# Media Watch...

is intended as an advocacy tool and change document. The weekly report is international in scope and distribution – to 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 inform discussion and encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

Pediatric palliative care: Scroll down to <u>Specialist Publications</u> and 'Was there a plan? End-of-life care for children with life-limiting conditions: A review of multi-service healthcare records' (p.9), in *Child: Care, Health & Development.* 

# <u>Canada</u>

# The DNR discussion

CBC RADIO | 'White Coat, Black Art' – 6 December 2012 – DNR is code for 'Do Not Resuscitate.' It's a signed order in a hospital chart telling attending staff not to start CPR if a patient's heart stops and not to put them on a ventilator if they stop breathing. Patients and their families are the ones who decide whether they'll consent to a DNR. But doctors and nurses are the ones who have to approach those families and begin that difficult DNR discussion. In the ideal world, talking to a family is all about exploring well thought-out and heartfelt wishes. But it often doesn't happen that way. <u>http://www.cbc.ca/whitecoat/episode/2012/12/06/the-dnrdiscussion/</u>

# **Specialist Publications**

'The public's viewpoint on the right to hastened death in Alberta, Canada: Findings from a population survey study' (p.11), in *Health & Social Care in the Community.* 

# Brain injured man at centre of legal battle over whether to remove feeding tubes

BRITISH COLUMBIA | *The Vancouver Sun* – 5 December 2012 – A 57-year-old Vancouver man who has languished in a vegetative state for seven years has become the focus of a tragic family tug-of-war over whether he should live or die. His wife Lora wants medical staff to remove Kenny Ng's feeding tubes, which will cause him to starve to death over about two weeks. His parents, siblings and relatives, however, have asked B.C. Supreme Court Justice Miriam Gropper to intervene and keep Ng alive in the hope he can benefit from recent neuroscience medical discoveries. http://www.vancouversun.com/health/Brain+injured+centre+legal+battle+over+whether+remove+f eeding/7652011/story.html

# Toronto man at the heart of a landmark life support case has a 'very low level' of consciousness, tests show

ONTARIO | The National Post - 2 December 2012 – Remarkable new tests that let scientists communicate with some vegetative patients have been tried on a desperately ill Toronto man at the heart of a landmark court case, suggesting that Hassan Rasouli is at a "very low level" of consciousness. As he was asked in his native Farsi to imagine performing tasks like playing tennis, Mr. Rasouli's brain seemed to respond on an MRI scan during some tests, but not on others, says a report from Dr. Adrian Owen, a leading neuroscientist. The examinations are far from conclusive, but indicate limited brain activity, not a fully functioning mind locked in a frozen body. Doctors treating the Iranian immigrant at Toronto's Sunnybrook Health Sciences Centre have submitted a report on the tests to the Supreme Court of Canada, which is to hear the muchanticipated case. At issue is whether physicians can decide without relatives' consent to unplug such patients from life support. http://news.nationalpost.com/2012/12/02/ha ssan-rasouli-tests-show-toronto-man-haslow-level-of-consciousness/

# The Hassan Rasouli case and the research of Dr. Adrian Owen

The first of many articles, etc., on the Rasouli case noted in Media Watch was published in the *Canadian Medical Association Journal* of 8 April 2011 – 'Court rules that withdrawal of life support is a plan of treatment requiring consent' (http://www.cmaj.ca/earlyreleases/). The most recent was in *Toronto Life* – 'A life interrupted: Hassan Rasouli's journey from an earache to a high-stakes battle over end-of-life decisions' (http://www.torontolife.com/daily/informer/fromprint-edition-informer/2012/11/27/a-lifeinterrupted/).

The first mention in Media Watch of Dr. Owen's ground-breaking research at the University of Western Ontario was of an article in *The Globe & Mail* of 29 October 2012 – 'Vegetative patients may be aware, newly-recruited researcher says' (http://www.theglobeandmail.com/news/national/vegatative-patients-may-be-aware-newly-recruited-researcher-says/article1779227/). The most recent was of an editorial in the *British Medical Journal* of 28 November 2012 – 'fMRI for vegetative and minimally conscious states' (http://www.bmj.com/content/345/bmj.e8045).

