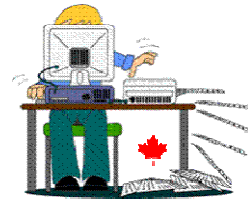


Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Drawing practical lines against encroaching professional control at the end of life: Scroll down to [International](#) and 'Expert warns change needed in attitude to end-of-life care.' (p.3)

Canada

Patchwork drug coverage causing financial hardship for many cancer patients

CANADIAN CANCER SOCIETY | Press release – 14 September 2009 – Canada's patchwork system of drug coverage is leading to financial hardship for many cancer patients, says a Canadian Cancer Society report. *Cancer Drug Access for Canadians* shows that 1 in 12 Canadians face catastrophic drug costs, defined as more than three per cent of a household's net income. While cancer drugs create treatment options for cancer patients, the newer generation of medications can be costly. If ... administered in a hospital they are free – paid for by Canada's publicly-funded health system. However, if drugs are taken at home, which is increasingly the case, they are paid for by the patient. Not all Canadians are insured for these costs. Low income, seasonal and self-employed workers often do not have access to affordable insurance.

http://www.cancer.ca/canada-wide/about%20us/media%20centre/cw-media%20releases/cw-2009/patchwork%20drug%20coverage%20causing%20financial%20hardship%20for%20many%20cancer%20patients.aspx?sc_lang=en

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALBERTA | *Western Catholic Reporter* – 21 September 2009 – '**Opponents say few MPs back legalization of assisted suicide.**' Opponents of ... [Bill] C-384 express confidence the bill will be defeated if it comes to a vote this fall. <http://www.wcr.ab.ca/news/2009/0921/bill092109.shtml>

Quotable Quotes

Some of us are a lot more than the mistakes we have made. Most people fear dying, especially those of us who have caused a great deal of pain to others. Hospice gives a chance to let go of those fears, a chance to feel compassion, to feel cared for, loved, and most of all a chance to feel human again – despite our circumstances. This is what prison hospice gives to the patients as well as to the volunteers.

Hospice Volunteer, Iowa State Penitentiary [Source: *Prison Terminal* website]

U.S.A.

Deconstructing grief

TEXAS | *Cure Today* – Fall 2009 – It's become axiomatic among grief counselors that grief is an individual journey, each path unique. It's a distinction that frustrates Dana-Farber's Prigerson. The journeys may be individual, she says, but it is a universal human experience, and studying it should make it easier to catch people before they fall. For example, she says that between 80-90% of people adjust well. For that small percentage at risk ... it's not that difficult to predict who is at risk for self-soothing in unhealthy ways, such as drinking and smoking, and at risk for many physical and mental health impairments. In a Swedish study of the parents of children lost to cancer, those who said their grief was unresolved were more likely to miss work and seek more medical care. http://www.curetoday.com/index.cfm/fuseaction/article.show/id/2/article_id/1248

N.B. Scroll down to [Specialist Publications](#) and '**Bereavement needs assessment in specialist palliative care: a review of the literature**' (p.10), a recent online article in *Palliative Medicine*.

Health care reform

The case for killing granny

NEWSWEEK | Online OpEd – 21 September 2009 – The idea that we might ration health care to seniors (or anyone else) is political anathema. Politicians do not dare breathe the R word, lest they be accused – however wrongly – of trying to pull the plug on Grandma. But the need to spend less money on the elderly at the end of life is the elephant in the room in the health-reform debate. Everyone sees it but no one wants to talk about it. At a more basic level, Americans are afraid not just of dying, but of talking and thinking about death. Until Americans learn to contemplate death as more than a scientific challenge to be overcome, our health-care system will remain unfixable.

