is therefore shifting to the community ... where the role of the general practitioner, with support from the

community palliative care team, is key. The onus is on all health and social care professionals to work collaboratively across settings to enable patients to receive quality end-of-life care in the place of their choice. <http://www.bmj.com/content/347/bmj.f4085>

#### **A lines-of-defense model for managing health threats: A review**

*GERONTOLOGY* | Online – 29 June 2013 – As older individuals face challenges of progressive disease and increasing disability and approach the end of their lives, their capacity for controlling their environment and own health and functioning declines. The Lines-of-Defense Model is based on the Motivational Theory of Life-Span Development and proposes that individuals can adjust their control striving to the progressive physical decline in distinctly organized cycles of goal engagement and goal disengagement that reflect sequentially organized lines of defense. <http://www.karger.com/Article/FullText/351269>

### **Quebec's end-of-life bill makes palliative care more transparent**

*CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online – 2 July 2013 – Quebec's proposed legislation to allow "medical aid in dying" to incurably ill and suffering patients also contains measures that would force more oversight of the province's palliative-care regime, say medical experts. While a plan to allow doctors to administer life-ending medication is by far the most ... controversial element of ... An Act Respecting End of Life Care, it also proposes a new provincial commission to oversee "all matters relating to end-of-life care." The commission would impose new requirements on hospitals and other facilities to report formally on their practices of treating patients at the end of their lives. [http://www.cmaj.ca/site/earlyreleases/4july13\\_Quebec\\_end-of-life\\_bill\\_makes\\_palliative\\_care\\_more\\_transparent.xhtml](http://www.cmaj.ca/site/earlyreleases/4july13_Quebec_end-of-life_bill_makes_palliative_care_more_transparent.xhtml)



**The End of Life Care Quality Assessment (ELCQuA) tool:  
A free online resource for health and social care professionals**

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(4):175-177. Easy to use and flexible, the ELCQuA tool provides the user with a selection of materials to support the self-assessment. At each point of the process, there are opportunities to click for help. There are help functions and links. The resources page directs the user to other documents and websites available nationally, making ELCQuA a comprehensive resource relating to end-of-life care for adults. A major feature of the ELCQuA tool is the reporting function, which enables users to produce a range of reports for local use. Those reports provide an aid for the organisation when exploring developments and actions required from staff and commissioners. They can be updated as the user inputs new data. The ELCQuA tool has been piloted extensively to ensure it is easy to use. It has been updated in collaboration with end-of-life care leads and social care champions to ensure it meets local needs and is "fit for purpose." The website has been made easier to navigate and a new facility to download reports has been added. The intention for the future is to keep updating and improving it in response to user feedback.

Of related interest:

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(4):196-198. **'Quality assessment in palliative care – an overview.'** In palliative care, assessing the impact of care is much more complex than in other areas of healthcare, because the main outcome is the improvement of quality of life. Palliative care encompasses several aspects, all of which need to be included in the attempt to improve the quality of care. Quality indicators allow us to identify areas where improvement is needed within three domains: structures, processes and outcomes. Quality improvement requires a strategic plan implemented with the active participation of all those involved in care provision.

**N.B.** Access to the *European Journal of Palliative Care* is by subscription only. Contents page: [http://www.haywardpublishing.co.uk/year\\_search\\_review.aspx?pageid=58&JID=4&Year=2013&Edition=480](http://www.haywardpublishing.co.uk/year_search_review.aspx?pageid=58&JID=4&Year=2013&Edition=480)

Noted in Media Watch, 1 July 2013, #312 (p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 28 June 2013 – **'Quality indicators for palliative care: Update of a systematic review.'** Recent developments in measuring quality of palliative care using quality indicators are mainly quantitative in nature, with a substantial number of new indicators being found. However, the quality of the development process varies considerably between sets. More consistent and detailed methodological descriptions are needed for the further development of these indicators and improved quality measurement of palliative care. [http://www.jpmsjournal.com/article/S0885-3924\(13\)00143-7/abstract](http://www.jpmsjournal.com/article/S0885-3924(13)00143-7/abstract)

**Palliative care consultation is associated with changes in patients' goals of care**

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(4):178-181. A study conducted at Oregon Health & Science University Hospital in the USA showed that patients and families frequently changed their goals of care following palliative care consultation, often from cure or prolongation of life to palliation or comfort. When the referring team had requested that the palliative care consultation should focus on clarifying goals of care, there was an eightfold increase in the association between consultation and change in goals of care. One explanation is that a request for palliative care consultation from a medical or surgical team represents a signal that patients and/or families are ready to change their goals of care. Another explanation is that consultation with the palliative care team is efficient in making patients and families change their goals of care because it helps to clarify prognosis.

