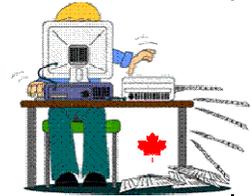


Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to [Specialist Publications](#) and 'Can comprehensive specialised end-of-life care be provided at home? Lessons from a study of an innovative consultant-led community service in the U.K.' (p.9), in *European Journal of Cancer Care*.

Canada

One-third of vegetative patients may be conscious: Study

MACLEAN'S | Online – 15 April 2014 – As many as one-third of vegetative patients are misdiagnosed, according to a new study.¹ Using brain imaging techniques, researchers found signs of minimal consciousness in 13 of 42 patients who were considered vegetative. "The consequences are huge," Dr. Steven Laureys, of the Coma Science Group at the Université de Liège [in Belgium]. "These patients have emotions; they may feel pain; studies have shown they have a better outcome [than vegetative patients]. Distinguishing between unconscious, and a little bit conscious, is very important." Detecting human consciousness following brain injury remains exceedingly difficult. Vegetative patients are typically diagnosed by a bedside clinical exam, and remain "neglected" in the health care system, Laureys says. Once diagnosed, "they might not be [re-examined] for years. Nobody questions whether or not there could be something more going on." <http://www.macleans.ca/society/health/one-third-of-vegetative-patients-may-be-conscious-new-study/>

Extract from *Maclean's* article

[Dr.] Laureys previously collaborated with neuroscientist Adrian Owen at University of Western Ontario...¹ They co-authored a now-famous paper...² Using functional magnetic resonance imaging they saw that a patient was activating two different parts of her brain, just like healthy volunteers did. Laureys and Owen also worked together on a 2010 follow-up study³ where the same technique was used to ask a patient to answer "yes" or "no" to various questions, presenting the stunning possibility that some vegetative patients might be able to communicate.

1. 'Inside a comatose mind,' *Maclean's*, 16 October 2013. [Noted in Media Watch, 21 October 2013, #328 (p.3)]
<http://www.macleans.ca/society/technology/beyond-words/>

2. 'Detecting awareness in the vegetative state,' *Science*, 8 September 2006.
<https://www.sciencemag.org/content/313/5792/1402.abstract>

3. 'Willful modulation of brain activity in disorders of consciousness,' *New England Journal of Medicine*, 18 February 2010. [Noted in Media Watch, 27 September 2010, #168 (p.2)]
<http://www.nejm.org/doi/full/10.1056/NEJMoa0905370>

Cont.

1. 'Diagnostic precision of PET imaging and functional MRI in disorders of consciousness: a clinical validation study,' *The Lancet*, 16 April 2014.
[http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(14\)60042-8/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(14)60042-8/fulltext)

Knowing when to give up a terminal illness fight may help people to enjoy the end of their lives better

THE NATIONAL POST | Online – 15 April 2014 – We're making enormous advances in the fight against the dreaded disease [of cancer]. We're now entering an era where medical treatment can be tailored specifically to you, on an individual level. But such aggressive combat against potentially serious diseases like cancer requires investments – in time, with lots of mornings and afternoons spent paging through magazines in various medical waiting rooms. It requires investments in effort, with lots of energy expended learning about various experimental therapies. And, frequently, it also requires investments of money, to cover travel expenses, say, as well as the doctor's fees required in the event the patient wishes to consult with out-of-country physicians. The question that my patient has encouraged me to mull over amounts to: Is all that effort worth it? Some doctors may be biased toward intervention, toward expending all possible effort to fight cancer at all costs. Some patients, however, may be inclined to accept the diagnosis of a terminal disease, and attempt to maximize the enjoyment of their remaining time. Or the doctor may be fatalistic and the patient might be the one girding for war. To be certain that the doctor and the patient are aligned in their approach, an article in last week's *Canadian Medical Association Journal* recommends doctors proactively inquire how their patients feel about end-of-life care.¹
<http://news.nationalpost.com/2014/04/15/dr-aw-knowing-when-to-give-up-a-terminal-illness-fight-may-help-people-to-enjoy-the-end-of-their-lives-better/>

1. 'Discussing goals of care with patients in hospital with serious illness,' *Canadian Medical Association Journal*, 2014;186(6):425-432. First published online 15 July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.2)] <http://www.cmaj.ca/content/early/2013/07/15/cmaj.121274>

U.S.A.

House calls are making a comeback

THE NEW YORK TIMES | Online – 19 April 2014 – A relic from the medical past – the house call – is returning to favor as part of some hospitals' palliative care programs, which are sending teams of physicians, nurses, social workers, chaplains and other workers to patients' homes after they are discharged. The goal is twofold: to provide better treatment and to cut costs.
http://www.nytimes.com/2014/04/20/business/house-calls-are-making-a-comeback.html?ref=health&_r=0

Noted in Media Watch, 11 February 2013, #292 (p.3):

- *THE WALL STREET JOURNAL* | Online – 4 February 2013 – '**Hospitals try house calls to cut costs, admissions.**' To keep patients out of the hospital, health-care providers are bringing back revamped versions of a time-honored practice: the house call.
<http://online.wsj.com/article/SB10001424127887324610504578278102547802848.html>

Noted in Media Watch, 2 July 2012, #260 (p.2):

- MASSACHUSETTS | *Boston Globe* – 1 July 2012 – '**Can house calls cut health costs?**' Daniel Oates, a Boston Medical Center geriatrician ... believes home visits provide more personalized, consistent care to people who might not otherwise see a doctor and can prevent hospitalizations or delay a move to a nursing home. <http://bostonglobe.com/lifestyle/health-wellness/2012/07/01/can-house-calls-cut-health-care-costs-house-calls-boston-medical-center-program-testing-home-care-for-homebound-seniors/s6jidObrL7oC43IkTDK8dL/story.html>