<http://www.newsweek.com/id/215291/page/1>

How the U.S. health care debate benefits Britain

U.K. | *Daily Telegraph* (OpEd) – 17 September 2009 – Whatever the outcome of President Barack Obama's attempt to overhaul America's health care system, it should at least alert people to the true scale of ballooning medical bills. Britain should be among the beneficiaries because few of its politicians are willing publicly to admit the unsustainable nature of the present system. A former board member of the U.S. Federal Reserve, Lawrence Lindsey, has encapsulated a global dilemma by focusing on his own country: "Health care spending in America is growing between two and four percentage points faster than GDP [gross Domestic product]. Washington views this as a long-term political challenge. As an economist, I view it as a long-term mathematical impossibility." <http://www.telegraph.co.uk/expat/6201453/How-the-US-health-care-debate-benefits-Britain.html>

Palliative care hotline plans state-wide rollout

CALIFORNIA | KPBS News – 15 September 2009 – San Diego's Institute for Palliative Medicine is planning to take its new hotline state-wide at the end of the month. The hotline, called Pal-Med Connect, will allow California doctors and nurses to call anytime for expert advice on caring for old, dying people. The hotline is free, but only medical professionals are allowed to use it.

<http://www.kpbs.org/news/2009/sep/15/palliative-care-hotline-plans-statewide-rollout/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *NATIONAL REVIEW* | Online posting – 21 September 2009 – '**A myth is as good as a mile.**' A powerful myth is propelling the assisted-suicide movement: the notion that Oregon's experiment with legalized assisted suicide has been a success, in which problems and abuses are rare or non-existent. <http://nrd.nationalreview.com/?q=MjAwOTA5MjE> [**N.B.** Access by subscription only.]

International

Expert warns change needed in attitude to end-of-life care

IRELAND | *Irish Times* – 17 September 2009 – An international expert ... warned that unless there is a major change of political attitude toward end-of-life care policy in the developed world "we will see a return to the widespread social neglect of the dying we first witnessed in our hospitals after [the Second] World War." Prof. Allan Kellehear, of the Centre for Death & Society ... delivered a lecture ... organised by the Forum on End of Life in Ireland.¹ "Dying as a deathbed experience ... covers a minor, nay, tiny minority of those whose illness has privileged them with awareness and a timely referral to hospice." For most, however, "either we move suddenly into an acute care facility such as a hospital, where we may be subject to aggressive rescue missions by well-meaning medical and nursing professionals, or we gradually become confined by chronic illness, imprisoned first in our own homes, and then later in an aged care institution." It was then "little wonder the voluntary euthanasia societies remain popular with the elderly in particular." <http://www.irishtimes.com/newspaper/ireland/2009/0917/1224254719976.html>

1. IRISH HOSPICE FOUNDATION | Press release – 16 September 2009 – '**International expert encourages a public health approach to death and dying.**' http://www.hospice-foundation.ie/index.php?option=com_content&task=view&id=474&Itemid=11

Of related interest:

- IRELAND | *Herald* – 16 September 2009 – '**Why the law must be changed to support living wills.**' Today, families in hospitals throughout the country will be asked the agonising question: should we resuscitate your relative if he or she has another heart attack or stroke? The question is asked for a very good reason: further treatment is pointless and resuscitation will bring the patient no more than hours or days of living, possibly in pain and discomfort, possibly without consciousness. But the question is asked by doctors and the decision is made by families. The patient doesn't have a say, even though it is the patient's life that is being talked about. That is why the Law Reform Commission's proposal that we legislate for advance directives, or living wills, is so welcome.¹ <http://www.herald.ie/opinion/why-the-law-must-be-changed-to-support-living-wills-1887639.html>

1. *Bioethics: Advance Care Directives*, Law Reform Commission of Ireland, 15 September 2009 (Press release includes a summary of key recommendations, which total more than forty). http://www.lawreform.ie/Press_Releases/Report%20ACD%20PR.pdf

N.B. Scroll down to [Specialist Publications](#) and '**Living will should be required to refuse treatment for future illness**' (p.8) for OpEd in the *Irish Medical Times* on the Law Reform Commission's recommendations.

