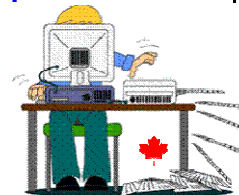


Media Watch...

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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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013, 2014 ©

Compiled & Annotated by Barry R. Ashpole

Appropriately resourced community care: Scroll down to [Specialist Publications](#) and 'Is effective, person-centred, home-based palliative care truly achievable?' (p.13), in *Palliative Medicine*.

Canada

Should doctors tell people they're dying? Why soft-pedaling the grim reality could help patients live longer

THE NATIONAL POST | Online – 2 May 2014 – Modern medicine and the concept of "patient autonomy" that is supposed to guide it encourage physicians to hold little back when explaining someone's prognosis, even if it means delivering the worst possible news. Dr. [Karen] Devon and two colleagues have subtly challenged that prevailing wisdom, suggesting there are times when complete openness may not be what patients want, when soft-pedaling the grim nature of an illness might be preferable to full disclosure.¹ The danger of crushing a patient's hope in certain instances outweighs the usual imperative to tell all, they argue in a new commentary that has touched off a debate on honesty during the darkest hours of the physician-patient relationship. Before exercising "therapeutic privilege" to withhold information, though, physicians need to determine how much knowledge the patient desires and be guided by those wishes, said

Dr. Devon. "It's very disconcerting to a medical professional; we really feel it's not ours to withhold information," she said. (But) some people don't feel that that knowledge will help them in any way ... Forcing people to know what they don't want to know can be harmful. Other surgeons caution, though, against too readily departing from the principle of full disclosure when explaining a patient's prognosis, their medical forecast. <http://news.nationalpost.com/2014/05/02/should-doctors-tell-people-theyre-dying-why-soft-pedaling-the-grim-reality-could-help-patients-live-longer/>

Specialist Publications

'Reining in patient and individual choice' (p.8), in *Journal of Medical Ethics*.

1. 'Tragic knowledge: Truth telling and the maintenance of hope in surgery,' April 2014, *World Journal of Surgery*. <http://link.springer.com/article/10.1007/s00268-014-2566-3>

National end-of-life care strategy

Angus changes motion to satisfy Conservatives

ONTARIO | *The Northern News* (Kirkland Lake) – 1 May 2014 – Timmins-James Bay Member of Parliament Charlie Angus is willing to change the wording in his palliative care motion, in the hope of gaining Conservative MPs' support. Angus says some Conservatives are having trouble supporting a pan-Canadian strategy on palliative care. As result he consulted some front-line palliative care activists to find wording that would help gain support for the motion. As a result he has amended to the motion to read "a pan-Canadian strategy and or framework for palliative care."

<http://www.northernnews.ca/2014/05/01/angus-changes-motion-to-satisfy-conservatives>

Noted in Media Watch, 24 March 2014, #350 (p.1):

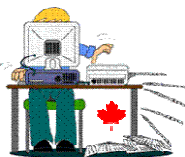
- ONTARIO | *The Regina Leader-Post* (Saskatchewan) – 22 March 2014 – '**New Democratic Party MP wants to close cracks in palliative care.**' Charlie Angus wants palliative care to be an issue that crosses political party lines. Angus has proposed motion M-456 calling on the federal government to establish a Pan-Canadian palliative and end-of-life care strategy with the provinces and territories. The bill will be debated in the House of Commons 1 April.¹ "We're taking the language right out of an all-party parliamentary committee that said there needs to be a national co-ordinating plan. I'm hoping the other parties will support it," said Angus.²
<http://www.leaderpost.com/health/wants+close+cracks+palliative+care/9648897/story.html>

1. Parliamentary discussion proposing a Pan-Canadian Palliative & End-of-life Care Strategy. [Noted in Media Watch, 7 April 2014, #352 (p.1)] A transcript can be accessed at: <http://openparliament.ca/debates/2014/4/1/charlie-angus-11/only/>
2. 'Not to be Forgotten: Care of Vulnerable Canadians,' Ad Hoc (All Party) Parliamentary Committee on Palliative & Compassionate Care. [Noted in Media Watch, 21 November 2011, #228 (p.1)] <http://pcpcc-cpspsc.com/wp-content/uploads/2011/11/ReportEN.pdf>

Family Caregivers Bill passes final vote

ONTARIO | *The Fountain Pen* (Guelph) – 29 April 2014 – The Employment Standards Amendments Act (Leaves to Help Families), 2014, passed third reading with all party support in the Ontario legislature. The legislation will allow caregivers to focus their attention on what matters most, providing care to their loved ones, without the fear of losing their job. The new legislation ... builds on the existing Family Medical Leave by creating [additional] job-protected leaves ... [including] ... family caregiver leave ... [which provides] ... up to eight weeks of unpaid, job-protected leave for employees to provide care or support to a family member with a serious medical condition.

<http://www.thefountainpen.com/s/showstory?id=12430>



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>

U.S.A.

Terminal neglect? How some hospices decline to treat the dying

THE WASHINGTON POST | Online – 3 May 2014 – For more than a million patients every year, the burgeoning U.S. hospice industry offers the possibility of a peaceful death, typically at home. But that promise depends upon patients getting the medical attention they need in a crisis, and hundreds of hospices provide very little care to such patients, a *Washington Post* investigation has found. To better understand the quality of services rendered to terminal patients, The *Post* analyzed the Medicare billing records for more than 2,500 outfits, obtained an internal Medicare tally of nursing care in patients near death, and reviewed complaint records at hundreds of hospices. The scarcity of care affects the patients most in need. While many home hospice patients require little more than weekly nursing visits, some encounter crises in which their symptoms – pain, breathing troubles, seizures and so on – flare up in ways that cannot be controlled without sustained attention. For those cases, hospices are supposed to be able to provide either "continuous" nursing care at home or inpatient care at a medical facility. But about

