# Media Watch...

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

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

Compiled & Annotated by Barry R. Ashpole

The most cited and revered article in the medical literature: Scrolled down to <u>Worth Repeating</u> and **'The care of the patient'** (p.11), published in 1927 in the *Journal of the American Medical Association*.

# <u>Canada</u>

# Doctors can't make life-support decisions on their own: Court

ONTARIO | *Globe & Mail* – 29 June 2011 – Ontario's top court has ruled doctors must get approval from a provincial medical board when their decision to withdraw life-support treatment goes against the wishes of a patient's family. The decision means physicians cannot decide on their own to disconnect the breathing machine they say keeps Hassan Rasouli alive in a vegetative state at Toronto's Sunnybrook Hospital. Mr. Rasouli's doctors had sought to stop his treatment, a move opposed by his wife and substitute decision maker Parichehr Salasel. The Ontario Court of Appeal agreed with Ms. Salasel, upholding a lower court ruling that Mr. Rasouli's physicians need the approval of Ontario's Consent & Capacity Board before they can take the patient off a ventilator. But the appeal court was careful to say its decision only applies in cases where there is a risk of immediate death. That means doctors will not need capacity board approval to discontinue treatment they deem ineffective in situations not life-threatening.<u>http://www.theglobeandmail.com/news/national/doctors-cant-make-life-support-decisions-on-their-own-court/article2080320/</u>

From Media Watch dated 6 June 2011:

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article – 2 June 2011 – 'Legal ambiguities surround authority to make end-of-life decisions.' Should physicians have to seek consent from patients, substitute decision-makers or an independent tribunal in order to pull the plug on life-sustaining treatments they deem futile? An informal survey of Canadian case law indicates that courts have been all over the map on the issue, which has recently resurfaced in the headlines. <a href="http://www.cmaj.ca/content/early/2011/06/06/cmaj.109-3910.full.pdf+html?sid=0ead2a3c-d25b-41fc-ad7b-59269d552615">http://www.cmaj.ca/content/early/2011/06/06/cmaj.109-3910.full.pdf+html?sid=0ead2a3c-d25b-41fc-ad7b-59269d552615</a>

**N.B.** Footnoted in this issue of Media Watch are several articles, reports, etc., on similar legal challenges in Canada noted in past issues of the weekly report.

# Assisted (or facilitated) death

Representative sample of recent news media coverage:

BRITISH COLUMBIA | The Province (Vancouver) – 29 June 2011 – 'Grandma wants to die with dignity.' A lawsuit challenging B.C.'s assisted-suicide laws is expected to be fast-tracked and heard as early as November, now that a woman suffering from Lou Gehrig's disease has joined as a plaintiff. The B.C. Civil Liberties Association in April filed suit to try to force B.C. to allow doctors to legally help terminally ill people commit suicide. The suit was filed on behalf of the surviving relatives of Kay Carter, 90, who ... in January travelled to Switzerland, where assisted suicide is legal, to die. <a href="http://www.theprovince.com/news/Grandma+wants+with+dignity/5021752/story.html">http://www.theprovince.com/news/Grandma+wants+with+dignity/5021752/story.html</a>

# <u>U.S.A.</u>

# Less concern over death panels

WASHINGTON POST | Online report – 1 July 2011 – Some 31% of Americans continue to mistakenly believe the health care reform law passed last year allows for government panels to make decisions about end-of-life care for those on Medicare, but that's down 10 points from a year ago. Some 22% of seniors now believe in the so-called death panels, down 14 points from last July. Despite the shift, there is no increase among seniors in the percentage who say the panels don't exist. Rather, more seniors say they "don't know" whether the law includes such a provision. <u>http://www.washingtonpost.com/blogs/behind-the-numbers/post/poll-watchers-less-concern-over-death-panels-millennials-need-history-lesson-and-sketchy-poll-numbers/2011/07/01/AGMEpytH\_blog.html</u>