Member of Scottish Parliament's bill to give 'good death'

U.K. (SCOTLAND) | *The Scotsman* – 15 September 2009 – If passed, the Palliative Care (Scotland) Bill would mean health boards have a legal duty to provide palliative care to all patients, putting the aims of the Scottish Government's Living and Dying Well strategy on a statutory footing. <http://news.scotsman.com/scotland/MSP39s-bill-to-give-39good.5646057.jp>

Of related interest:

- U.K. (SCOTLAND) | *Health Insider* – 16 September 2009 – '**Scotland plans palliative care summary.**' National Services Scotland's Annual Review has outlined plans to roll-out a national Palliative Care Summary during 2010. The move is part of the Living and Dying Well Palliative Care Strategy and will be based on the Gold Standards Framework Scotland and the Emergency Care Summary, which has already been rolled-out across the country. http://www.e-health-insider.com/news/5211/scotland_plans_palliative_care_summary

National audit shows dying patients receive high quality care

U.K. | Royal College of Physicians online report – 14 September 2009 – The second National Care of the Dying Audit of Hospitals¹ ... shows patients on the Liverpool Care Pathway (LCP) for the Dying Patient² are receiving high quality care in the last hours and days of life.

http://www.rcplondon.ac.uk/news/news.asp?PR_id=469

1. *National Care of the Dying Audit*, September 2009. <http://www.rcplondon.ac.uk/clinical-standards/organisation/Documents/National-Care-Of-The-Dying-Audit-Hospitals-Round-2.pdf>
2. Liverpool Care Pathway for the Dying Patient: <http://www.mcpcil.org.uk/liverpool-care-pathway/>

Of related interest:

- U.K. | *The Times* (Letter) – 21 September 2009 - '**Palliative carers should pay more attention to hydration.**' It is time for our palliative carers ... pay more attention to hydration at the end of life. <http://www.timesonline.co.uk/tol/comment/letters/article6841782.ece>
- U.K. | *The Times* (Letter) – 17 September 2009 – '**End-of-life palliative care needs to start earlier.**' Contrary to popular belief, doctors and nurses are not very accurate when they attempt to predict the length of a patient's survival before they are actually moribund. About the best we can do is recognise a patient on the brink of death. That is why the LCP focuses on the last hours. Unfortunately, by that time, it is virtually impossible to grant patients the choice of care setting that we would wish. <http://www.timesonline.co.uk/tol/comment/letters/article6837445.ece>

N.B. The letter is from the President of the Association for Palliative Medicine of Great Britain & Ireland. Scroll down to [Specialist Publications](#) and '**Doctors' view of care pathway for dying patients clashes with audit findings**' (p.7) for a report in the *British Medical Journal* on physician response to the national audit.

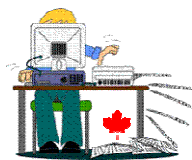
From Media Watch dated 14 September 2009:

- U.K. | *The Times* – 14 September 2009 – '**Families 'kept in the dark' as doctors make life-or-death decisions.**' One in four families are not informed when doctors decide that a patient in hospital is dying under a widely used NHS [National Health Service] scheme for palliative care, a national audit has found. http://www.timesonline.co.uk/tol/life_and_style/health/article6833149.ece

From Media Watch dated 7 September 2009:

- *Daily Telegraph* (Letter) – 3 September 2009 – '**Dying patients.**' The Government is rolling out a new treatment pattern ... based on experience in a Liverpool hospice. If you tick all the right boxes in the Liverpool Care Pathway, the inevitable outcome of the consequent treatment is death.¹ <http://www.telegraph.co.uk/comment/letters/6127443/Lack-of-strategic-planning-for-energy-policy-means-Britain-is-over-reliant-on-imported-gas.html>

[Barry R. Ashpole](#)



My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses, and facilitating issue specific workshops for frontline care providers.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *Daily Telegraph* – 19 September 2009 – **'DPP to set out assisted suicide law.'** Families who help terminally-ill loved ones kill themselves will not be prosecuted unless police can prove that they stood to gain from the death, landmark guidelines are expected to say next week. <http://www.telegraph.co.uk/news/newsttopics/politics/lawandorder/6207151/DPP-to-set-out-assisted-suicide-law.html>
- ITALY | Catholic News Agency – 16 September – **'Duke of Luxembourg awarded for fighting euthanasia.'** The Grand Duke of Luxembourg was awarded the Van Thuan Prize, an award given to those who have distinguished themselves in the promotion and defence of human rights. <http://www.catholicnewsagency.com/new.php?n=17128>
- U.K. (SCOTLAND) | *The Scotsman* – 15 September 2009 – **'Half of Britons want assisted suicide to be made legal.'** Research ... by... ComRes found 49% of people across the U.K. support legalisation [decriminalizing assisted suicide and euthanasia]. However, in Scotland, where a bill by ... MSP [Member of the Scottish Parliament] Margo McDonald allowing assisted suicide is due to be tabled at Holyrood, 52% were against legalisation compared to 42% in favour. <http://news.scotsman.com/politics/Half-of-Britons-want-assisted.5646125.jp> [See sidebar]