1 in 6 U.S. hospice agencies, serving more than 50,000 of the terminally ill, did not provide either form of crisis care to any of their patients in 2012, according to an analysis of millions of Medicare billing records. http://www.washingtonpost.com/business/economy/terminal-neglect-how-some-hospices-fail-the-dying/2014/05/03/7d3ac8ce-b8ef-11e3-96ae-f2c36d2b1245_story.html?hpid=z1

Medicare's rules meant to help end hospices being paid for drugs not for terminal illnesses

THE WASHINGTON POST | Online – 30 April 2014 – New Medicare guidance ... aims to stop the federal government from paying millions of dollars to hospice organizations and drug insurance plans for the same prescriptions for seniors. http://www.washingtonpost.com/politics/medicare-s-rules-meant-to-help-end-hospices-being-paid-for-drugs-not-for-terminal-illnesses/2014/04/30/cf2b174e-d0ad-11e3-9e25-188ebe1fa93b_story.html?tid=hpModule_308f7142-9199-11e2-bdea-e32ad90da239

Of related interest:

- REUTERS | Online – 28 April 2014 – **'How do you know when it's time for hospice?'** Hospices provide comfort care, rather than curative care, for people with any type of terminal illness or progressive disease that is no longer responding to treatment. But knowing when the choice is right is delicate and often daunting. For [palliative care physician] Charles von Gunten ... an honest dialogue about the patient's chances of recovery must precede any hospice talk. <http://in.reuters.com/article/2014/04/28/us-usa-time-hospice-idINKBN0DE1QL20140428>

How the CARE Act would help family caregivers

FORBES | Online – 1 May 2014 – Ten states are working to pass the CARE Act this year, with Oklahoma – where the bill has passed in the Senate and awaits action in the House of Representatives – leading the way. Hawaii, Illinois and New Jersey are following close behind, said Elaine Ryan, vice president of ... the American Association for Retired Persons' lobbying group. A 2012 study ... concluded that American family caregivers are increasingly being asked to provide medical tasks for loved ones.¹ <http://www.forbes.com/sites/nextavenue/2014/05/01/how-the-care-act-would-help-family-caregivers/?partner=yahootix>

1. 'Home Alone: Family Caregivers Providing Complex Chronic Care,' American Association for Retired Persons, October 2012. [Noted in Media Watch, 8 October 2012, #274 (p.3)] http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-AARP-ppi-health.pdf

Cont.

Of related interest:

- ALJAZEERA | Online – 1 May 2014 – **'How do you teach end-of-life care?'** Between 1.5 million to 1.6 million patients received hospice care in the U.S. in 2012, with at least 37% of patients spending one month or more in hospice care. So, is what's happening in a high school in upstate New York one sustainable idea to help treat an elderly population that's expected to mushroom for decades to come? <http://america.aljazeera.com/watch/shows/america-tonight/articles/2014/5/1/a-class-on-the-endoflife.html>

Poll: New Jersey residents mostly all talk, no action on end-of-life planning

NEW JERSEY.COM | Online – 29 April 2014 – Nearly two-thirds of New Jerseyans have discussed their wishes for end-of-life medical care, but fewer than half said they have made any formal plans such as drawing up a living will, according to a poll by Monmouth University Polling Institute and the New Jersey Health Care Quality Institute. Sixty-two percent have discussed their wishes for end of life medical treatment with someone, but only 45% had done anything about it. http://www.nj.com/politics/index.ssf/2014/04/poll_nj_residents_mostly_all_talk_no_action_on_end-of-life_planning.html

Of related interest:

- TEXAS | *North Texas e-News* – 27 April 2014 – **'Texoma Council of Governments counselors now certified to prepare advance directives.'** Area Agency on Aging's Benefits Counselors have received certification through the Texas Department of Aging & Disability Services ... and are authorized to prepare advance medical directives on behalf of Texoma seniors. Benefits Counselors are often able to dispel the confusion and frustration experienced by many seniors attempting to navigate the complexities of public and private benefits. http://www.ntxe-news.com/artman/publish/article_89284.shtml

International

Newly-bereaved parents

Sweeping changes in wake of report

U.K. (Scotland) | *The Edinburgh Evening News* – 1 May 2014 – Mandatory training for midwives on how to deal with bereaved parents is one of the changes recommended for the National Health Service...¹ The report said newly-bereaved parents were rushed into making decisions about their deceased babies without having the options clearly explained to them – and often regretted it later. Mothers [reported] they had been in physical pain or on strong medication when conversations took place about possible cremation arrangements. The report said: "At a time of deep distress and often shock, parents interviewed for the investigation stated they were under the impression they had to make quick decisions about the final act of care for their baby before leaving hospital." <http://www.edinburghnews.scotsman.com/news/mortonhall-sweeping-changes-in-wake-of-report-1-3395205>

1. Independent report commissioned by the City of Edinburgh Council's Chief Executive Officer and authored by the former Lord Advocate of Scotland, Rt. Hon Dame Elish Angiolini QC DBE. http://www.edinburgh.gov.uk/info/20004/council_and_democracy/957/mortonhall_investigation_report/2

Specialist Publications

'Respect, dignity and compassion to become mandatory for [U.K.] National Health Service training posts' (p.7), in *Health Service Journal*.

'Volunteers in palliative care – a comparison of seven European countries: A descriptive study' (p.11), in *Pain Practice*.

