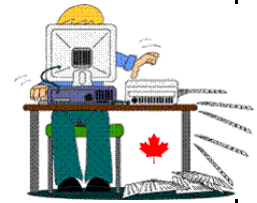


## Media Watch...

is intended as an advocacy, research and teaching 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.

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Compiled & Annotated by Barry R. Ashpole

Role of GPs in end-of-life care: Scroll down to [Specialist Publications](#) and 'The last 48 hours' (p.10), in *InnovAiT*.

## Canada

### Toronto hospital illegally imposed "do-not-resuscitate" order against wishes of dying man's family: Medical board

ONTARIO | *The National Post* – 3 September 2014 – Doctors at a major Toronto hospital violated the law by unilaterally imposing a do-not-resuscitate order on an elderly patient against his family's wishes, an appeal board has ruled in an extraordinary clash over end-of-life care. Douglas DeGuerre died from cardiac arrest at Sunnybrook Health Sciences Centre as his daughter, Joy Wawryzyniak, frantically tried to convince medical staff to save him, and health workers declined to help the severely ill war veteran. In a case that dramatizes the debate over who has ultimate power in such cases – doctors or patients' families – Ms. Wawryzyniak said she had only just learned that the "full code" response to emergencies she had requested on her father's behalf had been over-ruled by a do-not-resuscitate (DNR) order, which meant CPR would not be attempted during cardiac arrest. Ontario's medical regulator has twice rejected Ms. Wawryzyniak's complaint against the doctors, saying they acted properly. For the second time, however, the Health Profes-

sions Appeal & Review Board has rejected that decision as unreasonable, a rare event for a tribunal that upholds most of the College of Physicians & Surgeons' decisions. The board directed the province's medical regulator to re-open disciplinary proceedings against the physicians, bring its own policy in line with the legislation, and make sure hospitals understand their legal obligations. <http://news.nationalpost.com/2014/09/03/toronto-hospital-illegally-imposed-do-not-resuscitate-against-wishes-of-dying-veterans-family-medical-board/>

### [Specialist Publications](#)

'The future of decision-making in critical care after *Cuthbertson v. Rasouli*' (p.8), in *Canadian Journal of Anesthesia*.

'When should we not respect a patient's wish?' (p.9), in *Journal of Clinical Ethics*.

Cont.

Of related interest:

- *THE NATIONAL POST* | Online – 5 September 2014 – '**Doctors more reluctant to clash with families over end-of-life decisions in wake of Supreme Court ruling.**' Disputes over unplugging life support or withholding emergency treatments like cardiopulmonary resuscitation are undoubtedly [occurrences with] only a fraction of total hospital patients, yet courts and tribunals have repeatedly had to grapple with them in recent years. Central to the cases is the question of who has the final say over those patients' treatment – medical staff or family members? To what extent, in other words, can loved ones demand procedures doctors argue are futile and possibly harmful? <http://news.nationalpost.com/2014/09/05/doctors-more-reluctant-to-clash-with-families-over-end-of-life-decisions-in-wake-of-supreme-court-ruling/>

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

Representative sample of recent news media coverage:

- *THE GLOBE & MAIL* | Online – 1 September 2014 – '**Just what is a dignified death.**' Proponents of assisted suicide constantly evoke the "right to die with dignity" in seeking a Supreme Court of Canada ruling striking down Criminal Code provisions banning the practice. What they really mean is that they want to control the circumstances of their own deaths. This is an entirely legitimate desire, and the Supreme Court should grant them their wish. Our Charter right to life and liberty surely includes the right to choose when and how to end it all. But to suggest that ending one's life with the help of a doctor or loved one is the "dignified" way to go is as shallow as it is hubristic. <http://www.theglobeandmail.com/globe-debate/kill-yourself-sure-but-dont-call-it-dignified/article20280464/>

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

#### **When it's the doctor who can't let go**

*THE NEW YORK TIMES* | Online – 6 September 2014 – Palliative care itself suffers from an identity problem in that many people equate palliation with hospice – i.e., end of life. This mistaken association can make a palliative care consultation feel like a death sentence to even the most open-minded clinicians, patients and family members. Striving for a cure is historically seen as a unique pathway that restores health; easing suffering is a separate, non-curative path that ends with the patient dying. And it's true that palliative care does offer symptom management to patients who are expected to die soon... But it is more than that: It also helps patients with long-term illnesses like congestive heart failure and chronic obstructive pulmonary disease, people who are expected to live with their illness, but need careful managing of their symptoms. If it becomes clear that a patient receiving palliation along with curative treatment will not survive her illness, then the palliative care group works with the medical team to help her make the transition to hospice and help her decide how to spend the last of her time on earth. [http://opinionator.blogs.nytimes.com/2014/09/06/when-its-the-doctor-who-cant-let-go/?\\_php=true&\\_type=blogs&\\_r=0](http://opinionator.blogs.nytimes.com/2014/09/06/when-its-the-doctor-who-cant-let-go/?_php=true&_type=blogs&_r=0)

#### **Barry R. Ashpole**

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a 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 college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>