# Washington's Living Will Registry ends after nearly four years

WASHINGTON STATE DEPARTMENT OF HEALTH | Press release – 29 June 2011 – The 2011-2013 state budget doesn't include funding for the Washington State Living Will Registry. Since the registry was launched, 2,462 Washington residents submitted health care directives and 186 health care facilities signed up to have access to these directives. People who registered with the state's registry by the 20 June 2011 cut-off date will maintain a free lifetime registration with U.S. Living Will Registry, a private corporation. <u>http://www.doh.wa.gov/Publicat/2011\_news/11-098.htm</u>

# Concerns about costs rise with hospices' use

*NEW YORK TIMES* | Online article – 27 June 2011 – Medicare's bill for hospice care rose to more than \$12 billion in 2009 from \$2.9 billion in 2000. Although the benefit is intended for patients who have no more than six months to live, 19% now receive hospice services for longer, according to the Medicare Payment Advisory Commission, or MedPAC, an independent Congressional oversight panel. In 2009, 10% of patients remained in hospice beyond seven months. Once a patient is enrolled in hospice, Medicare pays a flat fee ranging from \$147 to \$856 a day, depending on the level of care, regardless of whether a hospice actually provides services. A primary concern of MedPAC is that this payment method encourages hospices to seek out patients likely to live longer. Commercial hospices in particular tend to have longer-staying patients. "The financial incentives do in fact dictate behavior," said Eugene Goldenberg, a research analyst. "It's a lucrative business, at least under the current reimbursement system." In response, Medicare has adopted a restriction: It won't pay for hospice beyond six months unless a physician or nurse practitioner visits the patient and attests that his or her condition is still terminal. But this requirement, part of the health care law passed last year, has provoked a backlash. <a href="http://www.nytimes.com/2011/06/28/health/28hospice.html?r=1&ref=hospicecare">http://www.nytimes.com/2011/06/28/health/28hospice.html?r=1&ref=hospicecare</a>

From Media Watch dated 20 June 2011:

 NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION (NHPCO) | Press release – 13 June 2011 – 'Position statement on ethical marketing practices released by National Hospice & Palliative Care Organization.' Hospice & Palliative Care: Ethical Marketing Practices ... reinforces the need for hospice and palliative care providers to utilize ethical marketing practices, which in turn, will ensure trust and support among those being served. <u>http://www.prnewswire.com/newsreleases/position-statement-on-ethical-marketing-practices-released-by-national-hospice-andpalliative-care-organization-123741174.html
</u>

**N.B.** Footnoted in this issue of Media Watch are several articles, reports, etc., on the growth of hospice in the U.S. noted in past issues of the weekly report.

From Media Watch dated 15 November 2010:

 PBS TV | FRONTLINE – 10 November 2010 – 'Facing death: How far would you go to sustain the life of someone you love, or your own?' In 'Facing death,' FRONTLINE ... takes a measure of today's complicated end-of-life decisions. <u>http://www.pbs.org/wgbh/pages/frontline/facing-death/</u>

From Media Watch dated 23 November 2009:

 CBS TV | 60 Minutes – 22 November 2009 – 'The cost of dying.' Last year, Medicare paid \$50 billion just for doctor and hospital bills during the last two months of patients' lives – that's more than the budget of the Department of Homeland Security or the Department of Education. It has been estimated that 20-30% of these medical expenditures may have had no meaningful impact. http://www.cbsnews.com/video/watch/?id=5737138n

# 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**

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#### 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.