Inspectors: Do not resuscitate forms for patients were completed incorrectly at Southern General Hospital in Glasgow

U.K. (Scotland) | *The Evening Times* (Glasgow) – 30 April 2014 – Healthcare Improvement Scotland (HIS) inspectors noted the incorrect forms during an inspection of care for older people at the Southern General Hospital in Glasgow. It has asked National Health Service Greater Glasgow & Clyde to make improvements in sixteen areas following the report, which also highlighted two areas of strength. <http://www.eveningtimes.co.uk/news/u/inspectors-do-not-resuscitate-forms-for-patients-were-completed-incorrectly-at-southern-gener.1398875610>

Dying patients' care survey plea by Marie Curie Cancer

U.K. (Wales) | BBC News – 29 April 2014 – Patients who are dying need better opportunities to have their say about the standard of care they receive, says charity Marie Curie Cancer Care. It wants the Welsh government to undertake an annual survey of bereaved families to see how they feel care services can be improved. Since 2009 patients have been able to rate specialist care in a questionnaire but the charity wants it to go further. The Welsh government said it would consider the proposal. But one of the country's leading palliative care doctors has defended the current Welsh system, claiming it provides "very rich" and "very important" data. Currently, patients who receive palliative care or their families have an opportunity to provide feedback on their experiences. <http://www.bbc.com/news/uk-wales-27213566>

N.B. 'Together for Health – Delivering End of Life Care: A Delivery Plan up to 2016 for National Health Service Wales and its Partners...' April 2013. [Noted in Media Watch, 22 April 2013, #302 (p.4)] <http://wales.gov.uk/docs/dhss/publications/130416careen.pdf>

With life expectancy rising, palliative care a must in Lebanon

LEBANON | *The Daily Star* (Beirut) – 28 April 2014 – Palliative care is a relatively new medical discipline, steadily gaining traction in Lebanon. It emphasizes pain relief, especially at the end of a patient's life. But its mandate is broader – to alleviate the emotional and spiritual suffering of patients while controlling the pain they endure as a result of an incurable disease. The growth of the field here is considered crucial because of the country's demographics. Life expectancy in Lebanon rose to 72 years in 2008. Most people now die of protracted illnesses, including cancer and heart disease, and improvements in medicine mean people are living longer with these illnesses. The percentage of the Lebanese population over the age of 65 is expected to double in the next 15 years, and many will need help coping with chronic diseases as they age. <http://www.dailystar.com.lb/News/Lebanon-News/2014/Apr-28/254606-with-life-expectancy-rising-palliative-care-a-must-in-lebanon.ashx#axzz30BtdViyK>

Noted in Media Watch, 15 July 2013, #314 (p.4):

- LEBANON | *The Daily Star* (Beirut) – 12 July 2013 – **'Palliative care recognition seen as boon to field.'** A recent decision to recognize palliative care as a medical specialization in Lebanon is expected to help encourage students interested in the field to stay in the country. <http://www.dailystar.com.lb/News/Local-News/2013/Jul-13/223512-palliative-care-recognition-seen-as-boon-to-field.ashx#axzz2Z0y1tq2x>

[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.16.

Cost of funerals in the U.K.

431 pauper's funerals in 2013 as figure doubles in five years

U.K. (England) | *The Plymouth Herald* – 28 April 2014 – The number of people given a "pauper's funeral" has doubled in the South West over the past five years. 431 families turned to the state to pay towards burying loved ones in 2013 in the six counties of the region, compared to 213 in 2009. The basic funerals, officially known as "public health funerals" and paid for by local councils, take place when the deceased has left insufficient funds to pay, and their families are unable or unwilling to meet the cost. The South West recorded the biggest surge over the 5-year period of nine English regions... <http://www.plymouthherald.co.uk/431-pauper-s-funerals-2013-figure-doubles-years/story-21023434-detail/story.html>

N.B. Researchers at the University of Bath recently published 'I can't afford to die: Addressing funeral poverty.' They report that the average cost of dying has risen by 7% in the past year to £7,622 and estimate more than 100,000 in the U.K. will struggle to pay for a funeral in 2014. http://www.ilcuk.org.uk/images/uploads/publication-pdfs/I_cant_afford_to_die_-_addressing_funeral_poverty.pdf

Of related interest:

- U.K. (Scotland) | *Christian Today* – 30 April 2014 – '**Bankruptcy from bereavement: Scottish funeral costs triple.**' The average increase across Scotland was found to be 62% from 2009. http://www.christiantoday.com/article/bankruptcy_from_bereavement.scottish_funeral_costs_triple/37102.htm

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIAN (Victoria) | *The Age* (Docklands) – 30 April 2014 – '**Euthanasia: The debate must start now.**' Over the past 20 years, state Parliament has rejected 16 euthanasia bills, and Victorian Attorney-General Robert Clark said this week the government would not explore such legislation; nor would it refer the matter to the Victorian Law Reform Commission. <http://www.theage.com.au/comment/the-age-editorial/euthanasia-the-debate-must-start-now-20140429-37fsk.html>

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

Death's worsening taboo is hampering the provision of high quality palliative care

BRITISH JOURNAL OF GENERAL PRACTICE, 2014;64(622):243. A reasonable mission statement for any health professional is that we strive to improve the quality and length of our patients' lives; nonetheless, death remains the inevitable end of that journey. In an age of unprecedented openness and access to information, where everything from sex to mental illness is discussed with candour unthinkable to our forbears, my personal experience is that the societal taboo around death has worsened. <http://bjgp.org/content/64/622/243.extract>

Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 29 April 2014 – '**Diagnosing dying: An integrative literature review.**' The findings of this review support the explicit recognition of "uncertainty in diagnosing dying" and the need to work with and within this concept. Clinical decision making needs to allow for recovery where that potential exists, but equally there is the need to avoid futile interventions. <http://spcare.bmj.com/content/early/2014/04/29/bmjspcare-2013-000621.abstract>

Cont.