## Is one hospice the same as any other? No. Why it's important to choose carefully

THE WASHINGTON POST | Online – 3 September 2014 – After *The Washington Post* reported ... about a North Carolina hospice accused of over-medicating a patient,<sup>1</sup> Peter Brunnick, the chief of the largest non-profit hospice in the state, warned readers in a *Charlotte Observer* opinion piece that "all hospices are not created equal."<sup>2</sup> He urged readers to choose a hospice carefully. In an interview this week, he offered his thoughts on the state of the industry and what consumers can do to shop wisely. [http://www.washingtonpost.com/news/business/wp/2014/09/03/is-one-hospice-the-same-as-any-other-no-why-its-important-to-choose-carefully/?tid=hpModule\\_a2e19bf4-86a3-11e2-9d71-f0feafdd1394](http://www.washingtonpost.com/news/business/wp/2014/09/03/is-one-hospice-the-same-as-any-other-no-why-its-important-to-choose-carefully/?tid=hpModule_a2e19bf4-86a3-11e2-9d71-f0feafdd1394)

1. 'As more hospices enroll patients who aren't dying, questions about lethal doses arise,' *The Washington Post*, 21 August 2014. [Noted in *Media Watch*, 25 August 2014, #372 (p.3)] <http://www.washingtonpost.com/news/storyline/wp/2014/08/21/as-more-hospices-enroll-patients-who-arent-dying-questions-about-lethal-doses-arise/?hpid=z5>
2. 'All hospices are not created equal; choose wisely,' *The Charlotte Observer*, 27 August 2014. <http://www.charlotteobserver.com/2014/08/27/5133002/all-hospices-are-not-created-equal.html>

### Specialist Publications

'The effects of the profit motive on the hospice movement' (p.5), in *American Journal of Nursing*.

'Economies of dying: The moralization of economic scarcity in U.S. hospice care' (p.6), in *American Sociological Review*.

## International

### ***A new settlement for health and social care***

U.K. (England) | Commission on the Future of Health & Social Care in England – 4 September 2014 – The final report from the independent commission discusses the need for a new settlement for health and social care to provide a simpler pathway through the current maze of entitlements. It proposes an approach that redesigns care around individual needs regardless of diagnosis, and with a graduated increase in support as needs rise, particularly towards the end of life. The commission concludes this vision fit for the 21st century and is affordable and sustainable if a phased approach is taken and hard choices are taken about taxation. <http://www.kingsfund.org.uk/publications/new-settlement-health-and-social-care>

### **Extract from Commission's report**

[End-of-life care] is a contentious issue, raising questions about how officiously the health service should strive to keep people alive. What is clear is that many people express the wish to die at home when they in fact die in hospital, and that some relatives feel on occasion that there can be excessive intervention.

### Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.15.

Cont.

Articles on the integration of health and social services noted in past issues of Media Watch:

- *INTERNATIONAL JOURNAL OF INTEGRATED CARE* | Online – 20 March 2014 – '**Integrated end-of-life care: The role of social services.**' If palliative care must be holistic, then it should include the social nature of the aid. [Noted In Media Watch, 31 March 2014, #351 (p.7)] <http://www.ijic.org/index.php/ijic/article/view/URN%3ANBN%3ANL%3AUI%3A10-1-114777/2376>
- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2014;4(18). '**Benefits of health and social care integration.**' Scotland's health boards and local authorities are moving towards integrated funding and service provision. [Noted in Media Watch, 24 March 2014, #350 (p.8)] <http://spcare.bmj.com/content/4/1/118.1.short>

### Australians left vulnerable without advanced care planning

AUSTRALIA | *The Sydney Morning Herald* – 3 September 2014 – Few Australians are organising advance directives to ensure they do not receive unwanted medical care, a large-scale study of end-of-life planning has found.<sup>1</sup> Experts say Australia needs to urgently address the over-treatment of elderly and very sick people at the end of their lives, and ensure they do not receive more invasive treatment than they would want if they were able to decide. Yet a new study of more than 7,200 people has found only about 14% had prepared an advance directive to dictate their future medical care. New South Wales and Victoria lagged behind ... Queensland and South Australia, where about one in five people were found to have

prepared an advance care document. Both states have long-standing, well-publicised statutory forms allowing a person to accept or refuse treatment, the study found. <http://www.smh.com.au/nsw/australians-left-vulnerable-without-advanced-care-planning-20140902-10bbkt.html>

#### Specialist Publications

'Care plans and care planning in the management of long-term conditions in the U.K.: A controlled prospective cohort study' (p.7), in *British General General Practice*.

1. 'Prevalence and predictors of advance directives in Australia,' *Internal Medicine Journal*, 11 August 2014. <http://onlinelibrary.wiley.com/doi/10.1111/imj.12549/abstract>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- SLOVAKIA | *The Slovak Spectator* (Bratislava) – 5 September 2014 – '**Euthanasia okay, according to most of Slovaks.**' 59% of people in Slovakia think it is important to deal with the issue of euthanasia, according to a survey... In terms of the religious affiliation of the respondents, 47% of those who consider themselves to be firm Catholics stated that the topic of euthanasia needs to be addressed in Slovakia. This opinion was shared by 61% of less committed Catholics, 52% of non-religious individuals, 66% of atheists and 57% of agnostics. [http://spectator.sme.sk/articles/view/55151/10/euthanasia\\_okay\\_according\\_to\\_most\\_of\\_slovaks.html](http://spectator.sme.sk/articles/view/55151/10/euthanasia_okay_according_to_most_of_slovaks.html)
- SPAIN | RIA Novosti (Russia) – 2 September 2014 – '**Spanish youths support death penalty, abortions, euthanasia: Study.**' The study ... [by the Reina Sofia Center of Adolescents & Youth] ... asked over 1,000 Spaniards aged 15 to 24 to express their opinions on various social norms. Over 56% rated death penalty to be "quite acceptable" or "fairly acceptable." Some 81% of respondents accept abortions and 82% stated that same-sex couples should be able to adopt children. Nearly 80% of Spanish youths believe that euthanasia should be legal. At the same time, 66.5% are against suicide. <http://en.ria.ru/analysis/20140902/192574254/Spanish-Youths-Support-Death-Penalty-Abortions-Euthanasia--Study.html>

Cont.