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

# Cost of dying: Some Bay Area hospitals combat death aggressively with expensive treatment

CALIFORNIA | *Mercury News* (San Jose) – 8 December 2012 – How you die – and what it costs – depends largely on where you get care. That's the revelation of a major national database widely regarded as the best hospital-by-hospital look at the cost of dying. It shows that Bay Area residents are about twice as likely to die in a high-cost, high-tech intensive care unit as people in Minot, North Dakota, or Portland, Oregon. But they are far less likely to get ICU care than residents of Manhattan. Within the Bay Area, the Dartmouth Atlas of Health Care depicts hospitals' widely different approaches to care for dying people: Hayward's St. Rose Hospital ranks twice as high as Stanford in "intensity of care," a measure that considers the amount of time that dying patients spend in the hospital and the aggressiveness of physician services. Major differences appear even within cities: In San Jose, Regional Medical Center and Good Samaritan Hospital are 15 miles apart – but Medicare spent an extra \$23,000, or a third more, per patient in their last two years of life at Regional than Good Samaritan, because of different care strategies.<sup>1,2</sup> America's varied landscape of end-of-life experiences reflects different philosophies in how aggressively hospitals combat death... <u>http://www.mercurynews.com/ci\_22143099</u>

- 1. 'Database: Intensity of end-of-life care for California hospitals.' The Dartmouth Atlas of Health Care. <u>http://www.mercurynews.com/data/ci\_22147095/database-intensity-end-life-care-california-hospitals</u>
- 2. 'Hospital Care Intensity Index, Last Two Years of Life,' The Dartmouth Atlas of Health Care. [Noted in Media Watch, 5 November 2012.] <u>http://www.dartmouthatlas.org/</u>

#### Contemplative care

### Being the bridge

WASHINGTON D.C. | The Washington Post - 6 December 2012 - For end-of-life clinicians or caregivers, being the bridge to what's next demands courageous presence in the face of death, the ability to listen without needing to fix the problem, maintaining compassion and avoiding empathy fatigue while caring for many suffering and dying patients. Such skills aren't taught consistently in medical or nursing schools, and working without them can be frustrating and draining for clinicians. Hence the growing interest in bringing contemplation into caregiving settings and the emergence of a new field that applies contemplative approaches to end-of-life (EOL) and palliative care. "Contemplative care" is what meditation practitioners bring to the bedside, integrating mindfulness practice, compassionate action, and moment-to-moment awareness into care, emphasizing well-being not only of patients but also of clinicians, family members and everyone involved in care. Stress, empathy fatigue, secondary trauma and

burnout are constant occupational hazards for EOL caregivers, which can also affect care. Prolonged imbalances lead to feelings of frustration, inadequacy, and guilt, as well as to higher rates of absenteeism, depression and even suicide. Attrition rates for EOL caregivers are shockingly high: 30% for nurses, 30-50% overall for physicians, including nearly 50% for oncologists. <u>http://www.washingtonpost.com/blogs/guestvoices/post/being-thebridge/2012/12/06/ea4385ba-3fe6-11e2-</u> bca3-aadc9b7e29c5 blog.html

# **Specialist Publications**

Of particular interest:

'Hospices' enrollment policies may contribute to underuse of hospice care in the U.S.' (p.10), in *Health Affairs*.

# Federal 'compassionate' prison release rarely given

NATIONAL PUBLIC RADIO | Online report -30 November 2012 – In 1984, Congress gave authorities the power to let people out of federal prison early, in extraordinary circumstances, like if inmates were gravely ill or dying. But a new report<sup>1</sup> says the Federal Bureau of Prisons blocks all but a few inmates from taking advantage of "compassionate release." The federal prisons house more than 218,000 inmates but, on average, they release only about two dozen people a year under the program. "Why are so few people getting out?" asks Jamie Fellner, a senior adviser at Human Rights Watch who helped write the new study. "You have a prison system that is grotesquely overcrowded, you have prisoners who pose no meaningful threat to public safety and yet they're being denied release?" Fellner says she's convinced the culture of the federal

prisons and the Justice Department acts as an iron curtain for all but the sickest inmates – people with less than a year to live, who can't even walk or use the bathroom on their own, let alone commit another crime. <u>http://www.npr.org/2012/11/30/166178036/fe</u> <u>deral-compassionate-prison-release-rarelygiven</u>

### Extract from Human Rights Watch report

In the U.S., federal prisoners who are dying, incapacitated by illness or age, or confronting other "extraordinary and compelling" circumstances may be eligible for early release from prison. However, last year only 30 out of 218,000 prisoners received such compassionate release, and prior years have yielded equally small numbers.