- *JAMA OTOLARYNGOLOGY-HEAD & NECK SURGERY* | Online – 24 April 2014 – '**Physician and patient and caregiver health attitudes and their effect on Medicare resource allocation for patients with advanced cancer.**' Physicians must participate in end-of-life discussions, but they understand poorly their patients' end-of-life values and preferences. A better understanding of these preferences and the effect of baseline attitudes will improve end-of-life discussions. <http://archotol.jamanetwork.com/article.aspx?articleid=1860302#Abstract>

Respect, dignity and compassion to become mandatory for [U.K.] National Health Service training posts

HEALTH SERVICE JOURNAL (U.K.) | Online – 1 May 2014 – New recruits to National Health Service training posts will be expected to pass a "values-based" test from next year in a bid to embed respect, dignity and compassion in future workforces. The test, due to be introduced in March 2015, will be devised by Health Education England [HEE] at the request of ministers who have issued the education agency with a "mandate" to introduce the measure. According to this mandate, the test should ensure the "importance of values as well as skills, and the need to treat patients with respect and dignity" in training programmes funded by HEE's £5 billion budget. This need to instil a system of values as well as skills into the NHS was one of the central lessons of the Francis report into the Mid Staffordshire scandal, according to the Department of Health. <http://www.hsj.co.uk/news/workforce/respect-dignity-and-compassion-to-become-mandatory-for-nhs-training-posts/5070399.article>

1. 'Report of the Mid Staffordshire National Health Service Foundation Trust Public Inquiry,' February 2013. [Noted in Media Watch, 11 February 2013, #292 (p.5)] <http://www.midstaffpublicinquiry.com/report>

Noted in Media Watch, 17 March 2014, #349 (p.6):

- U.K. | Care Quality Commission – 6 March 2014 – '**Emerging findings from radical new approach to hospital inspection – compassionate care is alive and well in the National Health Service.**' The Commission has published findings from its 18 pilot hospital inspections completed last year, the first step in a radical change to its approach.¹ The report concludes that compassionate care is alive and well in the National Health Service. However, inspectors found significant variations in quality between trusts and even between services within trusts. <http://www.cqc.org.uk/media/emerging-findings-radical-new-approach-hospital-inspection-%E2%80%93-compassionate-care-alive-and-well>

1. 'Our new approach to the inspection of National Health Service acute hospitals: Initial findings from the Wave 1 pilot inspections,' Care Quality Commission, March 2014. http://www.cqc.org.uk/sites/default/files/media/documents/20140305_acute_wave_1_report_-_final_for_publishing_2_formatted.pdf

Noted in Media Watch, 24 December 2012, #285 (p.9):

- *NURSING IN PRACTICE* | Online – 18 December 2012 – '**National Health Service to implement Chief Nursing Officer vision of compassionate care.**' The NHS [National Health Service] will drive forward a culture of compassionate care as set out by the NHS's Commissioning Board's chief nursing officer.¹ <http://www.nursinginpractice.com/article/nhs-implement-cno-vision-compassionate-care>

1. *Everybody counts: Planning for patients 2013/14*, National Health Service Commissioning Board, December 2012. <http://www.commissioningboard.nhs.uk/everyonecounts/>

[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>

Rural hospice in Kenya provides compassionate palliative care to hundreds each year

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 29 April 2014 – Kenya is 1 of 9 sub-Saharan African countries with a population of more than 39,000,000 and a life expectancy of 58 years... Human immunodeficiency virus/acquired immunodeficiency syndrome, lower respiratory infections, diarrheal diseases, tuberculosis, malaria, and cancer are common causes of death in Kenya. To assist in meeting the needs of those with serious, life-threatening illnesses, 32 hospices and palliative care facilities have been built throughout Kenya to support patients and families... In Chebairwa Village, located in Western Kenya, the 26-bed Kimbilio Hospice (Kiswahili for "refuge") was built in 2011 to assist the most vulnerable in the area. http://journals.lww.com/jhpn/Abstract/publishahead/Rural_Hospice_in_Kenya_Provides_Compassionate.99984.aspx

Noted in Media Watch, 24 February 2014, #346 (p.4):

- AFRICA (Kenya) | *Coast Week* (Nairobi) – 21 February 2014 – **'Kenya faces shortage of palliative care.'** Kenya is facing a shortage of facilities and experts who can take care of patients with life-threatening illness, the National Aids Control Council said. The government is currently in the process of implementing guidelines for the management of life limiting illnesses. <http://www.coastweek.com/3708-latest-news-Kenya-faces-shortage-of-palliative-care.htm>

Noted in Media Watch, 17 February 2014, #345 (p.8):

- *BMC PALLIATIVE CARE* | Online – 15 February 2014 – **'Public preferences and priorities for end-of-life care in Kenya: A population-based street survey.'** This first population-based survey ... revealed psycho-social domains were of greatest importance to the public... <http://www.biomedcentral.com/content/pdf/1472-684X-13-4.pdf>

Patient choice and informed consent

Reining in patient and individual choice

JOURNAL OF MEDICAL ETHICS, 2014;40(5):291-292. Patient choice, we might think, is the popular version of the ideas of informed consent and the principle of respect for autonomy and intimately connected to the politics of liberal individualism. There are various accounts to be given for why patient choice, in all its forms, has dominated thinking in bioethics and popular culture. All of them [the author suggests] will make reference to the decline of paternalism. The bad old days of "doctor knows best" are gone and were replaced by the primacy of patient choice and informed consent. The response to the dominance of the principle of patient choice has been slow in building but it has come in a number of ways. Two sets of papers in this issue of the *Journal of Medical Ethics* show just how far this response has come and the degree to which the pendulum is swinging back in the other direction.^{1,2} <http://jme.bmj.com/content/40/5/291.full>

1. 'Forced to be free? Increasing patient autonomy by constraining it.' <http://jme.bmj.com/content/40/5/293>
2. 'Against autonomy: Justifying coercive paternalism.' <http://jme.bmj.com/content/40/5/349>

Of related interest:

- *HEALTH LEADERS MEDIA* (U.S.) | Online – 2 May 2014 – **'Physician: "I almost killed a patient" because of an advance directive.'** While advance medical directives can be a benefit to patients, families, and healthcare costs, misinterpretation of these documents by clinicians is common, says a prominent emergency medicine physician, and can lead to irreversible medical errors. <http://www.healthleadersmedia.com/content/LED-304102/Physician-I-Almost-Killed-a-Patient-Because-of-an-Advance-Directive##>

Cont.