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### **When end-of-life care is the emergency: A case-based portrayal of end-of-life care in the emergency department**

*PALLIATIVE CARE & MEDICINE* | Online – Accessed 2 July 2013 – When one thinks of the emergency department (ED), one usually thinks of teams of providers hustling to save lives. And while that is often what is done in the ED, sometimes the situation calls for a different approach. ED providers may provide a new set of objective eyes and ears for a chronically ill patient with or without a change in their condition or the team may be presented with a patient suffering an acute catastrophic condition for which curative therapy is not possible or indicated. This article reviews why ED's are a necessary and important place for end-of-life (EOL) discussions and management and highlight real-life cases in which the ED team played an integral role in identifying appropriate patients for EOL care and providing these services. <http://www.omicsgroup.org/journals/2165-7386/2165-7386-3-146.pdf>

**N.B.** Noted in Media Watch, 16 July 2012, #262 (p.6), are several articles from past issues of the weekly report on the provision and delivery of palliative care in the emergency department.

### **White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care**

*PALLIATIVE MEDICINE* | Online – 4 July 2013 – The authors provide the first definition of palliative care in dementia based on evidence and consensus, a framework to provide guidance for clinical practice, policy and research. A total of 64 (72%) experts from 23 countries evaluated a set of 11 domains and 57 recommendations. There was immediate and full consensus on the following eight domains, including the recommendations: person-centred care, communication and shared decision-making; optimal treatment of symptoms and providing comfort (these two identified as central to care and research); setting care goals and advance planning; continuity of care; psychosocial and spiritual support; family care and involvement; education of the health care team; and societal and ethical issues. After revision, full consensus was additionally reached for prognostication and timely recognition of dying. Recommendations on nutrition and dehydration (avoiding overly aggressive, burdensome or futile treatment) and on dementia stages in relation to care goals (applicability of palliative care) achieved moderate consensus. <http://pmj.sagepub.com/content/early/2013/07/03/0269216313493685.abstract>

**N.B.** Noted in Media Watch, 14 January 2013, #288 (pp.8-9), are several articles from past issues of the weekly report on end-of-life care for people living with dementia.

### **Barriers to the provision of optimal palliative care in a patient awaiting lung transplantation**

*PULMONARY & RESPIRATORY MEDICINE* | Online – 24 June 2013 – This case report describes palliative and end of life care in a patient with end stage pulmonary fibrosis listed for lung transplantation and discusses the transition from curative restorative care and palliative care to end-of-life care. The goals of care of patients waiting for lung transplantation should be reviewed regularly and clarified as the clinical condition of the patient changes. End of life care should not only be considered in terminally ill patients or patients who do not fulfil the criteria for lung transplantation, but should also be raised with patients on the lung transplant waiting list. <http://www.omicsonline.org/2161-105X/2161-105X-3-151.pdf>



<http://www.worldday.org/>

12 October 2013

## Referral to palliative care in COPD and other chronic diseases: A population-based study

*RESPIRATORY MEDICINE* | Online – 27 June 2013 – Patients with COPD are underserved in terms of palliative care compared to those with other chronic life-limiting diseases. Awareness of palliative care as an option for patients with COPD needs to increase in palliative care services, physicians and the general public. Patients with COPD [i.e., study participants] (20%) were less likely than those with heart failure (34%), severe dementia (37%) or cancer (60%) to be referred to palliative care services. <http://www.sciencedirect.com/science/article/pii/S0954611113002151>

Noted in Media Watch, 27 May 2013, #307 (p.8):