From Media Watch dated 7 September 2009:

- Angus Reid Global Monitor | Online report – 4 September 2009 – **'Legal euthanasia supported in Britain, Canada [and the U.S].'** Many Britons and Canadians support legalizing euthanasia ... according to a poll. http://www.angusreid.com/polls/view/34149/legal_euthanasia_supported_in_britain_canada/
- AUSTRALIA | ABC News (Perth) – 14 September 2009 – **'Euthanasia conscience vote.'** Premier [of Western Australia] Colin Barnett says Liberal MPs will be allowed a conscience vote on voluntary euthanasia, but does not expect a [private member's] bill to pass [when introduced]. <http://www.abc.net.au/news/stories/2009/09/15/2686468.htm?site=perth>
- U.K. | *Daily Telegraph* (OpEd) – 11 September 2009 – **'Lord Falconer suggests Archbishop of Canterbury's stance on assisted suicide lacks Christian compassion.'** The former Lord Chancellor claimed Dr Rowan Williams should not want the relatives of terminally ill people to be prosecuted for helping them end their lives. He called on the Church of England to take part in a wider discussion on assisted dying, even though it has been at the forefront of opposition to possible changes in the law. <http://www.telegraph.co.uk/news/newsttopics/religion/6173652/Lord-Falconer-suggests-Archbishop-of-Canterburys-stance-on-assisted-suicide-lacks-Christian-compassion.html>

The language of public opinion polls

The wording used in a public open poll can influence (to a greater or lesser degree) the response to questions asked. For example, ComRes asked: "In principle, do you think it should be legal or illegal to help end the life of a suicidal person?" Angus Reid asked: "Generally speaking, do you support or oppose legalizing euthanasia." The following is a representative sample of recent survey questions and the participants' responses:

Ireland: "Do you believe assisted suicide for the terminally ill is ever justified?" Seventy-three per cent of respondents answered yes; 15% responded no. (*Irish Health*, June 2009)

U.S.: "Do you believe assisted suicide is unethical?" Seventy-five per cent of respondents answered yes; 18% no. (Fox News, March 2009)

U.K.: "Would you help a loved one to die?" Twenty-three per cent of respondents answered yes; 76% no. (*Cambridge News*, March 2009)

Canada: "Would you support making assisted suicide a choice available to terminally ill patients?" Fifty-five per cent of respondents answered yes; 45% no. (*Globe & Mail*, March 2009)

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

Last-resort options for palliative sedation

ANNALS OF INTERNAL MEDICINE, 2009;151(6):421-424. Despite receiving state-of-the-art palliative care, some patients still experience severe suffering toward the end of life. Palliative sedation is a potential way to respond to such suffering, but access is uneven and unpredictable, in part because of confusion about different kinds of sedation. Proportionate palliative sedation (PPS) uses the minimum amount of sedation necessary to relieve refractory physical symptoms at the very end of life. To relieve suffering may require progressive increases in sedation, sometimes to the point of unconsciousness, but consciousness is maintained if possible. Palliative sedation with the intended end point of unconsciousness (PSU) is a more controversial practice that may be considered for much fewer refractory cases. There is more ethical consensus about PPS than PSU. In this article, the authors explore the clinical, ethical, and legal issues associated with these practices. <http://www.annals.org/cgi/content/abstract/151/6/421>

The cost of end of life care

Life prolonging in name only?