- *JOURNAL OF LAW, MEDICINE & ETHICS* | Online – 28 April 2019 – **'Recognizing the right not to know: Conceptual, professional, and legal Implications.'** This article argues for the importance of conceptual clarity in the debate about the so-called right not to know. This is vital both at the theoretical and the practical level. It is suggested that, unlike many formulations and attempts to give effect to this right, what is at stake is not merely an aspect of personal autonomy and therefore cannot and should not be reduced only to a question of individual choice. Rather, it is argued that the core interests that can be protected by the right not to know are better conceived of as privacy interests rather than autonomy interests. <http://onlinelibrary.wiley.com/doi/10.1111/jlme.12118/abstract;jsessionid=9111D5D65158FB390586E929856623D1.f04t01?deniedAccessCustomisedMessage=&userIsAuthenticated=false>
- *VIRTUAL MENTOR*, 2014;16(5):348-356. **'Questions about an advance directive.'** As respect for patient autonomy has become a common fixture in treatment decision-making processes, it is ethically obligatory for physicians to offer and provide treatments that accord with patients' known preferences. However, physicians in the U.S. also have professional, ethical, and legal responsibilities to maximize patient well-being and minimize patient suffering. Treatment decision making is thus based on a combination of patient preferences and sound medical judgment. <http://virtualmentor.ama-assn.org/2014/05/ecas3-1405.html>

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.'** Autonomy is the current gold standard approach to patient communication and has grown to the point that patient preference dictates care, even when their choices are not possible or are medically non-beneficial. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0408>

Noted in Media Watch, 5 September 2011, #217 (p.8):

- *THE HASTINGS REPORT*, 2011;41(5):3. **'Patient autonomy and the twenty-first century physician.'** Daniel Groll suggests new ways to understand old tensions between autonomy and paternalism.¹ <http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=5492>

1. 'What health care providers know: A taxonomy of clinical disagreement,' *The Hastings Report*, 2011;41(5):27-36. Some assume that respecting patient autonomy means clinicians should refrain from expressing opinions about what's in a patient's best interests... <http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=5503>

Medical students as hospice volunteers: Reflections on an early experiential training program in end-of-life care education

JOURNAL OF PALLIATIVE MEDICINE | Online – 22 April 2014 – Despite an increase in the content of palliative medicine curricula in medical schools, students are rarely exposed to end-of-life (EOL) care through real-patient experiences during their pre-clinical education. [In this study] the following five themes were identified from students' reflective essays: 1) perceptions regarding hospice patients; 2) reactions regarding self; 3) normalcy of EOL care at home; 4) impact of witnessing death and dying; and, 5) suggestions for improving EOL care education for medical students. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0533>

Noted in Media Watch, 17 February 2014, #345 (p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 12 February 2014 – **'Should we involve terminally ill patients in teaching medical students? A systematic review of patient's views.'** Understanding the patient's perspective provides a number of practical points in relation to how clinical teaching should be adapted in this patient group; e.g., using smaller student group sizes; direct supervision if physical examination performed; short encounters with multiple patients rather than a longer encounter with one patient; adequate informed consent beforehand... <http://spcare.bmj.com/content/early/2014/02/12/bmjspcare-2013-000535.abstract>

Alzheimer, dementia and the living will: A proposal

MEDICINE, HEALTH CARE & PHILOSOPHY | Online – 28 April 2014 – The authors suggest that for adequate health care planning in Alzheimer disease the living will can be presented to the patient in the early days of their geriatric care, as soon as the clinical, metabolic or even genetic diagnosis is accomplished. They suggest the appointment of a health care proxy should be done when the person is still in full enjoyment of his cognitive ability, and that the existence and scope of advance directives should be conveyed to any patient in the early stages of the disease. It follows that ethical guidelines should exist so that neurologists as well as other physicians that deal with these patients should discuss these issues as soon as possible after a diagnosis is reached. http://download.springer.com/static/pdf/46/article%253A10.1007%252Fs11019-014-9559-8.pdf?auth66=1398877969_f7c9d36c1e860cd23da9554c5ad50642&ext=.pdf

The inconvenient truth of advance care planning

NEW ZEALAND DOCTOR | Online – 28 April 2014 – When it comes to advance care plans/directives ... timing is everything. There are clear moments in a person's life when future possibilities in terms of health outcome become probabilities, when inevitability looms large and future planning has high utility. But not before. In the healthcare system, there are many clear moments, such as admission to hospital, admission to elder care or recruitment into palliative care. Other than the latter, in primary care where continuity is central, in all our patient interactions, clear moments are few and far between. Most often they are clouded by the humdrum, the diffuse presentations of highly varied, slow developing conditions. The swamp mist of general practice. <http://www.nzdoctor.co.nz/blogs/2014/april-2014/28/the-inconvenient-truth-of-advance-care-planning.aspx>

Noted in Media Watch, 24 February 2014, #346 (p.11):

- *JOURNAL OF ALZHEIMER'S DISEASE* | Online – 14 February 2014 – **'Factors associated with initiation of advance care planning in dementia: A systematic review.'** Professional caregivers may initiate ACP [advance care planning] early if strategies carefully consider timing and family and patient receptiveness or reluctance, and are family and patient-centered. Interventions should address the complexity of interrelated system and personal factors affecting initiation of ACP. <http://iospress.metapress.com/content/a3m6617k78112131/fulltext.pdf>

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 29 April 2014 – **'Dialogue on ideal end-of-life care for those with dementia.'** Seniors living in various settings [i.e., study participants] identified obligatory requisites of care as time when the finality of death needed to be accepted, comfort was prioritized, family presence was valued, appearance remained important, and solitude or time "to be with God" was stressed. <http://ajh.sagepub.com/content/early/2014/04/28/1049909114532342.abstract>

Towards a philosophic care?