- AUSTRALIA (West Australia) | *The West Australian* (Perth) – 1 September 2014 – **'Doctors warn on euthanasia.'** West Australian palliative care specialists are urging Federal MPs to reject the legalisation of euthanasia, warning doctors do not want to be put in the position of having to end patients' lives. They have told a parliamentary inquiry looking at the proposed introduction of national right-to-die laws that rather than deliberately ending life, more should be done on improving care for the terminally ill. Perth Federal Labor MP Alannah MacTiernan and Greens Victorian senator Richard Di Natale are spearheading a push for national euthanasia laws. Under Senator Di Natale's "dying with dignity" private member's Bill, three doctors would need to give their approval before a terminally ill patient could undergo euthanasia. Euthanasia would be limited to adults and Australian residents. But members of the West Australia Palliative Medicine Specialists Group, which includes doctors from the State's major hospitals, worry that legalising euthanasia would change society's attitude to matters of life and death. <https://au.news.yahoo.com/thewest/a/24861793/doctors-warn-on-euthanasia/>

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

#### **Clinicians' perceptions of the usefulness of a communication facilitator in the intensive care unit**

*AMERICAN JOURNAL OF CRITICAL CARE*, 2014;23(5):380-386. Use of a communication facilitator – an additional staff member – to improve communication between clinicians and patients' families is the focus of an ongoing randomized trial. Clinicians (i.e., study participants) perceived facilitators as 1) facilitating communication between patients' families and clinicians; 2) providing practical and emotional support for patients' families; and, 3) providing practical and emotional support for clinicians. Clinicians were enthusiastic about the communication facilitator but concerned about overlapping or conflicting roles. <http://ajcc.aacnjournals.org/content/23/5/380.short>

Of related interest:

- *PROGRESS IN PALLIATIVE CARE* | Online – 4 September 2014 – **'The complexities of communicating palliative care in Chinese-based languages.'** Chinese-based cultures have many distinctive traditions associated with the end of life, including limitations around the use of language. As in Western countries, palliative care services have developed in Chinese-based cultures in response to local needs. Language too has developed locally with little agreement on how palliative care is titled and described. This opinion paper raises the many complexities in endeavouring to understand how palliative care is portrayed in Chinese-based cultures. <http://www.maneyonline.com/doi/abs/10.1179/1743291X14Y.0000000106>

#### **The effects of the profit motive on the hospice movement [in the U.S.]**

*AMERICAN JOURNAL OF NURSING*, 2014;114(9):21-22. Hospice has long been regarded as one of the last outposts of altruism in health care. Greed simply seemed incompatible with the work of attending to the gravely ill up to the last moments of their lives. The modern hospice movement began in the U.S. in the 1970s... Early U.S. hospices were run largely as not-for-profits serving patients with cancer. The 1983 enactment of the Medicare hospice benefit meant that Medicare would cover all end-of-life care, at a *per-diem* rate, for beneficiaries expected to live six months or less if the illness "runs its normal course." Now, with about 45% of deaths involving hospice care, most of it covered by Medicare, it's becoming an increasingly for-profit enterprise. [http://journals.lww.com/ajnonline/Fulltext/2014/09000/The\\_Effects\\_of\\_the\\_Profit\\_Motive\\_on\\_the\\_Hospice.20.aspx](http://journals.lww.com/ajnonline/Fulltext/2014/09000/The_Effects_of_the_Profit_Motive_on_the_Hospice.20.aspx)

**N.B.** Articles on for-profit hospice are noted in the issues of *Media Watch* of 25 August 2014, #372 (p.2); 23 June 2014, #363 (p.2); 3 March 2014, #347 (p.4, pp.9-10); and, 13 January 2014, #340 (pp.3-4).

Cont.

Of related interest:

- *AMERICAN SOCIOLOGICAL REVIEW* | Online – 26 August 2014 – '**Economies of dying: The moralization of economic scarcity in U.S. hospice care.**' As efforts are made to contain health care spending, the decision to stop trying to cure severely ill patients and focus on comfort care has become an economic as well as a moral issue. This article examines the intricate intersection of economics and morality in U.S. hospice care. Using historical, interview, and ethnographic methods, the author explains the resonance between hospice practitioners' moral motivations and policymakers', insurers', and providers' efforts to economize near the end of life. <http://asr.sagepub.com/content/early/2014/08/26/0003122414547756.abstract>

### **Social media and palliative medicine: A retrospective 2-year analysis of global twitter data to evaluate the use of technology to communicate about issues at the end of life**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 2 September 2014 – A lot of discussion about palliative care is taking place on Twitter, and the majority of this is positive. Social media presents a novel opportunity for engagement and ongoing dialogue with public and professional groups. A total of 683.5K tweets containing a combination of 13 palliative care terms were analysed. The tweet volume for all terms increased by 62.3% between 2011-2012 and 2012-2013. The most popular terms include "end-of-life" and "palliative care." Sentiment was high with 89% of tweets rated more positive than all other tweets sent on Twitter during this period. The term 'Liverpool Care Pathway' experienced the highest percentage increase in tweets reaching a peak in July 2013. <http://spcare.bmj.com/content/early/2014/09/02/bmjspcare-2014-000701.abstract>

#### [Media Watch: Editorial Practice](#)

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy 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.