# **International**

#### Palliative Care Funding Review report

#### 100,000 terminally ill 'do not get proper palliative care'

U.K. | The Telegraph - 1 July 2011 - Almost 100,000 terminally ill people do not get proper care, according to a Government review which concluded that a new funding system would save millions of pounds and better serve individuals.<sup>1</sup> A national payment structure would cut variation around the country in what the state pays for and what it does not, and support far more people to be cared for in their own homes, it said. Experts behind the report say the move could reduce deaths in hospital by up to 60,000 a year by 2021, translating into savings of £180 million annually. The amount primary care trusts in England spend on end-of-life care varies widely, from £186 per patient in one area to £6,213 in another. Access to services, including round-the-clock nursing care, also depends on where people live. Far more people die in hospital than wish to, and experts estimate that more than 90,000 people are not having their palliative care needs met. http://www.telegraph.co.uk/health/healthnews/8610266/10000 0-terminally-ill-do-not-get-proper-palliative-care.html

1. Palliative Care Funding Review: Funding the Right Care & Support for Everyone. <u>http://palliativecarefunding.org.uk/wp-</u> content/uploads/2011/06/PCFRFinal%20Report.pdf

Of related interest:

- U.K. | Institute for Public Policy Research online report 1 July 2011 – 'Home care in London.' Home-based care has the potential to reduce the pressure on more costly public services such as hospital beds and care-home places. http://www.ippr.org/publications/55/7688/home-care-inlondon
- U.K. (ISLE OF MAN) | Three FM News 28 June 2011 'Public's views sought for end of life care strategy.' Minister for Health David Anderson said the results of the consultation will provide valuable data and real insight into the taboo topic of death. <u>http://www.three.fm/news/isle-ofman-news/publics-views-sought-for-end-of-life-care-</u> strategy-3755/
- U.K. (SCOTLAND) | *The Daily Record* 25 June 2011 'Should National Health Service spend millions keeping alive terminally ill patients for few weeks?' Dr. Brian Keighley, British Medical Association Scotland questions whether the cash-strapped National Health Service should continue to spend a fortune keeping terminally ill patients alive. <u>http://www.dailyrecord.co.uk/news/scottishnews/2011/06/27/leading-doctor-should-nhs-spend-millionskeeping-alive-terminally-ill-patients-for-few-weeks-86908-23230013/
  </u>

# Money, morality and the care of the elderly

U.K. | The Guardian – 3 July 2011 – Economist Andrew Dilnot's independent review into how we pay for the care of older people and the disabled is published tomorrow [i.e., 4 July 2011]. It will be read against a backdrop that almost daily seems to illustrate our incapacity to care for many of our old and vulnerable. On Friday, an inquiry into the treatment of the terminally ill said that many, at the end of their lives, "do not get proper palliative care". The numbers of people forced to sell their homes to pay for residential care, only to find themselves out of funds and facing the stress of not knowing what will happen next. regularly sends the message that growing older in dignity and peace is a luxury that many cannot afford. http://www.guardian.co.u k/commentisfree/2011/jul /03/observer-editorialdilnot-review

#### Expressions of grief

#### Death finds a new domain online

AUSTRALIA N BROADCASTING CORPORATION | Online report – 29 June 2011 – Dr. Margaret Gibson of the Centre for Cultural Research at Griffith University, and Professor Peter Stephenson of Canada's University of Victoria, say there is an increasing trend toward using the internet as a space to memorialise and mourn the dead and to maintain a "living" version of the bereaved. "We are constantly recording and documenting our lives on these digital archives," says Gibson. "This is a repository that can become meaningful and valuable when we die and a posthumous legacy for others to explore." http://www.abc.net.au/science/articles/2011/06/29/3256522.htm

Of related interest:

THE JAPAN TIMES | Online article – 3 July 2011 – 'Grief not the same as mourning.' Mourning is not the same as grief, but the confusion of one with the other is one of the common confusions of life – like confusing school with education, or law with justice, or democracy with freedom, or religion with faith, information with knowledge, etc. Grief is chaotic and socially dangerous, while mourning applies a structure to the emotional purge that helps channel and contain it for the preservation of society. <a href="http://search.japantimes.co.jp/cgi-bin/rc20110703a3.html">http://search.japantimes.co.jp/cgi-bin/rc20110703a3.html</a>

#### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (VICTORIA) | The Age 2 July 2011 'Baillieu says euthanasia should be dealt with at a 'national level." PremierTed Baillieu has rejected a dying man's plea for voluntary euthanasia to be put back on the agenda in Victoria, saying it should be dealt with at a national level. <u>http://www.theage.com.au/victoria/baillieu-says-euthanasia-should-be-dealt-with-at-anational-level-20110701-1gv7z.html</u>
- BULGARIA | Sofia News Agency 29 June 2011 'Bulgarian Ombudsman suggest holding a referendum on euthanasia.' Ombudsman Konstantin Penchev has sent a letter to the Chairman of the Parliamentary Healthcare Commission asking him to state his opinion on the Euthanasia Act tabled by socialist MP Lyuben Kornezov Penchev. In Penchev's words the issue concerns the first of the basic human rights, the right to life, but it is not a legal or political matter and is not part of Bulgaria's commitments as an EU [European Union] member state and as a party to international treaties. <a href="http://www.novinite.com/view\_news.php?id=129762">http://www.novinite.com/view\_news.php?id=129762</a>
- THE NETHERLANDS | Daily Mail (U.K.) 29 June 2011 'Legally killed: 21 dementia victims given lethal injections by Dutch doctors in 2010.' A total of 21 patients with early-stage dementia, including Alzheimer's, died by lethal injection last year, according to a forthcoming annual report. This is the first time dementia sufferers have been included in the country's euthanasia statistics. <u>http://www.dailymail.co.uk/news/article-2009264/Legally-killed-21-dementia-victims-given-lethal-injections-Dutch-doctors-2010.html?ito=feeds-newsxml</u>
- SWITZERLAND | The Local (Stockholm, Sweden) 29 June 2011 'Stricter rules for euthanasia rejected.' The Swiss government ... rejected proposals to tighten rules on assisted suicide, saying that they could inadvertently legitimise organisations offering assisted suicide. Amid an emotional uproar sparked by several international media reports and documentaries on foreigners who had come to Switzerland to die as well as on the practice of assisted suicide in the country, Bern in 2008 decided to reassess legislation on the issue. <a href="http://www.thelocal.ch/422/20110629/">http://www.thelocal.ch/422/20110629/</a>
- CZECH REPUBLIC | České Noviny (Prague) 28 June 2011 'Most Czechs support abortion, euthanasia, death penalty – poll.' About two-thirds of Czechs support the possibility of euthanasia and abortion and the introduction of capital punishment, according to a CVVM institute's poll. <u>http://www.ceskenoviny.cz/news/zpravy/most-czechs-support-abortion-euthanasia-deathpenalty-poll/657180</u>

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

# Palliative care: What approaches are suitable in developing countries?

*BRITISH JOURNAL OF HAEMATOLOGY* | Online article – 28 June 2011 – Despite the demonstrated need, current provision of palliative care in Africa is at best limited, and at worst non-existent. Access to essential pain medicines, particularly oral morphine, for control of pain is extremely limited and far below the global mean. There is a general lack of government policies that recognize palliative care as an essential component of health care and there is inadequate training for both health care professionals and the general public about palliative care. A public health strategy offers the best approach for translating knowledge and skills into evidence-based, cost-effective interventions that can reach everyone in need of palliative care in developing countries. <a href="http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2141.2011.08764.x/abstract">http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2141.2011.08764.x/abstract</a>

From Media Watch dated 14 February 2011:

JOURNAL OF PALLIATIVE MEDICINE, 2011;14(2):129-131. 'What Africa has to teach the U.S. about hospice and palliative care.' Hospice in Africa does not seem to have the elitism and separatism that characterized many of our programs in the early hospice movement in the U.S. <a href="http://www.liebertonline.com/doi/pdfplus/10.1089/jpm.2010.9732">http://www.liebertonline.com/doi/pdfplus/10.1089/jpm.2010.9732</a>