 'The Answer is No: Too Little Compassionate Release in U.S. Federal Prisons,' Human Rights Watch, November 2012. <u>http://www.hrw.org/sites/default/files/reports/us1112ForUploadSm.pdf</u>

# Assisted (or facilitated) death

Representative sample of recent news media coverage:

NEW JERSEY | The Star-Ledger (Newark) – 3 December 2012 – 'New Jersey voters support doctor-assisted suicide, poll shows.' The Fairleigh Dickinson University PublicMind poll ... found 46% support [for a proposed] 'Death with Dignity Act,' while 38% oppose it. The bill would allow doctors to prescribe lethal doses of drugs to patients with under six months to live. Patients would self-administer the drugs after requesting them verbally and then in writing, signed by two witnesses, 15 days later. After that, the doctor would have to offer the patient a chance to rescind the request and recommend the patient's next of kin be notified. A second doctor would then have to certify the original doctor's diagnosis and affirm the patient is acting voluntarily and capable of making the decision. Patients deemed to have impaired judgment would not be eligible and the doctors would be required to refer them to counseling. Health care facilities would be able to prohibit their doctors from writing the prescriptions. The bill's introduction in September attracted a lot of media attention. But few voters had heard of the bill. Fifty-five percent had heard nothing about it. http://www.nj.com/politics/index.ssf/2012/12/nj\_voters\_support\_doctor-assis.html

# **International**

# More palliative-care nurses looking after elderly in Singapore

SINGAPORE | *Straits Times* – 10 December 2012 – There are now 337 palliative care-trained nurses in the public health-care institutions here , and this number is rising steadily. Minister of State for Health, Dr. Amy Khor, at the Tsao Foundation Experts Series 2012, spoke of the importance of nurses in caring for dying patients. Not only do they provide nursing care, but also counselling, emotional support, and the discussion of end of life issues, said Dr. Khor. At the forum results of Hua Mei Mobile Clinic's pilot palliative care programme for frail elderly in the community, was also shared.<sup>1.</sup> <u>http://www.straitstimes.com/breaking-news/singapore/story/more-palliative-care-nurses-looking-after-elderly-singapore-20121210</u>

1. Hua Mei Mobile Clinic, Tsao Foundation. http://www.tsaofoundation.org/huaMeiMobileClinic.html

### End-of-life care in Israel

### More nurses to be trained to take on doctors' duties, Health Ministry plans

ISRAEL | *Haaretz* (Tel Aviv) – 6 December 2012 – While the country's nurses struggle for higher wages and better working conditions, the Health Ministry is planning a significant expansion of its clinical nurse specialist training program, whose graduates are authorized to perform many duties that were once the sole province of physicians. The ministry's training program was launched on a small scale two years ago. Today 50 clinical nurse specialists are qualified to provide palliative care to terminal patients and end-of-life care to patients in home hospice care and hospital oncology wards. An additional 20 nurses are nearing certification as geriatric clinical nurse specialists. http://www.haaretz.com/news/national/more-nurses-to-be-trained-to-take-on-doctors-duties-health-ministry-plans.premium-1.482862

Noted in Media Watch, 27 February 2012:

- ISRAEL JOURNAL OF HEALTH POLICY RESEARCH | Published online 20 February 2012 'Progress in palliative care in Israel...' <u>http://www.ijhpr.org/content/pdf/2045-4015-1-9.pdf</u>
- ISRAEL JOURNAL OF HEALTH POLICY RESEARCH | Published online 20 February 2012 'Palliative care: Progress, needs, and challenges.' <u>http://www.ijhpr.org/content/pdf/2045-4015-1-10.pdf</u>

#### End-of-life care in New Zealand

#### University of Canterbury leads research in palliative care services for minority groups

NEW ZEALAND | Voxy.co.nz – 5 December 2012 – Elderly people of Asian background are least likely to access palliative and hospice services in New Zealand due to language and cultural barriers, and lack of information, according to the findings of a University of Canterbury project. The research found that while the majority of the Korean, Chinese and Japanese respondents reported little understanding of palliative and allied health services available, many were interested in knowing more about the services. Palliative care is a major issue as in the next 15 years the New Zealand population is expected to increase by almost 20%. <a href="http://www.voxy.co.nz/health/ucleads-research-palliative-care-services-minority-groups/5/142456">http://www.voxy.co.nz/health/ucleads-research-palliative-care-services-minority-groups/5/142456</a>