Connecticut's effort to expand patients' end-of-life care options

CONNECTICUT | *The Connecticut Mirror* (Hartford) – 17 April 2014 – The Senate passed a bill that would establish a process for people with terminal illnesses to document the sort of end-of-life care they want in a medical order for health care providers to follow. People who work in emergency medicine say it's needed to address shortcomings in the options people currently have for making their wishes known. The measure ... now goes to the House. The bill would let the state Department of Public Health create a pilot program for the use of "medical orders for life-sustaining treatment" ... a process in which terminally ill patients discuss their options with a health care provider, determine the type of end-of-life care they want, and document it in a medical order. Patients would be able to outline choices that include whether they would want only treatment that provides comfort, limited interventions such as antibiotics, or full treatment that could include intubation and intensive care. The bill would not require people to create medical orders (they would be voluntary) and would not require people to choose a particular type of end-of-life care. People could use the orders to ask for aggressive life-saving care or comfort measures only, or something in between. <http://ctmirror.org/the-basics-cts-effort-to-expand-patients-end-of-life-care-options/>

End of life decisions for the "oldest old"

OHIO | WVXU Radio (Cincinnati) – 14 April 2014 – The "oldest old," those 85 and over, are America's fastest growing age group. The growth rate for that segment is four times that of the total population. People with relatives in that age group or those who have reached that point themselves, may be familiar with the options for aggressive treatment modern medicine offers, options that weren't available when the previous generations of elderly approached the end. Dr. Elizabeth Rabkin, an internist and palliative care specialist with the University of Cincinnati physicians, says doctors, "have a little bit of a problem with accepting dying as a natural part of life." She says it can be hard for specialists who can fix conditions

that used to mean imminent death, to recognize the wearing out of the human body. <http://wvxu.org/post/end-life-decisions-oldest-old>

Extract from WVXU Radio report

Some elderly patients do choose to fight to the end. But doctors say when they're able to explain the benefits and burdens of a life extending treatment, patients often react ... choosing a peaceful end rather than enduring treatment that might add only very uncomfortable weeks or months to their lives.

Noted in Media Watch, 27 August 2012, #268 (p.2):

- NATIONAL PUBLIC RADIO | Online – 21 August 2012 – '**Oldest Americans living longer...**' Today's 65-year-olds can expect to live a tad over 20 more years. That's a jump from 1980, when 65-year-olds could expect 14 more years of life. When it comes to the end of life, there may be some consolation that death is less likely to happen in a hospital today (32%) than in 1999 (49%) – and, more likely to be at home under the ministrations of hospice care.¹ <http://www.npr.org/blogs/health/2012/08/21/159521631/oldest-americans-living-longer-and-are-fitter-and-richer-too>

1. 'Location of death for decedents aged ≥85 years – U.S., 1989-2007,' Centers for Disease Control & Prevention, September 2011. [Noted in Media Watch, 23 April 2012, #250 (p.4)] <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6037a9.htm>

[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.14.

Family caregivers providing complex chronic care to their spouses

UNITED HOSPITAL FUND | Online – 14 April 2014 – This report shows that spouses who are caregivers not only perform many of the tasks that health care professionals do – a range of medical/nursing tasks including medication management, wound care, using meters and monitors, and more – but they are significantly more likely to do so than other family caregivers, who are mostly adult children. According to the report, nearly two-thirds of spouses who are family caregivers performed such tasks (65%), compared to 42% of non-spousal caregivers. And despite these responsibilities, spouses were less likely than non-spousal caregivers to receive in-home support from health care professionals: 84% of spousal care recipients received no professional health care on site, compared to 65% of non-spousal care recipients. They were also less likely to receive help from family or friends or home care aides: 58% of the spouses reported no additional help from others, compared to

20% of non-spouses. The report notes it is unclear why spouses receive less help, hypothesizing that it could be choice, lack of awareness about resources, financial limitations, or fear of losing independence. The report calls for research to help tailor interventions that support but do not supplant the primary bond between spouses. file:///C:/Users/Barry/Downloads/SpousalCaregivers_web.pdf

Specialist Publications

'Reaction to caregiving by hospice caregivers upon enrollment' (p.8), in *American Journal of Hospice & Palliative Medicine*.

'Organizational and environmental correlates of the adoption of a focus strategy in U.S. hospices' (p.10), in *Health Care Management Review*.

N.B. Profile of the long-term care provider: Source PBS Newshour: <http://www.pbs.org/newshour/spc/multimedia/ltc-caregivers-profile/>

Noted in Media Watch, 15 October 2012, #275 (p.2):

- **FORBES** | Online – 12 October 2012 – **'We need better ways to train and support family caregivers.'** Family caregivers acknowledge they are largely untrained, and many say they learned how to perform difficult tasks on their own, or from a friend or neighbor. Few were taught by health professionals. They are the backbone of the support system for the frail elderly and younger people with disabilities. Yet ... they often don't know what they are doing. <http://www.forbes.com/sites/howardgleckman/2012/10/12/we-need-better-ways-to-train-and-support-family-caregivers/>

Noted in Media Watch, 8 October 2012, #274 (p.3):

- **SENIOR HOUSING NEWS** | Online – 1 October 2012 – **'Family caregivers providing more complex senior care to avoid nursing homes.'** The market for potential assisted living or skilled nursing facility residents is being depleted by family caregivers who are taking on more and more senior care responsibilities, including medical and nursing tasks once only provided in hospitals, according to a new American Association for Retired Person [AARP] report.¹ <http://seniorhousingnews.com/2012/10/01/family-caregivers-providing-more-complex-senior-care-to-avoid-nursing-homes/>