ARCHIVES OF INTERNAL MEDICINE, 2009;169(16):1540 (Letter). Zhang *et al* introduce their study about communication at the end of life by observing that "life-sustaining medical care of patients with advanced cancer at the end of life is costly."¹ However, their data suggest that such "life-sustaining" treatments do not prolong life, although they clearly show that such suffering-inducing treatments result in a poorer quality of death. If treatment at the end of life is to be appropriate to the context, linguistic changes are required. So long as treatments are invariably conceived of and offered to such patient groups as "life sustaining," physicians will have the very difficult task of convincing people that death is preferable to life. How many patients with terminal cancer would prefer suffering-inducing treatments over life-sustaining ones? <http://archinte.ama-assn.org/cgi/content/extract/169/16/1540-a>

N.B. Authors' response (extract): *We believe that Dr Workman makes an important point in highlighting the significance of language in clinical communications, particularly those occurring at the end of life.* <http://archinte.ama-assn.org/cgi/content/short/169/16/1540-b?rss=1>

1. *ARCHIVES OF INTERNAL MEDICINE*, 2009;169(5):480-488. **'Health care costs in the last week of life: associations with end-of-life conversations.'** <http://archinte.ama-assn.org/cgi/content/abstract/169/5/480>

Mixed methods study

GP and nurses' perceptions of how after hours care for people receiving palliative care at home could be improved

BMC PALLIATIVE CARE | Online article – 14 September 2009 – Primary health care providers play a dominant role in the provision of palliative care (PC) in Australia but many gaps in after hours service remain. In some rural areas only 19% of people receiving palliative care achieve their goal of dying at home. This study ... investigates the gaps in care from the perspective of general practitioners (GPs) and PC nurses. <http://www.biomedcentral.com/content/pdf/1472-684X-8-13.pdf>

From Media Watch dated 13 July 2009:

- *AUSTRALIAN NURSING JOURNAL*, 2009;17(1):45. **'After hours palliative care.'** A study by the Palliative Care Research Team at Monash University ... identified a number of barriers to the provision of after-hours community palliative care in both urban and rural areas of Victoria. <http://web.ebscohost.com.rap.bibliocentre.ca/ehost/pdf?vid=8&hid=6&sid=cb271859-b485-4a8c-8292-79a09cb61b63%40sessionmgr7>

Doctors' view of care pathway for dying patients clashes with audit findings

BRITISH MEDICAL JOURNAL | Online report – 16 September 2009 – Findings from an audit of nearly 4000 dying patients counter claims made by doctors last week that a care plan developed in a Liverpool hospice is "causing a national crisis in care." The doctors claimed in a letter to a national newspaper that families and friends of patients were angry at witnessing the denial of fluids and food to patients. However, the national care of the dying audit of hospitals, published this week, says that records show that most patients whose treatment followed the framework, known as the Liverpool care pathway, received high quality care and were comfortable in the last 24 hours of life. http://www.bmj.com/cgi/content/extract/339/sep16_2/b3799

- ASSOCIATION FOR PALLIATIVE MEDICINE OF GREAT BRITAIN & IRELAND | Press release – Accessed 18 September 2009 – **'The Liverpool Care Pathway.'** The Liverpool Care Pathway¹ is not a one-way street and, when further deterioration does not occur, it is common practice to take the patient off the Pathway and re-institute previous treatment. <http://www.palliative-medicine.org/>
 1. Liverpool Care Pathway for the Dying Patient: <http://www.mcpcil.org.uk/liverpool-care-pathway/>
- NATIONAL COUNCIL FOR PALLIATIVE CARE | Press release – Accessed 18 September 2009 – **'The Liverpool Care Pathway.'** The Liverpool Care Pathway is a nationally-recognised evidence-based tool intended to help clinicians give appropriate and high-quality care to people who have reached the last few hours or days of life. <http://www.ncpc.org.uk/newsroom/lcp.html>

Media Watch: Editorial Practice

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

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
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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.