Noted in Media Watch, 6 August 2012:

 NEW ZEALAND | Voxy.com.nz – 1 August 2012 – 'All parliamentary group on palliative care announced.' <u>http://www.voxy.co.nz/politics/all-parliamentary-group-palliative-careannounced/5/130830</u>

Noted in Media Watch, 23 April 2012:

 NEW ZEALAND | Community Scoop – 12 April 2012 – 'Hospice New Zealand standards for palliative care launch.' <u>http://community.scoop.co.nz/2012/04/hospice-nz-standards-for-palliativecare-launch/</u>

### Showing the Spanish what hospices are all about

SPAIN | *The Daily Telegraph* (U.K.) – 5 December 2012 – In Spain, older people have always been very much part of family life. Grandparents play a key role in bringing up their children's children, with around half tasked with babysitting them every single day. Small children answer to their *abuelos* almost in the same way they do to their mothers and fathers, while teenagers link arms lovingly with their silver-haired relatives during the evening walk. The idea it might be a bit embarrassing to be hanging out with Nan and Granddad doesn't cross their minds. It is just how things are. This family snugness is one of the reasons that, in Spain, palliative care – health care dedicated to relieving the suffering of seriously ill patients – has been slow to develop in the same way it did in the UK. It was Cicely Saunders who founded the modern hospice movement in 1970s Britain. Saunders recognised that, when a person is dying from terminal illness, their emotional, psychological, social and spiritual needs to be considered as well as the physical factors of their condition. And that the human aspect of this care is paramount. In 1970s Spain, meanwhile, it was the family that met most of these needs; and would for many more decades to come. But now, things have changed. <u>http://www.telegraph.co.uk/health/expathealth/9718436/Showing-the-Spanish-what-hospices-are-all-about.html</u>

**N.B.** Spain was rated 26th (of the 40 countries surveyed) in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, published by the Economist Intelligence Unit, July 2010. <u>http://graphics.eiu.com/upload/QOD main final edition Jul12 toprint.pdf</u>

### Nurses in drive for 'compassionate care'

U.K. (ENGLAND) | BBC News – 4 December 2012 – More emphasis should be placed on nurses providing compassionate care in hospitals, industry leaders have said. In a new campaign aimed at reassuring the public, chief nursing officer for England Jane Cummings said action must be taken to ensure the values nurses stand for are not betrayed. The call comes amid concern over reported neglect and abuse in hospitals and care homes. <u>http://www.bbc.co.uk/news/health-20583115</u>

Of related interest:

U.K. (England) | The Times (Editorial) – 4 December 2012 – 'Compassion in practice: Nursing has to change if patients are going to be treated well.' The greatest virtue of professions is that they are constant. A profession has a body of knowledge and a code of ethics by which it is defined in the face of different fashions and changes. But this virtue can become a vice because professions, which guard their reputations jealously, can easily thereby become resistant to change. http://www.thetimes.co.uk/tto/opinion/leaders/article3619506.ece

Noted in Media Watch, 5 March 2012:

 U.K. | The Guardian – 29 February 2012 – 'Dignity in Care report calls for shake-up in staff selection and appraisal.' Nurses, doctors and care workers should be recruited as much for their compassion as for their exam results, according to an inquiry into improving the dignity of treatment of elderly people... <u>http://www.guardian.co.uk/society/2012/feb/29/dignity-in-care-report-staff-selection</u>

# Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BELGIUM | European Institute of Bioethics 9 December 2012 'Euthanasia in Belgium: 10 years on.' <a href="http://www.ieb-eib.org/fr/pdf/dossier-euthanasia-in-belgium-10-years.pdf">http://www.ieb-eib.org/fr/pdf/dossier-euthanasia-in-belgium-10-years.pdf</a>
- THE NETHERLANDS | Regional Euthanasia Review Committees 9 December 2012 'Annual Report 2011.' <u>http://www.worldrtd.net/sites/default/files/newsfiles/RTE.JV2011.ENGELS.DEF\_.pdf</u>
- IRELAND | Independent (Dublin) 7 December 2012 'DPP fears 'road map' for assisted suicide.' The Director of Public Prosecutions [DPP] has said she would be aiding a crime if she granted a request from a terminally ill woman to outline what factors would be considered when deciding whether to prosecute for assisted suicide. Lawyers for Claire Loftus, the DPP, have told the High Court that she is very concerned not to set out "a road map" under which a person may more safely commit a crime and avoid prosecution. Counsel Paul O'Higgins, for the DPP, told a three-judge High Court that providing factors relevant to the DPP's prosecutorial discretion before a crime of assisted suicide occurs would amount to the DPP helping someone avoid prosecution. http://www.independent.ie/national-news/dpp-fears-road-map-for-assisted-suicide-3318367.html
  - IRELAND | Irish Central 5 December 2012 'Irish woman with terminal illness begins case for right-to-die lawsuit in Ireland.' A 58-year-old woman is due to begin the first court action of its kind in the Republic of Ireland aimed at allowing her to be assisted to die. Marie Fleming, a former lecturer at University College Dublin, was diagnosed with multiple sclerosis in 1986. She plans to establish her partner Tom Curran's legal right to help her to die when and if she chooses. Her illness is terminal. <a href="http://www.irishcentral.com/news/Irish-woman-with-terminal-illness-begins-case-for-right-to-die-lawsuit-in-Ireland-182161661.html">http://www.irishcentral.com/news/Irish-woman-with-terminal-illness-begins-case-for-right-to-die-lawsuit-in-Ireland-182161661.html</a>
- AUSTRALIA | Australian Ageing Agenda 6 December 2012 'Wide support for euthanasia.' More than four in five Australian adults support reform of voluntary euthanasia laws and almost a quarter of would change their vote if their usual election candidate opposed reform. The Newspoll survey also found that legalising voluntary euthanasia ranked third in importance among national policy issues. <u>http://www.australianageingagenda.com.au/2012/12/06/article/Wide-support-foreuthanasia/BZBAQTGAML.html</u>
- NEW ZEALAND | Nelson Mail 5 December 2012 'Euthanasia controversial survey.' MP Nick Smith says [the city of] Nelson is "quite evenly split" on attitudes towards voluntary euthanasia. The results of his annual electorate survey showed that 58% (1309) of respondents supported a legislative change, while 39% (893) opposed it and 3% (61) were undecided. This highlighted how contentious the issue was, Dr. Smith said. <u>http://www.stuff.co.nz/nelsonmail/news/8038918/Euthanasia-controversial-survey</u>

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

# End-of-life medical decisions in France: A death certificate follow-up survey 5 years after the 2005 Act of Parliament on Patients' Rights and End of Life

*BMC PALLIATIVE CARE* | Published online – 3 December 2012 – The 'Patients' Rights & End of Life Care' Act came into force in France in 2005. It allows withholding/withdrawal of life-support treatment, and intensified use of medications that may hasten death through a double effect, as long as hastening death is not the purpose of the decision. It also specifies the requirements of the decision-making process. This study assesses the situation by examining the frequency of end-of-life decisions by patients' and physicians' characteristics, and describes the decision-making processes. This study shows that end-of-life medical decisions are common in France. Most are in compliance with the 2005 law (similar to some other European countries). Nonetheless, the study revealed cases where not all legal obligations were met or where the decision was totally illegal. There is still a lot to be done through medical education and population awareness-raising to ensure that the decision-making process is compatible with current legislation, the physician's duty of care and the patient's rights. <a href="http://www.biomedcentral.com/content/pdf/1472-684X-11-25.pdf">http://www.biomedcentral.com/content/pdf/1472-684X-11-25.pdf</a>

Noted in Media Watch, 31 October 2011:

- SOINS; LA REVUE DE RÉFÉRENCE INFIRMIÈRE, 2011;Sep(758):50-51. 'The National Observatory on End of Life Care.' <u>http://www.ncbi.nlm.nih.gov/pubmed/22003797</u>
- SOINS; LA REVUE DE RÉFÉRENCE INFIRMIÈRE, 2011;Sep(758):52-53. 'The main missions of the National Palliative Care Resource Centre.' <u>http://www.ncbi.nlm.nih.gov/pubmed/22003798</u>
- SOINS; LA REVUE DE RÉFÉRENCE INFIRMIÈRE, 2011;Sep(758):47-49. 'Role and missions of the French Society of Support & Palliative Care.' <u>http://www.ncbi.nlm.nih.gov/pubmed/22003796</u>