1. 'Home Alone: Family Caregivers Providing Complex Chronic Care,' AARP, October 2012. http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-AARP-ppi-health.pdf

- **AARP MAGAZINE** | Online – 1 October 2012 – **'I'm a caregiver, but feel like a nurse!'** Ask yourself: Are you suited for the medical jobs of family caregiving? <http://www.aarp.org/home-family/caregiving/info-09-2012/im-a-caregiver-but-feel-like-a-nurse.html>

Talking about dying and death

Wounded by the language of war

THE NEW YORK TIMES | Online – 11 April 2014 – When did the language we use to talk about death start to resemble a Pentagon briefing, full of military references and combat analogies? Maybe it dates to 1971, when Richard Nixon declared a "war on cancer." Or much earlier, in the late 1800s, when doctors began using the word "armamentarium" to describe all the techniques, materials and equipment available to treat disease. Certainly these metaphors have since become pervasive, among patients and physicians, the public and the news media. Family members seek aggressive treatment for an ailing relative, saying, "He's a fighter," or "She's a survivor." We talk about whether people with terminal diseases want "heroic measures" or not. And when people die, we portray them not as having succumbed to disease, but as having struggled to the very end before being vanquished by a superior foe. Recent death notices in *The New York Times* (which are placed by families, as opposed to the obituaries written by reporters) memorialized a woman in her 90s who died "after a valiant battle against Alzheimer's and Parkinson's" and a 93-year-old man who died "after a long-fought battle with prostate cancer." The bellicose wording "reflects some of the death-denying and death-defying feelings we find in our culture," said Dr. Daniel Johnson, a palliative-care physician in Denver who directs the Kaiser Permanente Care Management Institute. "Society sees death as the enemy, so it's not surprising we turn to language that references war." <http://newoldage.blogs.nytimes.com/2014/04/11/wounded-by-the-language-of-war/?ref=health>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ARIZONA | Associated Press (Phoenix) – 16 April 2014 – **'Arizona bill targets assisted suicide.'** The Arizona Senate has given initial approval to a bill that aims to make it easier to prosecute people who help someone commit suicide. House Bill 2565 defines assisting in suicide as providing the physical means used to commit suicide, such as a gun. The bill originally also defined assisted suicide as "offering" the means to commit suicide, but a Senate amendment omitted that word. The proposal was prompted by a difficult prosecution stemming from a 2007 assisted suicide in Maricopa County. The Senate must still cast a full roll-call vote. <http://www.sfgate.com/news/article/Arizona-bill-targets-assisted-suicide-5408334.php>

Specialist Publications

'The changing legal climate for physician aid in dying' (p.15), *Journal of the American Medical Association*.

International

Aging in the U.K.

Pensioners could get life expectancy guidance

U.K. | BBC News – 17 April 2014 – Retirees could be issued guidance on how long they are likely to live, a government minister has said. Pensions Minister Steve Webb warned people often underestimate how long they might live and can be left without enough savings. Estimates of life expectancy would be based on factors such as gender, where they live, and whether they smoke. The information would help them plan their finances more efficiently, according to the minister. "We don't have a lot to go on" when planning for retirement, he told the BBC, suggesting that "we might think perhaps about how long our grandparents lived, and of course in the generation since then people are living a lot longer." People tend to underestimate how long they're likely to live, he explained. <http://www.bbc.com/news/uk-politics-27062273>

End-of-life care and bereavement in Ireland

IRELAND | Seanad Éireann (Upper House of the Oireachtas, the Irish legislature) – 16 April 2014 – Senator Marie-Louise O'Donnell proposed a Private Members Motion calling on the government to put in place a review to explore the components of an overarching strategy on end of life and bereavement, which would look at the wider societal issues arising including legal, financial, economic, educational, and cultural aspects. Senator O'Donnell's motion can be downloaded at: <http://oireachtasdebates.oireachtas.ie/debates%20authoring/debateswebpack.nsf/takes/seanad2014041600025?opendocument#Z00100>

Noted in Media Watch, 28 October 2013, #329 (p.5):

- IRELAND | *The Irish Times* (Dublin) – 22 October 2013 – '**Lack of hospice beds leaves terminal patients out in the cold.**' More than a decade ago a report from the National Advisory Committee on Palliative Care recommended there should be one hospice bed per 10,000 of the population.¹ According to the latest report from the Irish Hospice Foundation,² just "just two regions – the midwest and northwest – come close to fulfilling government policy." <http://www.irishtimes.com/life-and-style/health-family/lack-of-hospice-beds-leaves-terminal-patients-out-in-the-cold-1.1568194>
 1. *Report of the National Advisory Committee on Palliative Care*, Department of Health & Children, 2001. <http://www.dohc.ie/publications/pdf/nacpc.pdf?direct=1>
 2. *Access to Specialist Palliative Care Services & Place of Death in Ireland...* Irish Hospice Foundation, May 2013. <http://hospicefoundation.ie/wp-content/uploads/2013/06/Access-to-specialist-palliative-care-services-place-of-death-in-Ireland.pdf>

Noted in Media Watch, 21 January 2013, #289 (p.4):