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

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

## Talking about death is not outrageous – reducing it to a tickbox exercise is

*BRITISH MEDICAL JOURNAL* | Online – 29 August 2014 – *The Daily Telegraph* was outraged. The headline read, 'Elderly patients asked during home visits by nurses: Would you want to be resuscitated?'<sup>1</sup> The offending question is part of the direct enhanced service for unplanned admissions. Essentially, GPs are being paid to try not to send people to hospital. On the basis of recent attendance patterns we are meant to identify patients at high risk of being admitted and work out a plan, as the NHS [National Health Service] specification puts it, to "identify factors which could have avoided the admission or future A&E (accident and emergency) attendance with a view to taking appropriate action to prevent future episodes." The bias is obvious: no equivalent specification pays doctors for admitting patients to hospital when it is the best place for them. But millions of pounds are being spent on the illusory idea that millions more pounds can be saved if GPs make a plan for patients that avoids admitting so many to hospital. This is patently nonsense; evidence has shown that this kind of "case

management" doesn't reduce admissions. And where is the evidence of safety or the search for harms? How do we know that GPs' time is being well used? We don't. We are all living longer, with more long term conditions, but (as if planned in a parallel universe) the number of NHS beds is going down. We need what we've always needed: highly trained GPs with the professional freedom to listen and respond tactfully when people want or need to talk about death. <http://www.bmj.com/content/349/bmj.g5369.full>

### Extract from *British Medical Journal* article

Tickbox forms always insist on binary answers. But life is complicated and messy, and being ill, alone, or scared can make us vulnerable. Talking about death is not a bad thing to do, but when health professionals are driven by a policy designed to save money rather than serve patients, we hardly deserve our patients' trust.

1. 'Elderly patients asked during home visits by nurses: Would you want to be resuscitated?' *The Daily Telegraph*, 20 August 2014. [Noted in Media Watch, 25 August 2014, #372 (p.9)] <http://www.telegraph.co.uk/health/nhs/11044923/Elderly-patients-asked-during-home-visits-by-nurses-Would-you-want-to-be-resuscitated.html>

Noted in Media Watch, 1 September 2014, #373 (p.12):

- *NURSING STANDARDS* | Online – 27 August 2014 – '**Chief nurse orders review of DNR questionnaire after media outcry.**' England's chief nurse Jane Cummings has promised to review the content of a form that prompts district nurses to discuss do-not-resuscitate orders with older patients during home visits. <http://rcnpublishing.com/doi/full/10.7748/ns.28.52.7.s2>

Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 2 September 2014 – '**Improving care for patients whose recovery is uncertain. The AMBER care bundle: design and implementation.**' Difficulties in managing clinical uncertainty can result in delayed recognition that a person may be approaching the end of life, and a failure to address his/her preferences. Planning and shared decision-making for hospital patients need to improve where an underlying condition responds poorly to acute medical treatment and there is a risk of dying in the next 1-2 months. <http://spcare.bmj.com/content/early/2014/09/02/bmjspcare-2013-000634.abstract>
- *BRITISH GENERAL PRACTICE*, 2014;64(626):e568-e575. '**Care plans and care planning in the management of long-term conditions in the U.K.: A controlled prospective cohort study.**' In the U.K., the use of care planning and written care plans has been proposed to improve the management of long-term conditions, yet there is limited evidence concerning their uptake and benefits. <http://bjgp.org/content/64/626/e568.full>

Cont.

- *BRITISH GENERAL GENERAL PRACTICE*, 2014;64(626):e576-e583. '**Living in uncertain times: Trajectories to death in residential care homes.**' For some [of the 121] care home residents [i.e., study participants] there was an identifiable period when they were approaching the end-of-life and planned care was put in place. For others, death came unexpectedly or during a period of considerable uncertainty, with care largely unplanned and reactive to events. <http://bjgp.org/content/64/626/e576.abstract>
- *THE IRISH MEDICAL TIMES* | Online – 4 September 2014 – '**Advance care obligations are unmet.**' Legal moves are set to reflect a new culture of "think, talk and tell" in relation to end-of-life issues. Gary Culliton reports on mooted changes that would see legal liability where a valid Advance Healthcare Directives are not followed. Talking about death in Ireland is one of the final taboos we have to face. <http://www.imt.ie/news/uncategorized/2014/09/advance-care-obligations-are-unmet.html>