MÉDECINE PALLIATIVE | Online – 1 May 2014 – In front of the techno-scientific construction of medicine, philosophy must intervene by analysing the ethical issues that arise in the healthcare environment. This applied ethics approach is now the strongest link between care and philosophy. However, it is not the only one that can be conceived. There is currently a strong reflection on the end of life, supported in France by the palliative care movement. An important part of philosophy consists of a reflection on the meaning and value of life. However, this meaning is particularly questioned at the end of life. This reflection led by philosophy does not serve a purely speculative purpose. The Socratic maieutic is an example of support for others in their questioning. Is it possible to achieve a "philosophical care" for terminally ill patients? Psychology and religion have their place in the healthcare context. Can it be the same for an active philosophy? <http://www.sciencedirect.com/science/article/pii/S1636652214000336>

N.B. French language article.

Deathbed experiences

They all see dead people – but we (do)n't want to tell you about it

NEW DIRECTIONS IN FOLKLORE, 2014;12(1):5-56. This essay explores the relationship between traditional and digital legend telling through a comparison of hospice staff's stories of their patients' deathbed visions (DBV). DBV narratives are typically those in which witnesses report a terminally-ill person seems to speak to or otherwise interact with a person or persons, not seen by others in the room, who have come to take him or her to the "other world," however defined, shortly before his or her own death. The author ... found hospice staff and volunteers were posting narratives in cyberspace that hospice staff would not reveal in face-to-face interviews, and wanted to know why. <https://scholarworks.iu.edu/journals/index.php/ndif/article/view/12768>

Representative sample of articles on deathbed experiences noted in past issues of Media Watch:

- *IRISH MEDICAL NEWS* | Online – 14 June 2011 – **'Visions of dead relatives at deathbed "normal."** Deathbed experiences, an umbrella term for phenomena such as visions in which the dying person reports seeing dead relatives or religious figures, would appear to be a normal part of the dying process and comforting for many patients and relatives, research concludes. [Noted in Media Watch, 20 June 2011, #206 (p.10)] <http://www.imt.ie/news/latest-news/2011/06/visions-of-dead-relatives-at-deathbed-normal.html>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 October 2009 – **'Deathbed phenomena: Its role in peaceful death and terminal restlessness.'** Collective research supports mounting evidence that deathbed visions typically yield peaceful deaths. Yet within the literature, numerous hospice patients experience the symptoms of terminal restlessness and frequently succumb to anguished deaths. Why are some patients and caregivers guided by peaceful deathbed phenomena and others are not? [Noted in Media Watch, 12 October 2009, #118 (p.6)] <http://ajh.sagepub.com/cgi/content/abstract/1049909109347328v1>

Volunteers in palliative care – a comparison of seven European countries: A descriptive study

PAIN PRACTICE | Online – 28 April 2014 – In Europe, volunteers have an important role in the delivery of palliative care. As part of the European Union co-funded Europall project, four aspects of volunteering in palliative care were studied for 7 European countries (Belgium, England, France, Germany, the Netherlands, Poland, and Spain). These included: 1) involvement of volunteers in palliative care; 2) organization of palliative care volunteering; 3) legal regulations concerning volunteering; and, 4) education and training of palliative care volunteering. In all countries, volunteers appeared to be involved in palliative care, yet their involvement across health care settings differed per country. England, for example, has the highest number of volunteers whereas Spain has the lowest number. Volunteering is embedded in law and regulations in all participating countries except for England and The Netherlands. In all participating countries, training programs are available and volunteers are organized, both on a national and a regional level. <http://onlinelibrary.wiley.com/doi/10.1111/papr.12209/abstract>

Of related interest:

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 24 April 2014 – **'Volunteers trained in palliative care at the hospital...'** This study aimed to describe the experience of volunteers trained in palliative care in the context of a primary care hospital. The difficulties and the benefits ... were evaluated according to volunteers' own perceptions and words. Difficulties related to uncertainty of the context. As every situation is different, volunteers could not define their role once and for all. However, they derived great satisfaction from their activity. A supporting frame and a good balance between constraints and autonomy were facilitating factors. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9243398>

Cont.

Representative sample of articles on hospice volunteers noted in past issues of Media Watch:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 18 July 2012 – **'Holding on to what you have got: Keeping hospice palliative care volunteers volunteering.'** The items that received the highest mean importance ratings [in this study] included enjoying the work they do, feeling adequately prepared/trained, and learning from their patients' experiences/listening to their patients' life stories. [Noted in Media Watch, 23 July 2012, #263 (p.6)] <http://ajh.sagepub.com/content/early/2012/07/16/1049909112453643.abstract>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 12 January 2012 – **'Should I stay or should I go: A study of hospice palliative care volunteer satisfaction and retention.'** In five of the nine programs [studied], volunteers said that feeling appreciated by the patients/families they support gave them great satisfaction. Boundary issues and/or role ambiguities were among the least satisfying aspects of their work, mentioned by volunteers in four of the programs studied. [Noted in Media Watch, 16 January 2012, #236 (p.5)] <http://ajh.sagepub.com/content/early/2012/01/04/1049909111432622.abstract>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 10 February 2011 – **'Boundary issues for hospice palliative care volunteers...'** The authors distinguish between "definite boundary issues" (things that volunteers should never do, e.g., "accept money from a patient or family"), "potential boundary issues" (things that volunteers should stop and think twice about doing, e.g., "accept a gift from a patient or family"), and "questionable boundary issues" (things that volunteers should be aware of doing, e.g., "give your home phone number to a patient or family"). [Noted in Media Watch, 14 February 2011, #188 (p.6)] <http://ajh.sagepub.com/content/early/2011/02/08/1049909110397926.abstract>