### 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.

# Daily Mail story on care of sick babies was "highly misleading," says BMJ editor

BRITISH MEDICAL JOURNAL (BMJ) | Published online - 4 December 2012 - The BMJ's editor in chief ... has criticised the *Daily Mail* for misleading readers by publishing a highly inaccurate article on the care of severely disabled newborn babies that was based on a personal view article in the BMJ.<sup>1</sup> It claimed that the BMJ personal view<sup>2</sup> ... was evidence that sick children in the National Health Service were being put on the Liverpool Care Pathway. It added, "The Mail can reveal the practice of withdrawing food and fluid by tube is being used on young patients as well as severely disabled newborn babies." However, in a letter to the *Mail*, which had not been published when the BMJ went to press, Godlee pointed out that "the doctor who wrote the BMJ article does not practise in the U.K. Nor does the article mention the Liverpool Care Pathway." The Daily Telegraph ran a similar news item based on the Mail's story and that has been shared many hundreds of times on social media. That story has been deleted from the newspaper's website after a BMJ reader pointed out its inaccuracies, although the Telegraph has refused to post a retraction. http://www.bmj.com/content/345/bmj.e8240

- 'Now sick babies go on death pathway: Doctor's haunting testimony reveals how children are put on end-of-life plan,' *Daily Mail*, 28 November 2012, <u>http://www.dailymail.co.uk/news/article-2240075/Now-sickbabies-death-pathway-Doctors-haunting-testimony-revealschildren-end-life-plan.html</u>
- 'How it feels to withdraw feeding from newborn babies,' British Medical Journal, 1 November 2012. <u>http://www.bmj.com/content/345/bmj.e7319</u>

# A reader's response to *BMJ* personal view

I expect when the anonymous doctor wrote this heartfelt and thought provoking letter, the furthest thing from her/his mind was what the American media might make of it. But last night, under the shocking headline 'Will sick babies be starved to death under Obamacare? Doctor describes "horror" of British socialist healthcare system," the right-wing media stormed into action to use this doctor's concern and appeal for open discourse around questions of neonatal end-of-life and palliative care practices to rail against "socialism" which, as we Americans are repeatedly told, you Brits hate (so much so, in fact, that no government since Clement Attlee's has dared dismantle the National Health Service [founded in 1948], despite its shortcomings).

http://www.bmj.com/content/3 45/bmj.e7319/rr/618091



# 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>

### 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/owner/MediaWatch</u>

#### Pediatric palliative care

### Was there a plan? End-of-life care for children with lifelimiting conditions: A review of multi-service healthcare records

CHILD: CARE, HEALTH & DEVELOPMENT | Published online – 28 November 2012 – Planning for care at the end of life (EoL) is an essential component of support and care for families of children with life-limiting conditions. The purpose of this review was to compare documented EoL planning with published children's palliative care standards, across a range of children's healthcare services and to assess the impact on practice of written guidelines to support EoL care planning. Examples of good practice were found in the records of individual services. Services had each developed their own systems and documents to support EoL care planning rather than using a unified documentation system. Where documented practice fell short, this was related to a lack of evidence that choice in location of death had been offered, delays in sharing of information between services, and information being buried in the narrative of the notes, making it difficult to find. Current documented EoL planning varies between services. http://onlinelibrary.wilev.com/doi/10.1111/cc h.12020/abstract

The needs of professionals in the palliative care of children and adolescents

EUROPEAN JOURNAL OF PEDIATRICS | Published online – 4 December 2012 – The main objectives of this qualitative study were to describe the perceptions and needs of pediatric health care professionals (HCPs) taking care of children with palliative care needs and to develop a concept for the first Center of Competence for Pediatric Palliative Care (PPC) in Switzerland. HCPs expressed openness to PPC and reported distinctive needs for support in the care of these patients. The main tasks of specialized PPC teams in Switzerland would encompass the coaching of attending teams, coordination of care, symptom control, and direct support of affected families during and beyond the illness of their child. Specialized PPC teams could have a significant impact on the care of children and families with PPC needs. Whether hospices are an option in Switzerland remains unanswered: however, a place to meet other families with similar destinies was emphasized. http://link.springer.com/article/10.1007/s00431-012-1880-8