### End-of-life care in Canada

#### The future of decision-making in critical care after *Cuthbertson v. Rasouli*

*CANADIAN JOURNAL OF ANESTHESIA* | Online – Accessed 2 September 2014 – The Supreme Court of Canada (SCC) ruling on *Cuthbertson v. Rasouli* has implications for all acute healthcare providers. This ... case involved a disagreement between healthcare providers and a patient's family regarding the principles surrounding withdrawal of life support, which the physicians involved considered no longer of medical benefit and outside the standard of care, and whether consent was required for such withdrawals. The authors' objective in writing this article is to clarify the implications of this ruling on the care of critically ill patients. The SCC ruled that due to the legal definition of "health-related purpose," which is distinct from medical benefit, consent is required to withdraw life-support and outlined the steps to be taken should conflict arise. The SCC decision did not directly address the role of medical standard of care in these situations. In order to ensure optimal decision-making and communication with patients and their

families, it is critical for healthcare providers to have a clear understanding of the implications of this legal ruling on medical practice. <http://link.springer.com/article/10.1007/s12630-014-0215-9>

#### **Background on the Hassan Rasouli case**

In October 2010, retired engineer Hassan Rasouli underwent minor brain surgery for a benign tumour at Sunnybrook Hospital in Toronto. Days later, a bacterial meningitis infection left him severely brain damaged and comatose. With a prognosis that foresaw next to no chance of meaningful recovery, attending physicians in the intensive care unit announced plans to withdraw life support measures. Rasouli's wife, herself a medical doctor, and two adult children felt it was too early to make a life-ending judgment call. The family got a court injunction to block doctors from pulling the plug. **Source:** *The National Post*, 17 October 2013.

#### Commentaries:

- *CANADIAN JOURNAL OF ANESTHESIA* | Online – Accessed 2 September 2014 – '**In defence of consent and capacity boards for end-of-life care.**' Hawryluck *et al* express concern about the Supreme Court of Canada's determination that the [Ontario] Consent & Capacity Board is charged with resolving such conflicts since, in their view, this body is ill-equipped to fulfill this role. Instead, they take the position that these disputes should be adjudicated by the courts. The authors disagree with this position and, for the reasons set out in this editorial, take the position that provincial and territorial legislators across the country should follow the lead of the Ontario legislature... <http://link.springer.com/article/10.1007/s12630-014-0217-7#>

Cont.



- *CANADIAN JOURNAL OF ANESTHESIA* | Online – Accessed 2 September 2014 – **'The withdrawal of treatment is still treatment.'** In the paper by Hawryluck *et al* ... the suggestion is made that the Supreme Court of Canada (SCC) changed the rules of engagement around end-of-life decisions when doctors and patients disagree. In fact, the SCC did not disturb prior decisions on the role of experts and the jurisdiction of the courts and restated what has always been the case, i.e., the withdrawal of treatment is treatment and, as such, requires consent. The news for physicians is good. The court neither overreached nor tied the hands of physicians when it cited "health-related purpose." Important medical ethical principles remain in place and will continue to guide complex treatment choices as doctors and patients struggle to do the right thing at the end of life. <http://link.springer.com/article/10.1007/s12630-014-0216-8>

**N.B.** Ontario's Consent & Capacity Board: <http://www.ccboard.on.ca/scripts/english/index.asp>

Noted in Media Watch, 21 October 2013, #328 (p.1):

- CANADA | CBC News – 18 October 2013 – **'Rasouli life-support case: Top court upholds life-support right.'** In a split decision on what the Supreme Court of Canada called a "tragic, yet increasingly common conflict," Chief Justice Beverley McLachlin wrote for the majority that, under Ontario's Health Care Consent Act, treatment cannot be confined to something that doctors consider to be of medical benefit to the patient. Moreover, the court dryly observed that if death is considered a manifestation of ill health, then life support serves a preventive purpose. <http://www.cbc.ca/news/canada/toronto/rasouli-life-support-case-top-court-upholds-life-support-right-1.2125140>

Of related interest:

- *AUSTRALASIAN DISPUTE RESOLUTION JOURNAL* | Online – Accessed 2 September 2014 – **'Information, power and relationships: Minimising barriers to access to justice for end of life disputes.'** This article describes the unique dispute resolution processes of the Queensland Adult Guardian for resolving end of life disputes and analyses those processes from an access to justice perspective. Ultimately, the article argues that a statutory officer providing expert information and advice, as well as non-adversarial and adjudicative dispute resolution, may reduce three key barriers to accessing justice for end of life disputes: 1) lack of information or advice; 2) power differentials; and, 3) concerns about damage to an ongoing relationship. [http://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=2482912](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2482912)
- *JOURNAL OF CLINICAL ETHICS*, 2014;25(3):196-206. **'When should we not respect a patient's wish?'** Patients who face making a high-stakes decision – whether or not to accept a lifesaving intervention – may make a decision that their care providers believe is deeply and dangerously mistaken. How can care providers best help patients in such situations? The author presents approaches that care providers can adopt to help patients who "won't budge" when making what appear to be dangerously erroneous choices regarding lifesaving interventions. <http://www.clinicalethics.com/>

### **A survey about patients transferred from a specialist palliative care unit to an acute hospital setting**

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2014;21(6):219-221. Recent U.K. policy has highlighted the importance of smoothing the transition from curative to palliative care. However, translating the concept of this transition into clinical practice continues to raise challenges. A systematic review of the literature suggests that little is known in the U.K. about the potentially complex process of transition from curative to a palliative approach, although the implications are far-reaching, as transition potentially impacts on place of care, caregiver and goals of care. Recent models of transition favour a phased approach, rather than an abrupt one, incorporating palliative care in parallel with disease-modifying treatments to facilitate collaborative working and continuity of care during the transition phase.