- IRELAND | The Atlantic Philanthropies – 17 January 2013 – '**Evaluation: Programme to Support Palliative & Hospice Care in the Republic of Ireland.**' There has been significant expansion in palliative care services in Ireland over the last 25 years, although gaps in provision remain. This report presents the findings of a five-phased evaluation of the programme. http://www.atlanticphilanthropies.org/sites/default/files/uploads/Evaluation_Programme_Support_Palliative_and_Hospice_Care_%20Republic_of_Ireland.pdf

End-of-life care in Scotland

We can do more for those caring at the end

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 16 April 2014 – Caring for someone with a terminal illness or near the end of their life is both physically and emotionally draining. It's something that we will all likely have to do at some point in our lives, whether it is for a family member or a friend. Recently-published research by the University of Edinburgh, National Health Service Lothian, Voices of Carers Across Lothian and Marie Curie Cancer Care highlighted that more needs to be done to ensure that carers have access to support services and vital benefits.¹ The Scottish Government is currently consulting on new carers legislation and it is crucial that the Government's proposals reflect the needs of this specific care group. <http://www.scotsman.com/news/we-can-do-more-for-those-caring-at-the-end-1-3377635>

Specialist Publications

'Can comprehensive specialised end-of-life care be provided at home? Lessons from a study of an innovative consultant-led community service in the U.K.' (p.9), in *European Journal of Cancer Care*.

'Actual and preferred place of death of home-dwelling patients in four European countries: Making sense of quality indicators' (p.10), in *PLoS One*.

Cont.

1. 'Understanding the barriers to identifying carers of people with advanced illness in primary care: Triangulating three data sources,' *BMC Family Practice*, publish online 2 April 2014. <http://www.biomedcentral.com/1471-2296/15/48>

Noted in Media Watch, 24 March 2014, #350 (p.8):

- *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. Effective integration will depend on health, social care and third/independent sector partners pooling resources and planning care together, led by clinicians and other professionals. <http://spcare.bmj.com/content/4/1/118.1.short>

Greater occupational therapists emphasis needed for palliative care patients

AUSTRALIA (West Australia) | Science Network – 13 April 2014 – Local researchers are calling for a greater role for occupational therapists (OTs) in end-of-life palliative care in Western Australia. Curtin University experts Sharon Keesing and Professor Lorna Rosenwax say internationally accepted "standards" for best practice are not being implemented, and that unlike in the U.S. and U.K., OTs are not viewed as essential members of palliative care teams. "It is estimated that by 2016, the demand for palliative care services will outweigh available services in Western Australia," Ms Keesing says. "[This] means policies, models of service delivery, and organisational strategies must be developed so that dying people and their carers are able to receive quality, timely and easily accessible care, including occupational therapy. "Currently no OTs are employed in private community hospice or community 'hospice in the home' services. Similarly, limited opportunities for OTs are available to provide palliative care for people living in residential aged care facilities." <http://www.sciencewa.net.au/topics/health-a-medicine/item/2779-greater-ot-emphasis-needed-for-palliative-care-patients>

From the archives:

- *AUSTRALIAN OCCUPATIONAL THERAPY JOURNAL*, 2013;60(5):370-373. **'Establishing a role for occupational therapists in end-of-life care in Western Australia,'** There are differences between Australia, the U.S. and other countries regarding the role of occupational therapy in end-of-life care. The authors discuss these and recommendations to assist the occupational therapy discipline work towards the "best practice" model discussed by Burkhardt *et al.*¹ <http://onlinelibrary.wiley.com/doi/10.1111/1440-1630.12058/abstract;jsessionid=8B4036760969615360DDB30BA5C3C8A4.f03t03?deniedAccessCustomisedMessage=&userIsAuthenticated=false>
 1. 'The role of occupational therapy in end-of-life care,' *American Journal of Occupational Therapy*, 2011;65(6):S66-S75. Occupational therapy practitioners are an important part of hospice and palliative care teams as direct care providers and consultants. An occupational therapy practitioner's understanding of the meaning of occupation makes a powerful contribution to the process of caring for the dying person. <http://www.aota.org/-/media/Corporate/Files/AboutAOTA/OfficialDocs/Statements/Role-OT-End-of-Life.PDF>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE NETHERLANDS | *Dutch News* – 16 April 2014 – **'Pharmacists sometimes refuse to give doctors euthanasia drugs.'** Dutch pharmacists sometimes refuse to provide the drugs needed by people who have chosen to end their lives through euthanasia. Euthanasia has been legal in The Netherlands since 2002 under strict conditions and if approved by two doctors. More than half of doctors working for an independent clinic say they have been refused the drugs on the grounds pharmacists do not agree euthanasia is appropriate for a particular patient. Most refusals concern "controversial" cases, i.e., patients who have dementia, a psychiatric illness or who consider their lives "complete." Some refuse on religious grounds. http://www.dutchnews.nl/news/archives/2014/04/pharmacists_sometimes_refuse_t.php

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

End-of-life care in the U.S.

Reaction to caregiving by hospice caregivers upon enrollment

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 16 April 2014 – This study explores the reactions of hospice caregivers to their caregiving experience prior to enrollment in hospice and identifies potential stressors associated with those reactions. Results found anxiety to be a significant predictor in the reaction of caregivers to their caregiving experience. <http://ajh.sagepub.com/content/early/2014/04/15/1049909114531327.abstract>

"Nudge" in the clinical consultation – an acceptable form of medical paternalism?

BMC MEDICAL ETHICS | Online – 17 April 2014 – Overall the extremes of autonomy and paternalism are not compatible in a responsive, responsible and moral health care environment, and thus some compromise of these values is unavoidable. Nudge techniques are widely used in policy making and we demonstrate how they can be applied in shared medical decision making. <http://www.biomedcentral.com/content/pdf/1472-6939-15-31.pdf>

Noted in Media Watch, 10 March 2014, #348 (p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 3 March 2014 – **'When open-ended questions don't work: The role of palliative paternalism in difficult medical decisions.'** Paternalism, characterized as the antithesis of autonomy, is widely dismissed as having any role in medicine. The authors disagree and believe that paternalism still has an important role in medical decision making. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0408>

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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.