- *THE LANCET RESPIRATORY MEDICINE* | Online – 17 May 2013 – '**Palliative care for lung disease: Start early, stay late.**' At the end of life when all reasonable curative interventions have failed, many patients with end-stage lung disease still die in pain after much suffering. [http://www.thelancet.com/journals/lanres/article/PIIS2213-2600\(13\)70083-3/fulltext#article\\_upsell](http://www.thelancet.com/journals/lanres/article/PIIS2213-2600(13)70083-3/fulltext#article_upsell)

Noted in Media Watch, 10 December 2012, #283 (pp.9-10):

- *EUROPEAN RESPIRATORY REVIEW*, 2012;21(126):347-354. '**Palliative care in COPD patients: Is it only an end-of-life issue?**' The presence of acute or chronic respiratory failure is often seen as a terminal phase of chronic obstructive pulmonary disease. A great variability in end-of-life practice is observed in these patients mainly because physicians are not always able to correctly predict survival. <http://err.ersjournals.com/content/21/126/347.abstract>

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(4):168-171. '**Assisted dying – the current debate in The Netherlands.**' After 40 years of discussion and the introduction of physician-assisted suicide through the 2001 Act, assisted dying is still a matter of public debate in The Netherlands. The provision of palliative care is a professional duty of doctors, and a lot has been and continues to be invested in this type of care. In the public debate, however, initiatives that seek to give more autonomy to patients or citizens have generated much attention – but until now they have not brought about a change in the law.

**N.B.** Access to the *European Journal of Palliative Care* is by subscription only. Contents page: [http://www.haywardpublishing.co.uk/year\\_search\\_review.aspx?pageid=58&JID=4&Year=2013&Edition=480](http://www.haywardpublishing.co.uk/year_search_review.aspx?pageid=58&JID=4&Year=2013&Edition=480)

- *INTERNATIONAL JOURNAL OF CULTURE, TOURISM & HOSPITALITY RESEARCH*, 2013;7(3). '**When death is the destination: The business of death tourism – despite legal and social implications.**' This paper views the growing popularity of death tourism which directs the confrontation with grief and mortality with the expressed purpose of orchestrating travel which culminates in assistance to end one's life. The author describes the emerging phenomena of death tourism and situates it as a sub-niche of dark tourism; briefly presenting the social and legal aspects of assisted suicide in conjunction within the tourism industry, and concluding with how the trend of death tourism is potentially spreading to beyond Europe. <http://www.emeraldinsight.com/journals.htm?articleid=17091774&show=abstract>
- *INTERNATIONAL JOURNAL OF LAW & PSYCHIATRY* | Online – 29 June 2013 – '**Rational suicide, assisted suicide, and indirect legal paternalism.**' [The authors argue] that assisted suicide and voluntary active euthanasia can indeed be justified by establishing a claim of persons who want to die but are not able to kill themselves. This mainly means that being really free to die should be interpreted as involving the means to fulfil one's desire to die. <http://www.sciencedirect.com/science/article/pii/S0160252713000629>

Cont.

- *SPRINGERPLUS* | Online – 6 June 2013 – '**Euthanasia tactics: Patterns of injustice and outrage.**' Struggles over euthanasia can be examined in terms of tactics used by players on each side of the issue to reduce outrage from actions potentially perceived as unjust. From one perspective, the key injustice is euthanasia itself, especially when the person or relatives oppose death. From a different perspective, the key injustice is denial of euthanasia, seen as a person's right to die. <http://www.springerplus.com/content/2/1/256/abstract>

### Media Watch Online

#### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://APHN.ORG/?S=MEDIA+WATCH>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'Palliative Care Network: Media Watch')

#### **Australia**

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> (Scroll down to 'International Websites' to 'Palliative Care Network' to access the weekly report)

#### **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.hpcconnection.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>

ONTARIO | Toronto Central Hospice Palliative Care Network: <http://www.tcpcn.ca/uncategorized/media-watch-309-june-10-2013>

#### **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/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

#### **International**

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

PALLIATIVE CARE NETWORK COMMUNITY: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

PALLIMED (Hospice & Palliative Medicine Blog): <http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html> (Scroll down to 'Aggregators' and Barry Ashpole and Media Watch)

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