**N.B.** Access requires a subscription. Journal contents: [http://www.haywardpublishing.co.uk/year\\_search\\_review.aspx?JID=4&Year=2014&Edition=518](http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2014&Edition=518)

## **A summary of the European Association for Palliative Care White Paper on Core Competences for Education in Paediatric Palliative Care**

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2014;21(6):245-249. The White Paper contains recommendations from a multidisciplinary and multinational group of paediatric palliative care professionals and educators.<sup>1</sup> It is intended to provide guidance for the development of paediatric palliative care education initiatives and provides links to sample curricula that can be used for teaching students and care providers with different levels of experience and expertise.

1. 'European Association for Palliative Care White Paper on Core Competences for Education in Paediatric Palliative Care,' November 2013.  
<http://www.eapcnet.eu/LinkClick.aspx?fileticket=6elzOURzUAY%3d&tabid=1432>

**N.B.** Access requires a subscription. Journal contents:

[http://www.haywardpublishing.co.uk/year\\_search\\_review.aspx?JID=4&Year=2014&Edition=518](http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2014&Edition=518)

### **Palliative care and dementia**

*HOME HEALTHCARE NURSE*, 2014;32(8):466-469. This article examines the current literature with respect to palliative care for patients with dementia. Symptoms such as disorientation, tension, and anxiety occur in patients with dementia at moderate to severe levels as they approach the end of their lives, as well as other common symptoms found [for example] with cancer patients, yet the dementia population continues to be unrecognized for their need for palliative care.  
[http://journals.lww.com/homehealthcareonline/Abstract/2014/09000/Palliative\\_Care\\_and\\_Dementia.5.aspx](http://journals.lww.com/homehealthcareonline/Abstract/2014/09000/Palliative_Care_and_Dementia.5.aspx)

Noted in Media Watch, 18 August 2014, #371 (p.10):

- *JOURNAL OF ALZHEIMER'S DISEASE* | Online – 4 August 2014 – '**Needs of people with severe dementia at the end-of-life: A systematic review.**' Ten studies published from 1993-2013 were identified, encompassing qualitative, quantitative, and a mixed-methods study. Data synthesis yielded seven themes, with physical, social, and psychological needs the categories most frequently mentioned. <http://iospress.metapress.com/content/8wk34806v5630580/>

Of related interest:

- *DEMENTIA* | Online – 3 September 2014 – '**End-of-life care: The experiences of advance care planning amongst family caregivers of people with advanced dementia: A qualitative study.**' Family caregivers need encouragement to ask the right questions during advance care planning to discuss the appropriateness of nursing and medical interventions at the end of life. <http://dem.sagepub.com/content/early/2014/09/03/1471301214548521.abstract>

**N.B.** Several articles on end-of-life care for people living with dementia are noted in Media Watch, 23 June 2014, #363 (p.11).

### **Role of GPs in end-of-life care**

#### **The last 48 hours**

*INNOVAIT* | Online – 28 August 2014 – With an increasing number of patients identifying home as their preferred place of death, GPs are finding themselves at the frontline of providing end-of-life care. Although there is often support available from specialist palliative care teams in the community, GPs are themselves highly capable of providing good general palliative care, commencing advance care planning and supporting patients and their relatives through what can be a difficult time. Early identification of patients approaching the end of their life enables effective planning, prioritisation of care, and making sure that appropriate resources are available...  
<http://ino.sagepub.com/content/early/2014/08/28/1755738014546676.abstract>

Cont.

Noted in Media Watch, 18 August 2014, #371 (p.9):

- *EUROPEAN JOURNAL OF CANCER CARE* | Online – 6 August 2014 – '**Patients' perspectives on the role of their general practitioner after receiving an advanced cancer diagnosis.**' Themes [to emerge in this study]: 1) obtaining diagnosis and referral for advanced cancer treatment; 2) preference for specialist oncology care; 3) a preference for GP to act as an advocate; and, 4) obtaining ongoing routine care from their GP. Not all communication between GPs and patients was positive suggesting communication skills training [is] a priority. <http://onlinelibrary.wiley.com/doi/10.1111/ecc.12224/abstract;jsessionid=461B49675E320C51148D4FC397709C41.f03t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

### **Why did an out-of-hospital shift of death and dying occur in Canada after 1994?**

*INTERNATIONAL JOURNAL OF PALLIATIVE CARE* | Online – Accessed 31 August 2014 – It became evident through this review that an out-of-hospital shift in Canada was the result of many indirect and direct influences or factors that contributed to death and dying in other places. Future research should focus on the supports needed to ensure good deaths occur in all such places and that individuals are dying in the appropriate place. Abuse and unmet needs in the home or other nonhospital care facilities may go undetected. With low staffing levels and less qualified staff in nursing homes being asked to take on more caregiving responsibility, research is also needed now to determine how best to ensure high quality dying processes in nursing homes. Research and knowledge transfer about the benefits of non-hospital deaths are also needed now, as this shift out of hospital could reverse and hospitals once again could become the predominant place of death and dying. While the shift out of Ca-

nadian hospitals after 1994 was neither directly planned for, anticipated, nor supported by government policy, the maintenance of this shift is likely to need government policy in the years ahead as the number of deaths increases dramatically in Canada. The large baby boom generation has begun to reach old age and many will require end-of-life care in one form or another. Although this literature review was exclusively focused on Canadian literature and Canadian events or developments, many of these ... could have also occurred in other developed and possibly some developing countries. These same factors and influences could be initiating or supporting an out-of-hospital shift elsewhere, as Canada is not the only country where this out-of-hospital shift has occurred. <http://www.hindawi.com/journals/ijpc/2014/157536/>