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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.

Noted in Media Watch, 6 May 2013, #304 (p.7):

- *AMERICAN JOURNAL OF BIOETHICS* | Online – 3 May 2013 – **'Nudging and informed consent.'** ..."nudging" refers to steering individual decision making so as to make choosers better off without breaching their free choice. If successful, this may offer an ideal synthesis between the duty to respect patient autonomy and that of beneficence, which at times favors paternalistic influence.. <http://www.tandfonline.com/doi/abs/10.1080/15265161.2013.781704>

Can comprehensive specialised end-of-life care be provided at home? Lessons from a study of an innovative consultant-led community service in the U.K.

EUROPEAN JOURNAL OF CANCER CARE | Online – 15 April 2014 – This study found that 71% of patients cared for by the Midhurst Macmillan Specialist Palliative Care Service had died at home. The mean cost is about £3,000 (€3,461) per patient. The study quantified the cost of care in the last year of life for patients with cancer accessing community-based specialist palliative care. Specifically for the Midhurst service this was estimated at around £1,900 (€2,192) per patient. The major source of cost variation occurred pre-referral, with incremental cost of around £6,000 (€6,924) associated with later referral. Evidence from bereaved carers suggests that they receive good or excellent support from the Midhurst service. Reports by patients, carers and bereaved carers point to satisfaction with the Midhurst service when it has played a major role in end-of-life care. However, some carers reported the problem of the period of hands-on care for some patients being short, with care switched to Continuing Health Care at a late stage. This suggests that Midhurst-style services should include sufficient care assistants to cover the whole course of a patient's terminal illness. The Midhurst service was not reliant on high-quality primary care, but complementary to other services, operating at a secondary care level and filling gaps in existing community service provision. Further, it is likely that flexibility of the individuals concerned within the Midhurst team was crucial, and necessary for the model to work. <http://onlinelibrary.wiley.com/enhanced/doi/10.1111/ecc.12195/>

Of related interest:

- *BMC PALLIATIVE CARE* | Online – 17 April 2014 – **"It's alright to ask for help": Findings from a qualitative study exploring the information and support needs of family carers at the end of life.** Family carers experience multiple needs for information and education, but meeting these needs remains a challenge. Three domains could underpin this type of intervention: developing knowledge and competence; facilitating preparedness; and, supporting role recognition and confidence building. <http://www.biomedcentral.com/content/pdf/1472-684X-13-22.pdf>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 18 April 2014 – **'Clinical impact of a home-based palliative care program: A hospice-private payer partnership.'** A home-based palliative care program was developed between two local commercial payers and a not-for-profit hospice. Not only did this program improve symptom management, advance directives completion and satisfaction, but it also facilitated the transition of patients into hospice care, when appropriate. [http://www.jpmsjournal.com/article/S0885-3924\(14\)00185-7/abstract](http://www.jpmsjournal.com/article/S0885-3924(14)00185-7/abstract)

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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>

- *PLOS ONE* | Online – 8 April 2014 – '**Actual and preferred place of death of home-dwelling patients in four European countries: Making sense of quality indicators.**' The quality indicator "the percentage of home deaths" is easy for GPs to provide, but might give a narrow view of the quality of care, implying that home deaths are the golden standard. Hence it might seem that the quality indicator "dying at the preferred place" is a better alternative, as it takes into account all preferences met in all locations. However, it is not feasible at present to have this indicator measured by GPs due to the high percentage of cases where the preferences are unknown to the GP. The authors suggest using information from relatives as long as information from GPs on the preferred place of death is lacking. The authors recommend GPs pay attention to communication ... exploring patients' preferences, including the place of death. <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0093762#pone-0093762-g001>

Noted in Media Watch, 10 June 2013, #309 (p.9):

- *EUROPEAN JOURNAL OF CANCER* | Online – 18 February 2013 – '**Awareness of general practitioners concerning cancer patients' preferences for place of death: Evidence from four European countries.**' Despite the importance of being able to die in a preferred location, GPs [i.e., study participants] were often unaware about patient preferences. If GPs were informed, the preference was often met in all countries, indicating room for improvement in end-of-life care. [http://www.ejancer.info/article/S0959-8049\(13\)00044-0/abstract](http://www.ejancer.info/article/S0959-8049(13)00044-0/abstract)

Organizational and environmental correlates of the adoption of a focus strategy in U.S. hospices

HEALTH CARE MANAGEMENT REVIEW | Online – 10 April 2014 – The hospice industry has experienced rapid growth in the last decade and has become a prominent component of the U.S. health care delivery system. In recent decades, the number of hospices serving nursing facility residents has increased. However, there is paucity of research on the organizational and environmental determinants of this strategic behavior. The findings from this study indicate that organizational size, community wealth, competition, and ownership type are important predictors of the adoption of a nursing facility focus strategy. Hospices may be adopting a nursing facility focus strategy in response to increasing competition ... [and] ... to secure stability in referrals. http://journals.lww.com/hcmrjournal/Abstract/publishahead/Organizational_and_environmental_correlates_of_the.99868.aspx