End-of-life care in Romania

The involvement of the family physician in according palliative care

PALIAȚIA, 2014;7(2). In Romania almost 150,000 people annually require palliative care, but the coverage of specialized services is only 4.2% and 6.7 % for oncology patients. Palliative care is provided in various services: home palliative care, hospital palliative care teams, outpatient and day care centers. Currently there are many services but completely chaotic in terms of distribution in the country which makes many areas remain uncovered. To improve this situation quickly it is necessarily to coordinate and accelerate national development of palliative care services, based on a national strategy agreed by professionals and supported by the authorities. <http://www.paliatia.eu/new/2014/04/the-involvement-of-the-family-physician-in-according-palliative-care/>

N.B. Journal contents page: <http://www.paliatia.eu/new/>

Noted in Media Watch, 14 April 2014, #353 (p.11):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 7 April 2014 – **'Developing a costing framework for palliative care services.'** A standardized methodology and framework for costing palliative care is presented. The framework allows a country or provider of care to substitute its own local costs to generate cost information relevant to the health care system. [http://www.jpmsjournal.com/article/S0885-3924\(14\)00154-7/abstract](http://www.jpmsjournal.com/article/S0885-3924(14)00154-7/abstract)

Noted in Media Watch, 8 October 2012, #274 (p.10):

- *PROGRESS IN PALLIATIVE CARE* | Online – 4 October 2012 – **'Palliative care in Romania: Between poor resources and poor management.'** Palliative care must compete with other serious healthcare issues, including the highest European Union incidences for tuberculosis, infant mortality, and uterine cervix cancer mortality. Therefore, the evolution of palliative care in Romania was largely the result of important input from non-governmental organizations, now the main providers of palliative care services, including education on the subject. <http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.000000030>

Is effective, person-centred, home-based palliative care truly achievable?

PALLIATIVE MEDICINE, 2014;28(5):5373-5374. Palliative care at home has been a topic of interest for practitioners, researchers and, patients as well as families for some time; yet, the issue is often over-simplified in terms of choice, place of death and preferences for place of care. Indeed, it is standard practice in the U.K. for patients to be asked about their choice regarding place of care and place of death on admission to palliative care services, without necessarily exploring the issue further. Is this a considered person-centred issue or a tick-box exercise? Health policy around the world and in the U.K., in particular, see home as a panacea in terms of a place to die and attempts made to enable a shift from acute-based care to a community-focussed care, and in turn enable more people to be cared for and to die at home. Perhaps, however, the issues are often confused and misinterpreted. <http://pmj.sagepub.com/content/28/5/373.full.pdf+html>

Family communication and decision making at the end of life: A literature review

PALLIATIVE & SUPPORTIVE CARE | Online – 28 April 2014 – The three bodies of relevant literature that emerged during this review include: 1) the importance of family communication at the end of life (EoL); 2) family decision making at the EoL; and, 3) the inter-relationship of communication (both within the family and with healthcare professionals) and decision making at the EoL. While the literature highlights the role of communication between medical professionals and the patient or family members, there is very little focus on the process of how family communication among the family members themselves contributes to decision making at the end of life. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9247505&fulltextType=RV&fileId=S1478951514000388>

What is the physician's responsibility to a patient's family caregiver?

VIRTUAL MENTOR, 2014;16(5):330-338. When we think of family caregivers, we might think of two contrasting realities. One is the gratification, pride, and self-esteem experienced by caregivers who derive meaning and fulfillment from their caregiving role. Family caregiving, influenced in important ways by culture, can express intergenerational reciprocity and mutuality in intimate family relationships. The other reality is the grim daily grind of exhaustion and loss of self that can overwhelm the isolated family caregiver. In thinking about family caregivers, both of these realities are important, and as health professionals weigh their loyalties, roles, and responsibilities in the care of people with serious illness and disability, both must be kept in view. <http://virtualmentor.ama-assn.org/2014/05/ecas1-1405.html>

Of related interest:

- *JOURNAL OF AGING & HEALTH* | Online – 30 April 2014 – '**Older women discuss planning for future care needs: An explanatory framework.**' Although the majority [of study participants] undertook active steps to prepare for future care needs, many missed key steps or achievement of planning goals recommended by experts. Findings may be applied to long-term care planning research by providing added, rich detail on how aging women construct their options, make choices, and address this important area for future well-being. <http://jah.sagepub.com/content/early/2014/04/24/0898264314529330.abstract>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 28 April 2014 – '**Contradictions and dialectics in the palliative dialogue: Enhancing the palliative dialogue by dialectical principles.**' Accepting the principles of dialectics, in which the existence of contradictions is seen as an inherent part of a reality that is undergoing constant change, give the caregiver the flexibility to interpret dichotomic thoughts and emotions as a dialectic failure and, in accordance, to move towards a synthesis of the ideas of living and dying. This approach provides caregivers the means to promote the palliative dialogue, to implement varied communication skills to clarify the patient's goals, and to implement a therapeutic plan to realize them. [http://www.jpsmjournal.com/article/S0885-3924\(14\)00222-X/abstract](http://www.jpsmjournal.com/article/S0885-3924(14)00222-X/abstract)

Cont.