# Can rationing possibly be rational?

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article - 27 June 2011 -Health expenditures consume more than 50% of revenues in six of Canada's 10 provinces, not including federal transfers, and are on pace to consume some 75% of revenues in five provinces by the year 2019, according to the Fraser Institute. Canada's aging population and the ongoing development of expensive therapies for lifethreatening illnesses are further escalating pressures on the health care system, particularly intensive care units. "We have to start making some difficult rationalizations about who we're going to treat," argued a cardiac surgeon at a ... [recent] ... town hall meeting on health care transformation

From Media Watch dated 3 May 2010:

hosted by the Canadian Medical Association.<u>http://www.cmaj.ca/earlyrelease</u> s/27june11\_can-rationing-possibly-berational.dtl

#### Seniors overmedicalized, experts say

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article – 27 June 2011 – Seniors in Canada are overdrugged and overtested, to the detriment of both their health and the health care system, as billions of dollars are being spent that could more productively be spent elsewhere. http://canadianmedicaljournal.ca/content/early/20 11/06/27/cmaj.109-3886.full.pdf

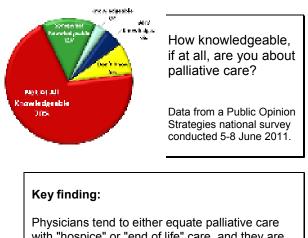
U.S. | Public Broadcasting Service (Newshour) – 26 April 2010 – 'Debating the ethics of rationing end-of-life care.' Arguing for rationing: Ira Byock, a doctor and director of palliative medicine at Dartmouth-Hitchcock Medical Center in Lebanon, New Hampshire, and Arthur Caplan, director of the Center for Bioethics and a professor at the University of Pennsylvania. Arguing against rationing: Ken Connor, chair of the Center for a Just Society, and a lawyer in private practice, and Marie Hilliard, director of bioethics and public policy at the National Catholic Bioethics Center. http://www.pbs.org/newshour/bb/health/jan-june10/miller\_04-26.html

# 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. <u>http://www.pcn-e.com/community/pg/file/world/world/</u>

# 2011 Public Opinion Research on Palliative Care: A Report Based on Research by Public Opinion Strategies

**[U.S.] CENTER TO ADVANCE PALLIATIVE** CARE | Online report – Accessed 1 July 2011 – Although consumers may be content with the quality of health care they receive, they have concerns about the level of care patients with serious illness receive. The biggest concerns relate to information sharing between doctor and patient and other doctors, patient control and choice over treatment options, patient understanding about their illness and treatment, and the quality of time doctors spend with patients. This research confirms palliative care is a relative unknown among consumers. There is a clear need to inform consumers about palliative care and provide consumers with a definition of palliative care. http://www.capc.org/tools-for-palliative-careprograms/marketing/public-opinionresearch/2011-public-opinion-research-onpalliative-care.pdf



with "hospice" or "end of life" care, and they are very resistant to believing otherwise. Although these physicians say they have referred patients to palliative care services, they admit they only do so when it is end of life care.

Of related interest:

 AGENCY FOR HEALTHCARE RESEARCH & QUALITY (AHRQ) | Online posting – 27 June 2011 – 'Closing the quality gap: End-of-life and hospice care.' The AHRQ [an agency of the U.S. Department of Health & Human Services] has requested a systematic review on end-of-life and hospice care as part of the 2011 'Closing the Quality Gap: Revisiting the State of the Science (CQG)' series. <u>http://www.effectivehealthcare.ahrq.gov/index.cfm/search-for-guides-reviews-andreports/?productid=717&pageaction=displayproduct</u>