Mapping the literature: Palliative care within adult and child neurology

JOURNAL OF CHILD NEUROLOGY | Online – 9 April 2014 – The objectives of this review were to examine definitions and background of palliative care, as well as address whether there is an increased need for palliative care education among neurologists. The review also explores what literature exists regarding palliative care within general neurology and child neurology. A literature review was conducted examining use of palliative care within child neurology. More than 100 articles and textbooks were retrieved and reviewed. Expert guidelines stress the importance of expertise in palliative care among neurologists. Subspecialties written about in child neurology include that of peripheral nervous system disorders, neurodegenerative diseases, and metabolic disorders. Adult and child neurology patients have a great need for improved palliative care services, as they frequently develop cumulative physical and cognitive disabilities over time and cope with decreasing quality of life before reaching the terminal stage of their illness. <http://jcn.sagepub.com/content/early/2014/04/09/0883073814527159.abstract>

Of related interest:

- *NEUROLOGY*, 2014;82(10):S45.005. '**Utilization of in-hospital palliative care for ischemic stroke deaths In U.S.**' In-hospital palliative care is associated with more conservative resource utilization. http://www.neurology.org/content/82/10_Supplement/S45.005.short

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Noted in Media Watch, 17 March 2014, #349 (p.10):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2014;21(2):57. **'Reflections on neurological palliative care.'** The European Federation of Neurological Societies and the European Association for Palliative Care have been working on a consensus paper on neurological palliative care. Neurological palliative care has led the authors to consider new aspects of care, new interventions, different symptoms and challenging issues, setting an example for how palliative care services should deal with non-cancer diagnoses.

N.B. Access to this article requires a subscription. <http://www.haywardpublishing.co.uk/ejpc.aspx>

Noted in Media Watch, 24 February 2014, #346 (p.13):

- *NEUROLOGY*, 2014;18;82(7):640-642. **'Emerging subspecialties in neurology: Palliative care.'** Individuals with conditions including stroke, multiple sclerosis, Parkinson disease, muscular dystrophies, amyotrophic lateral sclerosis, and nervous system malignancies share a host of physical, emotional, and existential symptoms that can be difficult to treat. <http://www.neurology.org/content/82/7/640.extract>

N.B. Noted in this issue of Media Watch is a representative sample of articles on palliative care for people living with a neurology condition or disorder noted in past issues of the weekly report.

Improving communication on hope in palliative care. A qualitative study of palliative care professionals' metaphors of hope: Grip, source, tune and vision

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 18 April 2014 – Participants described the hope of patients, patients' families, or themselves as: 1) a grip, which implied safety; 2) a source, which implied strength; 3) a tune, which implied harmony; and, 4) a vision, which implied a positive perspective. Compared with Dutch participants, Canadian participants generally put more emphasis on spirituality and letting go of their own hope as a grip (safety). Compared with other included professionals, physicians used hope as a grip (safety) most often, whereas chaplains used hope as a tune (harmony) most often. [http://www.jpmsjournal.com/article/S0885-3924\(14\)00190-0/abstract](http://www.jpmsjournal.com/article/S0885-3924(14)00190-0/abstract)

Representative sample of articles on hope in the context of end-of-life care noted in past issues of Media Watch:

- *GLOBAL JOURNAL OF HEALTH SCIENCE*, 2014;6(2):128. **'Disclosing the truth: A dilemma between instilling hope and respecting patient autonomy in everyday clinical practice.'** Withholding the truth is mainly based in the fear of causing despair to patients. However, fostering a spurious hope hides the danger of its total loss, while it can also disturb patient-doctor relationship. [Noted in Media Watch, 6 January 2014, #339 (p.7)] <http://www.ccsenet.org/journal/index.php/gjhs/article/view/31080>
- *PALLIATIVE MEDICINE* | Online – 15 April 2013 – **'Should palliative care patients' hope be truthful, helpful or valuable? An interpretative synthesis of literature describing health-care professionals' perspectives on hope of palliative care patients.'** Three perspectives on hope ... were found: 1) realistic perspective – hope as an expectation should be truthful, and healthcare professionals focused on adjusting hope to truth; 2) functional perspective – hope as coping mechanism should help patients, and professionals focused on fostering hope; and, 3) narrative perspective – hope as meaning should be valuable for patients, and healthcare professionals focused on interpreting it. [Noted in Media Watch, 22 April 2013, #302 (p.12)] <http://pmj.sagepub.com/content/early/2013/04/11/0269216313482172.abstract>
- *CLINICAL ETHICS*, 2009;4(1):38-43 **'Hope and terminal illness: False hope versus absolute hope.'** Sustaining hope in patients is an important element of health care, allowing improvement in patient welfare and quality of life. However in the palliative care context ... it might seem that in order to maintain hope the palliative care practitioner would sometimes have to deceive the patient about the full nature or prospects of their condition by providing a "false hope." [Noted in Media Watch, 13 April 2009, #92 (p.6)] <http://ce.rsmjournals.com/cgi/content/abstract/4/1/38>

What is a good death?