Communicating with Muslim parents: "the four principles" are not as culturally neutral as suggested

EUROPEAN JOURNAL OF PAEDIATRICS, 2009;168(11):1383-1387. The "four principles approach" has been popularly accepted as a set of universal guidelines for biomedical ethics. Based on four allegedly trans-cultural principles (respect for autonomy, non-maleficence, beneficence and justice), it is supposed to fulfil the need of a "culturally neutral approach to thinking about ethical issues in health care." On the basis of a case-history, this paper challenges the appropriateness of communicating in terms of these four principles with patients with a different background. The case describes the situation in which Muslim parents bring forward that their religion keeps them from consenting to end-of-life decisions by non-religious paediatricians. <http://www.springerlink.com/content/u11xkt7155204272/fulltext.pdf>

Of related interest (from Media Watch dated 6 April 2009):

- U.K. | *New Statesman* – 3 April 2009 – '**Death and Islam.**' For Muslims, life decides the afterlife. Death is divinely willed and when it arrives it should be readily accepted. There should, therefore, be no reasoning by the bereaved as to why they have lost their loved one. <http://www.newstatesman.com/blogs/the-faith-column/0000/00/holy-qur-muslims-life-death>

Living will should be required to refuse treatment for future illness

IRISH MEDICAL TIMES | Online OpEd – 17 September 2009 – Legislation is required to allow people to make written or verbal statements about lifesaving medical treatments they do not want in the event of future illness ... according to the Law Reform Commission's Report *Bioethics: Advance Care Directives*.¹ The legislation would allow people who would like to plan ahead to make advance care directives or "living wills" about refusal of treatment if they suffered an accident or stroke, for example. It would also "assist healthcare professionals who are currently faced with making decisions without a legal framework." The Commission said treatment, such as a blood transfusion, could be refused on religious grounds but legislation would not alter existing criminal law under which euthanasia and assisted suicide are prohibited. Furthermore, a person could not refuse basic care such as oral nutrition, hydration, hygiene measures or palliative care. However, they could refuse "treatment which is intended to sustain or prolong life and that replaces or maintains the operation of vital bodily functions that are incapable of independent operation." http://www.imt.ie/news/2009/09/living_will_required_to_refuse.html

1. *Bioethics: Advance Care Directives*, Law Reform Commission of Ireland, September 2009 <http://www.lawreform.ie/publications/Report%20ACD.pdf>

Muddled message

Not all future doctors can aspire to be the next Patch Adams due to compassion fatigue

THE JOURNAL (Queens University, Ontario) | Online OpEd – 15 September 2009 – Based on very strong research ... working with patients can lead to compassion fatigue, vicarious trauma and burnout. These problems can degenerate into clinical depression, post-traumatic stress disorder, anxiety disorders and can lead to alcoholism, suicide and serious clinical errors – to name a few. The good news is that there are simple and effective strategies that can protect doctors and help to mitigate these effects. Doctors can provide care without suffering, and the answer is certainly not to deny or blame themselves for experiencing burnout. My concern is that Dr. ['Patch'] Adams's message to medical students ... was that if you don't devote every waking hour of your life to patient care, you are a failure and possibly a shallow, selfish, materialistic human being. Dr. Adams may be thriving in his own rapid lifestyle and is clearly accomplishing wonderful things in the world. But for the rest of us mere mortals, the best way to provide care to others is to first and foremost start with ourselves. <http://www.queensjournal.ca/story/2009-09-15/opinions/muddled-message-meds/>

'I am willing to take the risk': politics, policy and the translation of the hospice ideal

JOURNAL OF CLINICAL NURSING, 2009;18(19):2700-2709. Existing scholarship of the modern hospice movement typically focuses on the contributions of physicians to its inception and development. However, very little is known about the multifaceted role of nurses in the development of hospice care and the impact of Medicare policy on contemporary hospice care in the U.S. Nurses were central to the inception and development of hospice care in the U.S. While they were intricately involved with most aspects of the hospice movement and helped to frame the policy debate, they were ultimately unable to wholly determine national policy or extend their influence beyond their own circles. The standardisation of hospice care ... served to improve the quality of care for many dying patients and their families. Yet, it also served to reinforce a false dichotomy between care for the living and care for the dying. As a result, the integration of palliative care concepts into standard clinical nursing practice remains problematic. This study illuminates the socio-political complexities that shape health policy and the subsequent impact on nursing practice. Its findings have broad implications for contemporary palliative care initiatives regardless of locale. <http://www3.interscience.wiley.com/journal/122591200/abstract>