# End-of-life care in an acute care hospital: Linking policy and practice

DEATH STUDIES, 2011;35(6):481-503. Federal and state government policymakers in Australia are promoting shared decision making in acute care hospitals as a means to improve the quality of end-of-life care. If policy is to be effective, health care professionals who provide hospital care will need to respond to its patient-centered purpose. Health services will also be called upon to train health care professionals to work with dying people in a more participatory way and to assist them to develop the clinical processes that support shared decision making. Health professionals who manage clinical workplaces become central in reshaping this practice environment by promoting patient-centered care policy objectives and restructuring health service systems to routinely incorporate patient and family preferences about care at key points in the patient's care episode. http://www.tandfonline.com/doi/abs/10.1080/07481187.2011.553336

Of related interest:

 CANADIAN JOURNAL OF NURSING RESEARCH, 2011;43(2):18-37. 'Advance care planning: Re-visioning our ethical approach.' This ... study explored the applicability and usefulness of a promising advance care planning (ACP) intervention and examined the ACP process. The process was found not to be one of preparing a substitute decision-maker to speak for oneself and direct health care at a time when one is incapacitated; rather, the families engaged in a deeply relational process where meaning, values, and preferences were negotiated in conversation. http://www.ingentaconnect.com/content/mcgill/cjnr/2011/0000043/0000002/art00004

Cont.

- GP (U.K.) | Online report 29 June 2011 'GPs must co-ordinate end-of-life plans.' GPs should be placed at the centre of plans to co-ordinate end-of-life care, an analysis of eight pilot schemes has found. The report said that the input of clinical data should only be carried out by a GP or other clinical lead for the patient. <u>http://www.gponline.com/News/article/1077494/gps-co-ordinate-end-oflife-plans/</u>
- JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2011;13(4):249-256. 'Quality care at the end of life: The lived experience of surrogate decision makers.' The purpose of this study was to identify the factors that are important to families who must decide to either prolong or end treatment for patients who are seriously ill. Five themes were identified ... knowing end-of-life wishes; communication with healthcare providers; acceptance/acknowledging futility; strengthening relationships with loved ones; and, pain and symptom management. Knowing end-of-life wishes, communication with healthcare providers, acceptance/acknowledging futility, and strengthening relationships with loved ones influenced decisions made by surrogates. Pain and symptom management was expected regardless of the decision made by surrogates. Surrogates were more likely to terminate aggressive treatment for patients in pain with little chance of recovery. <a href="http://journals.lww.com/jhpn/Abstract/2011/07000/Quality\_Care\_at\_the\_End\_of\_Life\_The\_Lived.12.aspx">http://journals.lww.com/jhpn/Abstract/2011/07000/Quality\_Care\_at\_the\_End\_of\_Life\_The\_Lived.12.aspx</a>

# HIV: Long-term management and palliative care

*INNOVAIT* | Online article – 23 June 2011 – The advent of antiretroviral therapy has radically changed the prognosis of human immunodeficiency virus (HIV) infection. HIV is now a treatable medical condition and is increasingly managed as a chronic disease. The majority of those living with the virus remain fit and well on treatment. However, those living with HIV are at risk of adverse effects due to antiretroviral treatment and increased risk of cardiovascular disease. http://rcgp-innovait.oxfordjournals.org/content/early/2011/06/23/innovait.inr061.abstract

# Palliative care, double effect and the law in Australia

INTERNAL MEDICINE JOURNAL, 2011;41(6):485-492. Care and decision-making at the end of life that promotes comfort and dignity is widely endorsed by public policy and the law. In ethical analysis of palliative care interventions that are argued potentially to hasten death, these may be deemed to be ethically permissible by the application of the doctrine of double effect, if the doctor's intention is to relieve pain and not cause death. In part because of the significance of ethics in the development of law in the medical sphere, this doctrine is also likely to be recognized as part of Australia's common law, although hitherto there have been no cases concerning palliative care brought before a court in Australia to test this. Three Australian States have, nonetheless, created legislative defences that are different from the common law with the intent of clarifying the law, promoting palliative care, and distinguishing it from euthanasia. However, these defences have the potential to provide less protection for doctors administering palliative care. In addition to requiring a doctor to have an appropriate intent, the defences insist on adherence to particular medical practice standards and perhaps require patient consent. Acting in accordance with the common law doctrine of double effect may not provide legal protection. Similar changes are likely to occur in other States and Territories as there is a trend towards enacting legislative defences that deal with the provision of palliative care. http://onlinelibrary.wilev.com/doi/10.1111/i.1445-5994.2011.02511.x/abstract