NEW BIOETHICS | Online – 10 April 2014 – This study sets out to understand what might constitute a good death in the current U.K. context. It uses the demographic changes which have taken place in U.K. society over the period of the twentieth century to offer explanations for our relative unfamiliarity with dying and death. The implications of the findings for end-of-life care are discussed in the light of recommendations of the recent report 'More Care Less Pathway' (2013), which criticizes the implementation of the 'Liverpool Care Pathway for the Dying Patient' in some hospital settings.¹ <http://essential.metapress.com/content/372412n5646t3083/>

1. *More care, less pathway: Review of Liverpool Care Pathway for dying patients* [in England], Department of Health, July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

Examining do-not-resuscitate orders among newly admitted residents of long-term care facilities [in Ontario, Canada]

PALLIATIVE CARE: RESEARCH & TREATMENT, 2014;8:1-6. A large number of long-term care [LTC] residents have DNR orders on file, and there are a number of factors related to, or predictive of, completion of DNR orders among those who arrive at LTC facilities without them. Clearly, some work remains to increase the number of DNR orders on file, especially among residents who are older, are in a state of functional or cognitive decline, or have been admitted from home. This study is important to the current literature because it is the first to examine DNR orders among LTC residents in Canada using administrative data. It is distinctive because it used a comprehensive instrument to examine multiple domains. An important next step will be to examine compliance rates with DNR orders in LTC facilities. In summary, findings show that 70% of LTC residents in Ontario have recorded DNR orders and that future research needs to examine rates of compliance. <http://www.la-press.com/palliative-care-research-and-treatment-journal-j86>

Advanced medical decision-making in long term care: Patient, provider and policy perspectives

Among the findings of a 2005 Ontario study:

Elderly persons do not remember formulating advance directives or the specifics of treatments on which decisions were made, calling into question whether they are truly informed.

Elderly individuals do not appear to receive the type of support they need when formulating an advance directive.

Many long-term care facilities declined to participate in the study; this may be because they do not have policies in place despite the governmental mandate.

Facilities that do have policies in place do not meet basic criteria that would ensure compliance with the applicable laws and protect the patients and professionals involved.

N.B. For details of the availability of this study, published by The Change Foundation of Ontario: <https://www-dev.library.yorku.ca/find/Record/2034991>

- *THE MEDICAL POST* (Canada) | Online – 8 April 2014 – '**Navigating the murky waters of DNR orders.**' Requirements vary by province and doctors are not always familiar with them. <http://www.canadianhealthcarenetwork.ca/physicians/your-practice/professional-development/navigating-the-murky-waters-of-dnr-orders-33411>

[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>

Making decisions about implantable cardioverter-defibrillators from implantation to end of life: An integrative review of patients' perspectives

THE PATIENT – PATIENT-CENTERED OUTCOMES RESEARCH | Online – 26 March 2014 – Three common themes from patients' perspectives were the influence of the patient–practitioner consultation on knowledge uptake, patients' decision-making preference, and their desire to live. Patients faced with decisions often misunderstood the functionality of their implantable cardioverter-defibrillators (ICD), or overestimated its benefit. They also expressed mixed preferences for the desire to be involved in decisions. The decisions around ICDs are particularly difficult for patients given the life and death trade off. <http://link.springer.com/article/10.1007/s40271-014-0055-2#>

Noted in Media Watch, 24 March 2014, #350 (pp.9-10):

- *CURRENT HEART FAILURE REPORTS* | Online – Accessed 18 March 2014 – '**Ethical challenges of deactivation of cardiac devices in advanced heart failure.**' While patients with ICDs are routinely counseled with regard to the benefits of ICDs, they have a poor understanding of the options for device deactivation and related ethical and legal implications <http://link.springer.com/article/10.1007/s11897-014-0194-8>

N.B. Footnoted in this issue of Media Watch is additional articles on the issue of defibrillator deactivation in end-of-life care. Other articles on the subject are also noted in Media Watch, 27 February 2012, #242 (p.13).

"You put it all together" – families' evaluation of participating in family health conversations

SCANDINAVIAN JOURNAL OF CARING SCIENCES | Online – 9 April 2014 – Families' experiences of the conversations embraced their structure and the interactions with the conversation leaders. All families [i.e., study participants] were satisfied with the conversations, pointing to the importance of having them early in the illness process. The opportunity to talk with someone outside the family was strongly emphasised as promoting well-being. The experienced significance of the conversations was captured in four categories: 1) creating a whole picture, that is, being given the opportunity to listen to other family members' experiences and fill in potential memory gaps; 2) making the situation manageable, that is, receiving support from other participants in order to handle problems and gain control; 3) facilitating healing, that is, being able to tell their story about what had previously been "the unspeakable"; 4) and, strength-

ened family cohesion, that is, increased understanding for each other's experiences, thus bringing family members closer together. <http://onlinelibrary.wiley.com/doi/10.1111/scs.12141/abstract>

Preliminary development and validation of a new end-of-life patient-reported outcome measure assessing the ability of patients to finalise their affairs at the end of life

PLOS ONE | Online – 16 April 2014 – The end-of-life patient-reported outcome measure (EOL-PRO) captures the ability to complete physical tasks and finalise practical matters although it is unclear whether emotional tasks or resolution of relationship issues are considered. Personal and financial affairs should be separated to allow for differences in ability for these two types of affairs. <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0094316>

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Quotable Quotes

Write as if you were dying. At the same time, assume you write for an audience consisting solely of terminal patients. That is, after all, the case. What would you begin writing if you knew you would die soon? What could you say to a dying person that would not enrage by its triviality? **American author Annie Dillard.**

Of related interest:

- *GERONTOLOGIST* | Online – 15 April 2014 – '**Does end-of-life planning help partners become better surrogates?**' Surrogates who want extensive care for themselves may need extra attention when practitioners assist them in making a substituted judgment. <http://gerontologist.oxfordjournals.org/content/early/2014/04/14/geront.gnu031.abstract>
- *JOURNAL OF PEDIATRICS* | Online – 9 April 2014 – '**Families facing language barriers in healthcare: When will policy catch up with the demographics and evidence?**' A substantial body of literature from decades of research documents the often-profound adverse impact of language barriers on health and healthcare, including access to care ... quality of care, patient-physician communication... [http://www.jpeds.com/article/S0022-3476\(14\)00173-5/abstract](http://www.jpeds.com/article/S0022-3476(14)00173-5/abstract)
- *MEDICAL DECISION MAKING* | Online – 14 April 2014 – '**Framing options as choice or opportunity: Does the frame influence decisions?**' A "choice" frame, where all treatment options are explicit, is less likely to bias preferences. Tailoring of information to initial preferences would be ill-advised as preferences may change following detailed information. <http://mdm.sagepub.com/content/early/2014/04/14/0272989X14529624.abstract>