Ethics and advance care planning in a culturally diverse society

JOURNAL OF TRANSCULTURAL NURSING, 2009;20(4):405-416. Emerging international research suggests that in multicultural countries, such as Australia and the U.S., there are significant disparities in end-of-life care planning and decision making by people of minority ethnic backgrounds compared with members of mainstream English-speaking background populations. Despite a growing interest in the profound influence of culture and ethnicity on patient choices in end-of-life care, and the limited uptake of advance care plans and advance directives by ethnic minority groups in mainstream health care contexts, there has been curiously little attention given to cross-cultural considerations in advance care planning and end-of-life care. Also overlooked are the possible implications of cross-cultural considerations for nurses, policy makers, and others at the forefront of planning and providing end-of-life care to people of diverse cultural and language backgrounds. <http://tcn.sagepub.com/cgi/content/abstract/20/4/405>

Health care reform

End-of-life care: Who decides when to pull the plug

MODERN MEDICINE | Online OpEd – 18 September 2009 – Efforts to thwart the increasing costs of healthcare cannot succeed without addressing the question of how much care to provide the terminally ill. The author makes the following key points: a) the notion that patients are entitled to any type of care, regardless of its propriety, has long been disavowed; b) denial of treatment may be appropriate, but it cannot be based on the concept of futility; and, c) denial of treatment should be justified by openly stated principles of ethics and acceptable standards of care. <http://www.modernmedicine.com/modernmedicine/Modern+Medicine+Now/End-of-life-care-Who-decides-when-to-pull-the-plug/ArticleStandard/Article/detail/625589?contextCategoryId=40137>

Of related interest:

- *AMERICAN JOURNAL OF PUBLIC HEALTH* | Online pre-publication draft – Accessed 18 September 2009 – '**Health insurance and mortality in U.S. adults.**' Uninsurance is associated with mortality. <http://pnhp.org/excessdeaths/health-insurance-and-mortality-in-US-adults.pdf>
- *THE HASTINGS CENTER* | Press release – 16 September 2009 – '**Confronting the costs of medical technology is essential for health care reform.**' *Taming the Beloved Beast: How Medical Technology Costs are Destroying Our Health Care System* ... explores a basic dilemma: medical technology saves lives and relieves suffering, but it is making our health care system unaffordable. <http://www.thehastingscenter.org/News/Detail.aspx?id=3900>

Compassion in nursing: Defining, identifying and measuring this essential quality

NURSING TIMES (U.K.) | Part 1 of a two-part online article ¹ – 14 September 2009 – There is agreement in nursing literature and practice that the delivery of compassionate care is more than the competent execution of clinical skills; it involves a "doing role" and a "being role." Patients consider it is vital that they are "cared for" and "cared about." Nurses themselves have to appreciate that clinical practice is changing and will continue to do so, and need to recognise that advanced clinical skills and compassionate care are not mutually exclusive; high tech does not have to mean low care. <http://www.nursingtimes.net/nursing-practice-clinical-research/compassion-in-nursing-1-defining-identifying-and-measuring-this-essential-quality-/5006242.article>

1. Part 2: **'Factors that influence compassionate care in clinical practice.'** Exploring the professional, personal, cultural and educational factors that influence compassionate care. <http://www.nursingtimes.net/nursing-practice-clinical-research/compassion-in-nursing-2-factors-that-influence-compassionate-care-in-clinical-practice-/5006506.article>

Of related interest:

- *HOME HEALTHCARE NURSE*, 2009;27(8):463-467. **'Benefits of hospice and palliative care certification.'** The author explores the benefits to certification ... and ways to lobby for employer support. http://journals.lww.com/homehealthcareonline/Abstract/2009/09000/Benefits_of_Hospice_and_Palliative_Care.3.aspx

Bereavement needs assessment in specialist palliative care: a review of the literature

PALLIATIVE MEDICINE | Online article – 17 September 2009 – From fifty-nine full text papers appraised, 10 measurement tools were analysed in detail. Some tools had been tested on specific populations which limited transferability to specialist palliative care settings; some lacked adequate theoretical links and were not effective in discriminating between normal and complicated grief reactions; and some lacked clear evidence of validity or reliability. <http://pmj.sagepub.com/cgi/content/abstract/0269216309107013v1>