# One big happy family? Interdisciplinary variation in job satisfaction among hospice providers

JOURNAL OF PALLIATIVE MEDICINE | Online article – 28 June 2011 – Job satisfaction is particularly important in the hospice industry, given the emotional and interpersonal challenges that hospice staff face in providing care to patients near the end of life and their families. Little is known about the job satisfaction of hospice providers, or about variation in satisfaction among disciplines. Results [of this study indicate that] there is significant variation in job satisfaction both among hospices and disciplines. <u>http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0057</u>

# Posthumous reproduction and palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online article – 28 June 2011 – Posthumous reproduction [i.e., posthumous sperm retrieval] is an issue fraught with legal, ethical, religious, and moral debate. The involvement of the hospice and palliative care community in this debate may be peripheral due to the fact that other health care professionals would be actually delivering the services. However, the hospice and palliative care community are more likely to treat patients considering posthumous reproduction as they near the end of their lives. This article provides ... a review of the medical, ethical, and legal considerations associated with posthumous reproduction. Having knowledge of these issues, and a list of available resources, will be useful if hospice and palliative care staff find themselves facing a patient or family that is considering posthumous reproduction. http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0102

# Design and evaluation of an online social support application for family caregivers

LECTURE NOTES IN COMPUTER SCIENCE, 2011;6778:267-276. A lot of people who live with a loss of autonomy related to ageing or disease benefit from the daily support of some of their relatives in order to perform their day-to-day duties (waking up in the morning, shopping, cooking). Family caregivers are strongly committed to the support relationship with their ailing relative. The assistance they provide takes up a large part of their time and energy. Offering them places for social support appears as a relevant solution. Besides, more and more people are turning towards the Internet to find support when they experience difficult situations. The authors' research deals with the complex issue of providing online social support to family caregivers through an interdisciplinary research project which aims at getting a better understanding of peer-to-peer social support practices. http://www.springerlink.com/content/pt043x2412628225/

# Hospice wards 'better staffed and better quality'

NURSING TIMES (U.K.) | Online report – 4 July 2011 – Hospice wards are better staffed than National Health Service [NHS] palliative care wards and provide better quality care, at a higher cost, according to research shared with Nursing Times. Researchers monitored occupancy levels of 28 wards for a month, along with the seriousness of patients' condition (measured as dependency), staffing levels and quality standards. They found hospice beds had a higher average occupancy and more dependent patients. They also had more staff – 3.82 whole time equivalent nurses per bed, compared to 2.21 for hospitals. The effect ... was a higher cost of running each bed for hospices at £258, compared to £142

for hospital wards. An assessment of quality based on an "extensive audit" gave hospice wards a score of 87% and hospital wards 82%. <u>http://www.nursingtimes.net/nursingpractice/clinical-specialisms/end-of-life-andpalliative-care/hospice-wards-better-staffedand-better-quality/5031983.article</u>

# Extract from Nursing Times

Hospice staff face markedly heavier workloads; are better staffed, more expensive to run, but deliver higher-quality care compared to NHS palliative care wards.



# Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses, and facilitating issue specific workshops, for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <a href="http://www.ipcrc.net/barry-r-ashpole.php">http://www.ipcrc.net/barry-r-ashpole.php</a>

# Experiences of dying, death and bereavement in motor neurone disease: A qualitative study

*PALLIATIVE MEDICINE* | Online article – 28 June 2011 – The needs of [the] patients and carers [i.e., participants in this qualitative study] are not being adequately met in the final stages of motor neurone disease and there appears a need for increased, co-ordinated support from palliative care services. The use of advance care planning tools is regarded as beneficial for patients and carers, but health professionals demonstrate a limited understanding of them. Anxiety and distress in patients, carers and bereaved carers is heightened during this period. Carer burden is excessive and may exacerbate patient distress and desire for hastening death. http://pmj.sagepub.com/content/early/2011/06/28/0269216311410900.abstract

# Assisted (or facilitated) death

Representative sample of recent articles, etc:

- BRITISH MEDICAL JOURNAL | Online article 1 July 2011 'Doctors back British Medical Association's refusal to join debate on assisted dying.' Doctors ... this week have backed the association in its stance to refuse to give evidence to the former lord chancellor Charles Falconer's Commission on Assisted Dying – and implied that the British Medical Journal had not reported the issue in a balanced way . <u>http://www.bmj.com/content/343/bmj.d4188.extract</u>
- JOURNAL OF MEDICAL ETHICS | Online article 27 June 2011 'Do guidelines on euthanasia and physician-assisted suicide in Dutch hospitals and nursing homes reflect the law?' Compared with hospital guidelines, nursing home guidelines were more often stricter than the law in excluding patients with dementia (30% vs. 4%) and incompetent patients (25% vs. 4%). http://jme.bmj.com/content/early/2011/06/26/jme.2010.041020.abstract

From Media Watch dated 13 June 2011:

 JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online article – 7 June 2011 – 'Advance directives for euthanasia in dementia: How do they affect resident care in Dutch nursing homes?' Advance directives for euthanasia are never adhered to in the Netherlands in the case of people with advanced dementia, and their role in advance care planning and end-of-life care of people with advanced dementia is limited. <u>http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2011.03414.x/full</u>

# Media Watch Online

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

#### Canada

Ontario | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: http://www.hnhbhpc.net/Resources/UsefulLinks/MediaWatch/tabid/97/Default.aspx

Ontario | HPC Consultation Services: http://www.hpcconnection.ca/newsletter/inthenews.html

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

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

#### The care of the patient

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 1927;88;877-882. It is probably fortunate that systems of education are constantly under the fire of general criticism, for if education were left solely in the hands of teachers the chances are good that it would soon deteriorate. Medical education, however, is less likely to suffer from such stagnation, for whenever the lay public stops criticizing the type of modern doctor, the medical profession itself may be counted on to stir up the stagnant pool and cleanse it of its sedimentary deposit. The most common criticism made at present by older practitioners is that young graduates have been taught a great deal about the mechanism of disease, but very little about the practice of medicine – or, to put it more bluntly, they are too "scientific" and do not know how to take care of patients. One is, of course, somewhat tempted to question how completely fitted for his life work the practitioner of the older generation was when he first entered on it, and how much the haze of time has led him to confuse what he learned in the school of medicine with what he acquired in the harder school of experience. But the indictment is a serious one and it is concurred in by numerous recent graduates, who find that in the actual

This article derives from a talk given by Frances W. Peabody to the students at the Harvard Medical School on 21 October 1926. It is the most cited and revered article in the medical literature

practice of medicine they encounter many situations which they had not been led to anticipate and which they are not prepared to meet effectively. Where there is so much smoke, there is undoubtedly a good deal of fire, and the problem for teachers and for students is to consider what they can do to extinguish whatever is left of this smoldering distrust. To begin with, the fact must be accepted that one cannot expect to become a skillful practitioner of medicine in the four or five years allotted to the medical curriculum. Medicine is not a trade to be learned but a profession to be entered. It is an ever widening field that requires continued study and prolonged experience in close contact with the sick. All that the medical school can hope to do is to supply the foundations on which to build. http://cell2soul.typepad.com/files/the care o f the patient-1.pdf

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