**N.B.** Hospital deaths in Canada peaked at 80.5% in 1994.

Noted in Media Watch, 11 May 2009, #96 (p.8):

- *SOCIAL SCIENCE & MEDICINE*, 2009;68(10):1752-1758. '**The rapidly changing location of death in Canada, 1994-2004.**' A substantial and continuing decline in hospitalized deaths was found (77.7-60.6%). <http://www.sciencedirect.com/science/article/pii/S0277953609001506>

### **Deficiencies and missed opportunities to formulate clinical guidelines in Australia for withholding or withdrawing life-sustaining treatment in severely disabled and impaired infants**

*JOURNAL OF BIOETHICAL INQUIRY* | Online – 31 August 2014 – This paper examines the few, but important legal and coronial cases concerning withdrawing or withholding life-sustaining treatment from severely disabled or critically impaired infants in Australia. Although sparse in number, the judgements should influence common clinical practices based on assessment of "best interests" but these have not yet been adopted. Although courts have discounted assessment of "quality of life" as a legitimate component of determination of "best interests," this remains a prominent component of clinical guidelines. This paper highlights the lack of uniform clinical guidelines available to medical professionals and parents in Australia when making end-of-life decisions for severely ill infants. <http://link.springer.com/article/10.1007/s11673-014-9572-x>

## Social work, religion and palliative care

*JOURNAL OF RELIGION & SPIRITUALITY IN SOCIAL WORK*, 2014;33(3-4):339-352. While courses on spirituality have recently been on the curriculum in some schools of social work, religion is not incorporated into social work programs. In spite of a decline in church attendance in Canada, religion continues to be a salient force in the lives of many people particularly when they are nearing the end of life. Social workers working in palliative care need to be knowledgeable of religion and have sensitivity to religious practices. This requires a familiarity with religious language and skills in supporting people who look to religion for answers to the meaning and purpose in their lives and their deaths. It is frequently in times of crisis and uncertainty that people's faith becomes central. Social workers need skills to support them on the end of life journey. <http://www.tandfonline.com/doi/abs/10.1080/15426432.2014.930638>

### Exploring meaning in end-of-life care practice

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2014;21(6):240-244. There is considerable overlap and interaction between physical, psychological, social and spiritual approaches to meaning in end-of-life and palliative care. However, in developing interventions in the future, it may be helpful to distinguish between the spiritual emphasis on existential meaning for individuals of death and bereavement experiences, and the psychological and social approach to their attributions of significance to behaviour and relationships within their environment.

**N.B.** Access requires a subscription. Journal contents: [http://www.haywardpublishing.co.uk/\\_year\\_search\\_revew.aspx?JID=4&Year=2014&Edition=518](http://www.haywardpublishing.co.uk/_year_search_revew.aspx?JID=4&Year=2014&Edition=518)

Selected articles on religion and end-of-life care noted in past issues of Media Watch:

- *JOURNAL OF SURGICAL RESEARCH* | Online – 2 June 2014 – '**Religiously affiliated ICU patients receive more aggressive end-of-life care.**' Religiously affiliated patients [i.e., study participants] incurred 23% more hospital charges, 25% more ventilator days, 23% more hospital days, and 30% longer time until death than their non-affiliated counterparts... [Noted in Media Watch, 9 June 2014, #361 (p.14)] [http://www.journalofsurgicalresearch.com/article/S0022-4804\(14\)00540-X/abstract](http://www.journalofsurgicalresearch.com/article/S0022-4804(14)00540-X/abstract)
- *SOCIAL FORCES* | Online – 10 August 2012 – '**Religion and end-of-life treatment preferences: Assessing the effects of religious denomination and beliefs.**' Fundamentalist Catholics and fundamentalist Protestants were more likely than their non-fundamentalist counterparts to desire life-extending treatments... [Noted in Media Watch, 20 August 2012, #267 (p.7)] <http://sf.oxfordjournals.org/content/early/2012/08/09/sf.sos061.abstract>
- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 18 March 2009 – '**Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer.**' Positive religious coping is associated with receipt of more intensive life-prolonging medical care at the end of life. [Noted in Media Watch, 23 March 2009, #89 (p.7)] <http://jama.jamanetwork.com/article.aspx?articleid=183578&resultClick=3>

## Final arrangements: Examining debt and distress

*MORTALITY* | Online – 2 September 2014 – Prevailing discourses condemn funerals as a costly distress purchase where funeral directors have greedily preyed upon funeral arrangers' grief laden vulnerability. They explain funerals as distress purchases and so debt as the outcome of irrational decisions made while emotionally overwhelmed. These discourses ignore how people might use funeral purchases in dealing with the experience of death as they obscure rather than explain the emotionally infused decision-making that incurs funeral debt. This paper aims to shed light on this aspect of funeral purchases through a New Zealand-based empirical investigation of how intense feelings connect with decision-making associated with funeral cost and debt. <http://www.tandfonline.com/doi/abs/10.1080/13576275.2014.948413?queryID=%24%7BresultBean.queryID%7D>