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 2 May 2014 – **'The communication experiences of patients with palliative care needs: A systematic review and meta-synthesis of qualitative findings.'** A line-of-argument synthesis of 15 studies yielded four overarching themes: 1) talking – facilitating and inhibiting factors; 2) the importance of humanitarian qualities within communication encounters; 3) perceptions of autonomy within communication experiences; and, 4) individual differences in preferences for honesty within interactions. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9252628&fulltextType=RV&fileId=S1478951514000455>

"It's been quite a challenge": Redesigning end-of-life care in acute hospitals

PALLIATIVE & SUPPORTIVE CARE | Online – 28 April 2014 – Organization of end-of-life care in acute hospitals is challenging and care pathways provide a degree of guidance as to how services can be delivered. However, even when there is effective leadership at all levels of an organization and an extensive program of education for all staff support the use of care pathways significant barriers to their introduction remain. These include staff anxieties concerning diagnosing dying and discussing dying and end-of-life care planning with patients and their families. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9247489&fulltextType=RA&fileId=S1478951514000170>

Noted in Media Watch, 3 March 2014, #347 (p.8):

- *HEALTH & PLACE*, 2014;27:77-83. **'The acute hospital setting as a place of death and final care: A qualitative study on perspectives of family physicians, nurses and family carers.'** Little is known about perceptions of the acute hospital setting as a place of final care or death. Study participants generally perceived the acute hospital setting to be inadequate for terminally ill patients, although they indicated that in some circumstances it might be a "safe haven." <http://www.sciencedirect.com/science/article/pii/S1353829214000215>

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[Media Watch: Editorial Practice](#)

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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, 20 May 2013, #306 (p.15):

- *PALLIATIVE MEDICINE* | Online – 13 May 2013 – '**Patient and family experiences of palliative care in hospital: What do we know? An integrative review.**' This review has identified that ... our knowledge of patient and family experiences of palliative care in an acute hospital remains limited to discrete aspects of care. Further research is required ... taking into account all aspects of care including potential benefits of hospital admissions in the last year of life. <http://pmj.sagepub.com/content/early/2013/05/10/0269216313487568.abstract>

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 April 2014 – '**Families' concerns after bereavement in hospital: What can we learn?**' Of the 1,384 bereaved relatives who were written to, 142 requested follow-up and 119 culminated in a bereavement follow-up meeting. The most common questions asked were for further details regarding the diagnosis, why the patient had deteriorated so quickly, what the diagnosis was, and the sequence of events. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0483>

A communication training perspective on AND versus DNR directives

PALLIATIVE & SUPPORTIVE CARE | Online – 28 April 2014 – From a communication perspective, the term "do not resuscitate" (DNR) is challenging to use in end-of-life discussions because it omits the goals of care. An alternative, "Allow Natural Death" (AND), has been proposed as a better way of framing this palliative care discussion. The authors contrast the advantages and disadvantages of the term AND from the communication training perspective and suggest that AND-framing language replace DNR as a better way to facilitate meaningful end-of-life communication. One well-designed, randomized, controlled simulation study supports this practice. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9247509&fulltextType=CR&fileId=S147895151400039X>

Noted in Media Watch, 9 July 2012, #261 (p.11):

- *HEC FORUMS* | Online – 1 July 2012 – '**Allow-Natural-Death (AND) orders: Legal, ethical, and practical considerations.**' Conversations with patients and families about the allow-natural-death (AND) order, along with the standard do-not-resuscitate (DNR) order during end-of-life (EOL) decision-making, may create engagement and understanding while promoting care that can be defended using enduring notions of autonomy, beneficence, and professional duty. <http://www.springerlink.com/content/112grh2277342362/>

N.B. Footnoted is articles on allow-natural death noted in past issues of Media Watch.



11 October 2014

Home page: <http://www.worldday.org/>
Materials: <http://www.worldday.org/materials/>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *JAMA PSYCHIATRY* | Online – 23 April 2014 – '**Requests for euthanasia/physician-assisted suicide on the basis of mental suffering: Vulnerable patients or vulnerable physicians?**' Arguments in favor of legalization of EAS [euthanasia/physician-assisted suicide] are that it might function as a safeguard to semi-legal practices, that it fosters transparency, and that it enables one to verify whether criteria of due care are met. It also provides legal safety for the physicians involved. In these places, EAS has increasingly become an acceptable option for patients with serious irreversible diseases, such as cancer, that are accompanied by unbearable physical suffering and that finally lead to death. Euthanasia/physician-assisted suicide in cases of mental suffering, however, is much more controversial. In Belgium, euthanasia for mental suffering is possible under certain extra due care conditions, such as the advice of two other physicians. In 2011, "unbearable mental suffering due to an irreversible disease" was the only motive for euthanasia in 3.5% of all the reported euthanasia cases in Belgium. However, requests for euthanasia based on unbearable mental suffering are much more common. <http://archpsyc.jamanetwork.com/article.aspx?articleid=1861510>

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>

Worth Repeating

Palliative care 101

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online – 18 April 2011 – With the burgeoning of the palliative model in recent decades, I thought this meant more palliative wards, more palliative doctors and teams. I don't think that's the only answer. Many dying patients with complex palliative needs do require specialized palliative units and skills, but most patients just need their doctor to be able to provide basic pain management and to be comfortable in a discussion about death and dying. Despite guidelines that recommend advanced care planning for patients with a prognosis of less than one year, there is good, recent evidence that physicians tend to delay these conversations. Patients will die in every medical specialty; palliative concepts need to take a place in medical curricula as central to every discipline, not just segregated as a specialty practice. Growing education about palliative principles and treatments has social benefit beyond cost-cutting and patient satisfaction. <http://www.cmaj.ca/content/183/10/E696.short>

A more recent article along the same lines:

- *CANADIAN FAMILY PHYSICIAN*, 2013;59(11):1149-1150. **'Defining and measuring a palliative approach in primary care.'** The most frequently cited statistic about palliative care in Canada, quoted in numerous publications from Canadian policy makers, politicians, academics, advocates, and the mass media, is that "only 16-30% of those who need it receive palliative care." The fallacy in this claim, of course, is the implication that all Canadians approaching the end of life should be cared for by specialist palliative care teams. The widely held perception is that primary care's role in providing palliative care is both minor and shrinking, and that the system's response should be to build webs of specialist palliative care to assume responsibility for the growing numbers of these patients. <http://171.66.125.180/content/59/11/1149.full>

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