# Palliative care in COPD patients: Is it only an end-of-life issue?

EUROPEAN RESPIRATORY REVIEW, 2012;21(126):347-354. 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. There is a need for a clear discussion about decision making earlier than when acute respiratory failure ensues. Indeed, a perceived poor quality of life does not necessarily correlate with a clear willingness to refuse invasive or non-invasive mechanical ventilation. It has been suggested to start palliative care earlier ... when there is an increased intensity of symptoms. The patients eligible for palliative care are those complaining of breathlessness, pain, fatigue and depression, which in some studies accounted for a prevalence much higher than 50%. <a href="http://err.ersjournals.com/content/21/126/347.abstract">http://err.ersjournals.com/content/21/126/347.abstract</a>

Of related interest:

 THORAX, 2012;67 (Suppl.):A166-A167 | Published online – 'Death and the respiratory physician: Challenges to providing optimal end-of-life care by generalists.' There is a pressing need for greater expertise in general palliative care amongst hospital doctors. Patients with COPD and other progressive respiratory conditions have extensive palliative care needs. http://thorax.bmj.com/content/67/Suppl\_2/A166.2.abstract Noted in Media Watch, 16 July 2012:

 CHEST, 2012;142(1):128-133. 'The effect of end-of-life discussions on perceived quality of care and health status among patients with COPD.' <u>http://journal.publications.chestnet.org/article.aspx?articleid=1206615</u>

Noted In Media Watch, 23 April 2012:

 CHRONIC RESPIRATORY DISEASE | Published online – 12 April 2012 – 'Pulmonary rehabilitation and palliative care in COPD: Two sides of the same coin?' http://crd.sagepub.com/content/early/2012/04/03/1479972312441379.abstract

# Hospices' enrollment policies may contribute to underuse of hospice care in the U.S.

HEALTH AFFAIRS, 2012;31(12):2690-2698. Hospice use in the U.S. is growing but little is known about barriers that terminally ill patients may face when trying to access hospice care. This article reports the results of the first national survey of the enrollment policies of 591 U.S. hospices. The survey revealed that 78% of hospices had at least one enrollment policy that may restrict access to care for patients with potentially high-cost medical care needs, such as chemotherapy or total parenteral nutrition. Smaller hospices, for-profit hospices, and hospices in certain regions of the country consistently reported more limited enrollment policies. The authors observe that hospice providers' own enrollment decisions may be an important contributor to previously observed underuse of hospice by patients and families. Policy changes that should be considered include increasing the Medicare hospice *per diem* rate for patients with complex needs, which could enable more hospices to expand enrollment. <a href="http://content.healthaffairs.org/content/31/12/2690.abstract">http://content.healthaffairs.org/content/31/12/2690.abstract</a>

Noted in Media Watch, 3 December 2012:

 NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online report – 27 November 2012 – 'While number of patients receiving hospice care increases, larger percentage have short length of service.' <u>http://www.nhpco.org/i4a/pages/index.cfm?pageID=6846</u>

### Barriers to nurses providing psychosocial care in the Australian rural context

NURSING & HEALTH SCIENCES | Published online – 4 December 2012 – Current knowledge of psychosocial care in rural areas is limited, despite the centrality of nurses in the provision of this care. The global theme [that emerged in this study], "Managing multiple roles, demands and relationships," reflected the notion that provision of psychosocial care is impacted on by the multiple roles and tasks rural nurses undertake and the impact of contextual and interpersonal relationships. Strategies are needed to support nurses in their role and while clinical supervision has been identified as potentially useful, attention must be given to strong leadership, development of a positive culture, recognition of the centrality of client care, and evidence-based education. http://onlinelibrary.wiley.com/doi/10.1111/nhs.12014/abstract?systemMessage=Wiley+Online+Lib rary+will+be+disrupted+on+15+December+from+10%3A00-12%3A00+GMT+%2805%3A00-07%3A00+EST%29+for+essential+maintenance&userIsAuthenticated=false&deniedAccessCusto misedMessage=