## Hospice Friendly Hospitals in Ireland – taking stock of an innovative programme

UNIVERSITY OF GLASGOW | Online (Blog) – 3 September 2014 – Imagine a project which seeks to take the best attributes of hospice care and inculcate them into the fabric of the acute hospital. Not just one hospital, but all hospitals in a whole country. Consider a project that is about a joined up approach to clinical care when death is near, that takes seriously the relationship between hospital design and the potential to deliver dignified care, and that adopts an 'all systems' approach to its mode of operation. Think of a project that has been able to attract support from major celebrities, politicians and people from the creative media to promote better end of life care in hospitals and advocate for change. These are just some of the ingredients of the Hospice Friendly Hospitals initiative that first began to develop in Ireland in the late 1990s. This week the Irish Hospice Foundation – the home and source of inspiration for the idea of Hospice Friendly Hospitals – is publishing two reports on this work, and taking stock of where it can go in the future.<sup>1,2</sup> <http://endoflifestudies.academicblogs.co.uk/hospice-friendly-hospitals-in-ireland-taking-stock-on-an-innovative-programme/>

1. 'The Hospice Friendly Hospitals Programme in Ireland: A Narrative History,' Irish Hospice Foundation. <http://hospicefoundation.ie/wp-content/uploads/2014/09/The-Hospice-Friendly-hospitals-programme-in-Ireland-a-narrative-history.pdf>
2. 'The Hospice Friendly Hospitals Programme in Ireland: Overview 2007-2013,' Irish Hospice Foundation. <http://hospicefoundation.ie/wp-content/uploads/2013/04/The-Hospice-Friendly-Hospitals-Programme.-Overview-2007-2013.pdf>

## Two reports that shaped the history of end-of-life care in the U.K.

UNIVERSITY OF GLASGOW | Online (Blog) – 29 August 2014 – The U.K. welfare state upon its creation in 1948 sought to vouchsafe care "from the cradle to the grave," yet the early years of the National Health Service [NHS] saw little attention to care at the end of life and focused instead on addressing the widespread acute and chronic health problems of a society grappling with post-war social and economic reconstruction. In the first two decades of its existence there is little evidence that the NHS offered any strategic or operational guidance on the care of the dying. Indeed, where such guidance did appear, it was usually from charitable and philanthropic sources. Two major reports prepared during the 1950s are particularly relevant in this context. They provide evidence on the social conditions encountered by dying people in Britain in the 1950s and also sketch out the actual and potential organisation of terminal care services. Both emanated from outside the portals of the NHS. Yet they contributed to a modest shift in medical discourse on terminal care and paved the way for some important future developments. Upon these two rather fragile edifices the ground breaking and deeply consequential work of Dr. Cicely Saunders was established, from the appearance of her

first publication on terminal care in 1958 to the opening of St. Christopher's Hospice a decade later. Led by her efforts, a new way of thinking about terminal care began to emerge in the 1950s, which eventually had the power to consolidate into a strategy for action, initially at arm's length from the NHS itself but eventually with wide ranging effect. <http://endoflifestudies.academicblogs.co.uk/two-reports-that-shaped-the-history-of-end-of-life-care-in-the-united-kingdom/>

### Extract from Glasgow of University article

On their own, these reports were not sufficient to create a sea-change in policy. However, they did stimulate, and were in turn strengthened by, a growing clinical interest in questions of terminal care which served slowly to draw further attention to the needs of those in the final stages of life.

### Worth Repeating

'The evolution of palliative care' (p.14), by Cicely Saunders, in *Journal of the Royal Society of Medicine*.

## Worth Repeating

### **The evolution of palliative care**

*JOURNAL OF THE ROYAL SOCIETY OF MEDICINE*, 2001;94(9):430-432. There remains a clamant need to address attitudes to end-of-life care among the professions, the public and the media. The losses of parting cannot be removed but their devastating effects can be ameliorated. For this we must give attention to the whole person, with all the insights the humanities can give us. We need to focus more on the discrepancy between the developed and developing worlds in terms of medical care and research, epidemiological and clinical. Validated tools for assessing quality of life should be more widely used with this challenge in mind. Psychological issues for patients and families should be studied, with recognition of profound (though often unarticulated) spiritual and existential distress. Academic centres with multiprofessional teams have the potential to develop recognized standards. These should be offered as part of the ongoing commitment to every person in need of care for progressive disease, and should incorporate the same urge for exploration as characterized at the earlier stages. Our common humanity demands no less. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1282179/>

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## Media Watch Online

### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/8/media-watch/>

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]

### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://aphn.org/category/media-watch/>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/updates/international-palliative-care-resource-center-media-watch/>

### **Australia**

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> [Scroll down to 'International Websites' and [www.ipcrc.net/archive-global-palliative-care-news.php](http://www.ipcrc.net/archive-global-palliative-care-news.php) to access the weekly report]

### **Canada**

ONTARIO | Central Regional Hospice Palliative Care Program: <http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1>

ONTARIO | Central West Palliative Care Network: [http://cwpcn.ca/Health\\_Practitioners/resources.htm?mediawatch=1](http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1)

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://hpcconnection.ca/general-resources/in-the-news/>

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

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/> [Scroll down to 'Additional Resources']

### **Europe**

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://www.eapcnet.eu/Themes/Organization/Links.aspx> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes>

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>