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/4/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 to access the weekly report]

Canada

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://www.hpcconnection.ca/newsletter/inthenews.html>

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://www.hospicehaz.hu/en/training/> [Scroll down to 'Media Watch']

U.K. | Omega, the National Association for End-of-Life Care: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

The value of palliative medicine for the economy

ZEITSCHRIFT FÜR PALLIATIVMEDIZIN, 2014;15(2):78-83. Expenditure for health care is assessed as a good investment in the economy as long as it is spent for the human labor force. Palliative medicine, however, causes costs for people who will not return to the production process. Despite that it would be wrong to assume that these costs are merely consumption. A functional economy in the postmodern era requires coworkers who are flexible, intrinsically motivated, strong in trust and willing to take risks. This moral capital of the economy requires ultimate reliability in life. Palliative medicine produces the trust that life can be lived in dignity irrespective of economic success or the materialization of risks. Consequently, palliative medicine is producing a value of high economic significance. <http://cat.inist.fr/?aModele=afficheN&cpsid=28200713>

N.B. German language article.

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 17 April 2014 – '**Pediatric euthanasia in Belgium: Disturbing developments.**' The amended Belgian euthanasia law aims at empowering children who are able to provide assent to life-ending interventions. The goal of reducing suffering in children at the end of life is a laudable one. However, the ethical way to achieve this goal should be expanded education and clinical guidance around the provision of aggressive palliative care. In the face of intolerable suffering in a newborn or child, aggressive interventions, such as palliative sedation, that risk, but do not intend, death are ethically justified. Such interventions are far more ethical than allowing clinicians to euthanize children who do not possess the cognitive and emotional sophistication to either need or comprehend what they might appear to seek. Assistance in dying is best left to the competent adult. Aggressive pain management is best for those whose dying entails the relief of their pain. <http://jama.jamanetwork.com/article.aspx?articleid=1863566>
- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 14 April 2014 – '**The changing legal climate for physician aid in dying.**' While once widely rejected as a health care option, physician aid in dying is receiving increased recognition as a response to the suffering of patients at the end of life. With aid in dying, a physician writes a prescription for life-ending medication for an eligible patient. Following the recommendation of the American Public Health Association, the term aid in dying rather than "assisted suicide" is used to describe the practice. The authors describe the changing legal climate for physician aid in dying occurring in several states (see table). <http://jama.jamanetwork.com/article.aspx?articleid=1861875>

State	Year of Legalization	Path of Recognition	Eligibility Criteria	Citation for Statute or Court Decision
Oregon	1994 and 1997	Public referenda	Mentally competent, terminally ill adults	Or Rev Stat §§127.800-127.897
Washington	2008	Public referendum	Mentally competent, terminally ill adults	Rev Code Wash § 70.245
Montana	2009	State supreme court decision	Mentally competent, terminally ill adults	<i>Baxter v State of Montana</i> , 224 P3d 1211 (Mont 2009)
Vermont	2013	Legislation	Mentally competent, terminally ill adults	18 Vt Stat §§5281-5292
New Mexico	2014	State trial court decision (subject to reversal on appeal)	Mentally competent, terminally ill adults	<i>Morris v Brandenburg</i> , No. D-202-CV 2012-02909 (Bernalillo County, NM, January 13, 2014)

Worth Repeating

Surrogate decision makers' responses to physicians' predictions of medical futility

CHEST, 2009;136(1):110-117. The authors' findings provide new insight about the perspectives of surrogate decision makers on the medical futility rationale and point to practical considerations that may help to refine how physicians approach discussions about futility with surrogates. Most surrogates they interviewed were reluctant to immediately accept physicians' predictions of medical futility. The authors identified several explanations, including beliefs that individual physicians' predictions may be unreliable, a need for surrogates to see for themselves the futility of a situation before accepting physicians' prognostications, and the possibility that God will intercede to change patients' outcomes. Those surrogates who objected to the futility rationale based on a belief in miracles were more likely to insist on continued life support in the face of a very poor prognosis, whereas those who objected based on secular or experiential grounds were not. Prior commentaries have proposed the following two main sources of conflict around medical futility: misunderstandings about prognosis; and, religiously grounded objections. Data revealed several new types of objections by surrogates to the futility rationale that merit further investiga-

tion, most importantly non-religious doubts about the accuracy of physicians' predictions and the need for surrogates to see futility for themselves rather than rely solely on physicians' prognostications. These findings not only are important sociological observations, but also may be valuable in helping physicians to diagnose the true nature of the conflict about futility and respond skillfully. <http://journal.publications.chestnet.org/article.aspx?articleid=1089903>

Extract from *Chest* article:

By understanding that a religious objection is at the heart of a conflict, physicians may avoid using more strident attempts at scientific explanations to convince surrogates of the prognosis and instead enlist the help of a chaplain or a representative of the surrogate's religion to help mediate the conflict. Seeking the input of multiple senior clinicians may help to mitigate conflict with surrogates who have non-religious concerns about the accuracy of prognostic estimates. A careful explanation of the prognostic significance (or lack thereof) of the physical appearance of the patient may help surrogates to see for themselves the gravity of the patient's illness.

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