### Can we truly offer a choice of place of death in neonatal palliative care?

SEMINARS IN FETAL & NEONATAL MEDICINE | Published online – 4 December 2012 – In the developed world, more than 90% of neonatal deaths occur in hospital and most deaths on the neonatal unit follow the planned withdrawal of ventilation. The authors look at what choices of place of death can be considered, the support that is available outside the hospital environment and the practicalities of achieving parental choice. Choices of place of death are usually possible, although there may be practical or resource restraints that affect which choices are available or can be achieved. <a href="http://www.sciencedirect.com/science/article/pii/S1744165X12001278">http://www.sciencedirect.com/science/article/pii/S1744165X12001278</a>

# Impact of consideration of transplantation on end-of-life care for patients during a terminal hospitalization

*TRANSPLANTATION* | Published online – 28 November 2012 – Twenty-five percent of decedent patients [in this medical record-based study] were considered for transplantation. In adjusted models, patients considered for transplantation received lower-quality end-of-life care, had longer hospital stays before death, and were more likely to receive aggressive life-sustaining treatments. http://journals.lww.com/transplantjournal/Abstract/publishahead/Impact\_of\_Consideration\_of\_Transplantation\_on.98795.aspx

# Assisted (or facilitated) death

Representative sample of recent articles, etc:

HEALTH & SOCIAL CARE IN THE COMMUNITY | Published online – 6 December 2012 – 'The public's viewpoint on the right to hastened death in Alberta, Canada: Findings from a population survey study.' Of all 1203 [survey respondents], 72.6% said yes to: 'Should dying adults be able to request and get help from others to end their life early, in other words, this is a request for assisted suicide?' Among all who provided an answer, 36.8% indicated 'yes, every competent adult should have this right,' and 40.6% indicated 'yes, but it should be allowed only in certain cases or situations.' http://onlinelibrary.wiley.com/doi/10.1111/hsc.12007/abstract

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Media Watch Online
Canada
ONTARIO   Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <u>http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx</u> (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: <u>http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1</u>
ONTARIO   Palliative Care Consultation Program (Oakville): http://www.palliativecareconsultation.ca/?q=mediawatch
U.S.A.
Prison Terminal: http://www.prisonterminal.com/news%20media%20watch.html
Europe
HUNGARY   Hungarian Hospice Foundation: http://www.hospicehaz.hu/en/training/ (Scroll down to 'Media Watch')
U.K.   Omega, the National Association for End of Life Care: <a href="http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm">http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm</a> ?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c
Asia
SINGAPORE   Centre for Biomedical Ethics (CENTRES): <u>http://centres.sg/</u> (Scroll down to 'What's New: Reading List Update')
International
Australasian Palliative International Link: http://www1.petermac.org/apli/links.htm (Scroll down to 'Media Watch')
Palliative Care Network Community: http://www.pcn-e.com/community/pg/file/owner/MediaWatch
International Palliative Care Resource Center: http://www.ipcrc.net/archive-global-palliative-care-news.php

PROGRESS IN PALLIATIVE CARE | Published online – 4 December 2012 – 'Palliative care ethics: The problems of combining palliation and assisted dying.' The performing of euthanasia is now offered as an option by certain palliative care service institutions in Belgium. The approach is known as the 'integral' model. Although it is understandable that some physicians are in favour of it, the model is rejected in this article, for both clinical and ethical reasons. Furthermore, the idea of 'palliative futility' associated with the model is shown to be incoherent. In countries where assisted dying is legal, palliative care providers should refrain from participating in such practices if they are to remain true to the basic values of such care. The widespread conception that withholding and withdrawing treatment amounts to a 'hastening' of death is also rejected. http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000040

# Worth Repeating

# Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2009;301(11):1140-1147. This study demonstrates that most patients with advanced cancer rely on religion to cope with their illness and that greater use of positive religious coping is associated with the receipt of intensive life-prolonging medical care near death. This association was not attributable to other predictors of aqgressive end-of-life care established in the literature, and remained after controlling for advance care planning and other potential psychosocial confounders. These results suggest that relying upon religion to cope with terminal cancer may contribute to receiving aggressive medical care near death. Positive religious coping was commonly endorsed within the study sample, consistent with other studies that demonstrate it to be the normative mode of religious coping within predominantly Christian patient samples.<u>http://jama.jamanetwork.com/article.asp</u> x?articleid=183578

# Extract from JAMA article

To the author's knowledge, this is the first study to examine the influence of any religious factor on medical care received near death, and it is novel in demonstrating that positive religious coping is associated with receipt of aggressive end-of-life care.

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