Assisted (or facilitated) death

Gut reactions: Moral conviction, religiosity, and trust in authority

PSYCHOLOGICAL SCIENCE, 2009;20(9):1059-1063. Theory and research point to different ways moral conviction and religiosity connect to trust in political authorities to decide controversial issues of the day. Specifically, the authors predicted that stronger moral convictions would be associated with greater distrust in authorities such as the U.S. Supreme Court making the "right" decisions regarding controversial issues. Conversely, they predicted that stronger religiosity would be associated with greater trust in authorities. The authors tested these hypotheses using a survey of a nationally representative sample of Americans that assessed the degree to which people trusted the U.S. Supreme Court to rule on the legal status of physician-assisted suicide. <http://www3.interscience.wiley.com/journal/122521480/abstract>

Of related interest:

- *BRITISH MEDICAL JOURNAL* | Letter – 14 September 2009 – **'Assisted dying debate.'**¹ The vulnerability of disabled people to collateral harm from the legalisation of assisted dying depends on the impact of their illness, their degree of dependence on others, and the beliefs of some that their lives are less worth living. http://www.bmj.com/cgi/content/extract/339/sep14_1/b3762
1. Letter written in response to an OpEd in the *British Medical Journal* (14 September 2009): **'Assisted dying: what's disability got to do with it?'** The debate on assisted dying has been hijacked by disabled people who want to live. It needs to be reclaimed for terminally ill people who want to die. http://www.bmj.com/cgi/content/full/339/aug26_1/b3446?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&fulltext=Delamothe&searchid=1&FIRSTINDEX=0&sortspec=date&resourcetype=HWCIT

Using mediation in situations of withholding or withdrawing life-sustaining treatment

THOMPSON REUTERS (PROFESSIONAL) AUSTRALIA | Online article – 27 August 2009 – Whether to withhold or withdraw life-sustaining treatment from a person lacking competency is an extremely difficult decision for both the person's family and for a medical practitioner. Family members face being part of a decision which may lead to the death of a loved one. Practitioners face considerable pressure to make the right care recommendations and to protect their patient's best interests. This creates a charged emotional environment, where clear and unambiguous communication between all involved is essential. Mediation may be under-utilised in these situations, offering, as it does, the prospect of improved decision-making processes and outcomes. However, certain aspects of the American "bioethics mediation" model would not work well in New South Wales or elsewhere in Australia. Instead, a more "classical" mediation model, utilising the New South Wales Health Conciliation Registry in a few way, is preferable. http://www.dibbsbarker.com/assets/document/13485056_1.PDF

Of related interest:

- *PEDIATRIC ANESTHESIA*, 2009;19(10):972-978. **'Withholding and withdrawing life-sustaining treatment in children.'** The authors advocate the use of a structured framework to help guide decision-making, particularly in the more difficult situations. The lack of a morally or legally significant difference between withholding and withdrawing treatment is discussed, as is the role of the doctrine of double effect. <http://www3.interscience.wiley.com/journal/122591758/abstract>

Worth Repeating

Personal reflection

A "good death" nonetheless

JOURNAL OF PALLIATIVE MEDICINE, 2001;4(4):509-510. Three people came to her funeral service: the hospice chaplain, the hospice nurse, and the funeral director. As they concluded the service for this perfect stranger, each said that it was the most meaningful funeral service that they had ever attended. Tearful and unburdened, they felt a powerful presence in the room. They described a palpable quiet and peacefulness, and spoke of a sense of awe and mystery. What was it that made this service so meaningful? The intensity that was felt lacked a context. We did not know this woman. We could not talk of the life that she had lived or the people that she had had touched. So what was the presence felt? No answers are possible, of course. None seem desirable either. The questions that remain at the end-of-life are often far more enriching than the answers or the explanations that we conjure up. Learning to live with mystery is part of what makes our work so special. There may be times when only a stranger can remind us of the larger meaning of our work. <http://www.liebertonline.com/doi/pdfplus/10.1089/109662101753381665>

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/>

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