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 and research.

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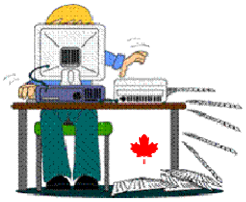


Compiled & Annotated by Barry R. Ashpole

American Society of Clinical Oncology provisional clinical opinion: Scroll down to Specialist Publications and 'Palliative care: A lifeline to quality of life ' (p.10), published in the *Journal of Clinical Oncology*. Related: 'End-of-life care discussions among patients with advanced cancer' (p.10), published in *Annals of Internal Medicine.*

U.S.A.

Why traditional burying of the dead still matters

MASSACHUSETTS | *Boston Globe* – 12 February 2012 – Americans increasingly cremate remains, at least in part with hopes of saving on funeral expenses. One-third of those who chose cremation in 2010 had said cost was a factor, up from 19% in 1990, according to a Funeral & Memorial Information Council survey. In Nevada, where unemployment and foreclosure rates are through the roof, 73% of those who died were cremated. That was up from 65% in 2006 and more than any other state. But financial matters can't be the sole driver of the trend. Cremations are least common, at just 12.5%, in Mississippi, the nation's poorest state. So some other factor must account for why cremation rates are sky-high in some cash-strapped places, but not in others. Where commitments to the religious death rituals are strong, the vast majority of people still bury their dead, even if it's in a pine box at an unmarked site. Where commitments to the bodily burial and its symbolism are weak, the dead get cremated, especially when pocketbook pressures intensify. http://www.bostonglobe.com/magazine/2012/02/12/why-traditional-burying-dead-still-matters/Tf4SXczuUo3S1tuyb0JvQL/story.html

Open conversation about end of life care

Palliative care program intended to ease the suffering associated with end-of-life stresses

OREGON | *Mail Tribune* (Medford) – 12 February 2012 – Medical and social workers are setting up a network and training system to help dying people define their own end-of-life choices – so families and caregivers can move forward knowing where death should take place, who should be there, how pain should be handled and where money should go. 'Choosing Options, Honoring Options,' is designed to overcome widespread resistance to the discussion of such issues, opening the way for dying people to be in charge of their own end-of-life choices by writing "advance directives." http://www.mailtribune.com/apps/pbcs.dll/article?AID=/20120212/NEWS/202120326/-1/NEWSMAP

Understanding veterans' challenges at the end of life

DELAWARE | NewsWorks – 8 February 2012 – A quarter of Americans facing the end of life today are veterans, and they often experience specific challenges related to their military service. Delaware Hospice is emerging as a national leader in helping vets and their families with this difficult transition. Military service, especially during wars, changes people; it often has lifelong effects. "Veterans have often gone through a traumatic experience when they were very young," said Dr. Andrew Himelstein, medical director of Delaware Hospice. "It's a sentinel experience at a very formative time in their growth." The effects of this life-changing experience often become more pronounced toward the end of life, said Himelstein. "Veterans can sometimes be very stoic, and not communicate how much pain and discomfort they are having," he said. A lifelong respect for authority may make them unwilling to complain about things, and they may not always communicate their needs. http://www.newsworks.org/index.php/local//item/33755-understanding-veterans-challenges-at-the-end-of-life/

From Media Watch dated 3 January 2011:

- CALIFORNIA | *Los Angeles Times* – 28 December 2010 – ' **Helping the brave fight their final battle.'** [Dr. Scott] Shreve ... oversees palliative care at the ... [Lebanon VA (Veterans Affairs) Medical Center, Pennsylvania] ... and directs hospice and palliative care nationally for the VA. The initiative has gained momentum with the recent completion of a new training curriculum, the Education on Palliative & End-of-Life Care for Veterans Project, due to be rolled out to all 153 VA medical centers by the end of 2011. http://www.latimes.com/health/sc-fam-1228-senior-health-veteran-20101228,0,7667701.story

Some physicians are not always open or honest with patients, survey says

FOX NEWS | Online report – 8 February 2012 – Doctors are not always open and honest with their patients, according to a study published ... in *Health Affairs*,[1] making it hard for patients to make informed decisions about the best treatments and course of care. The study used the Charter on Medical Professionalism,[2] which lists communication topics among its three guiding principles, as the back drop against which physician attitudes and behaviors are measured. Despite the charter's endorsement by more than 100 professional groups worldwide and by the Accreditation Council for Graduate Medical Education, the study claims it is unknown how widely the charter's communication provisions are accepted or followed by U.S. physicians. This *ad hoc* endorsement raises doubts about the viability of broad-based patient-centered care. Of the 1,891 physicians nationwide, about one out of 10 physicians admitted they had told patients something that was not true, according to the study. Lead study author Dr. Lisa I. Lezzoni ... adds that about 55% of U.S. doctor's claim they described a prognosis more positively than facts warranted. http://www.foxbusiness.com/personal-finance/2012/02/08/some-physicians-are-not-always-open-or-honest-with-patients-survey-says/

1. 'Survey shows that at least some physicians are not always open or honest with patients,' *Health Affairs*, 2012;31(2):383-391. http://content.healthaffairs.org/content/31/2/383.abstract

2. 'Medical professionalism in the new millennium: A physician charter,' *Annals of Internal Medicine*, 2002;136(3):243-246. http://www.annals.org/content/136/3/243.full

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

Palliative care in the emergency room

Relieving the stress of dying – palliative care

NEW JERSEY | Channel 5 News – 8 February 2012 – Everyday, terminally ill patients flood emergency rooms. They often receive invasive treatments, even if they only have months or weeks left to live. These therapies can be dangerous and costly. Patients spend 40% of their Medicare expenses in their last month of life. Now, one hospital is trying to remedy the problem by combining two fields of medicine. Dr. [Mark] Rosenberg heads one of the country's only palliative care programs that operates out of the hospital's emergency room palliative care is specialized medical care focused on providing patients with relief from the symptoms, pain and stress of a serious illness. Instead of repeat trips to the emergency room or extended hospital stays, the team helps these terminal patients find ways to stay home. The Institute of Medicine estimates that if palliative care was fully integrated into U.S. hospitals, healthcare spending could be reduced by $6 billion a year! http://www.newschannel5.com/story/16768559/relieving-the-stress-of-dying-palliative-care

From Media Watch dated 9 January 2012:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2012;43(1):1-9. **'Does palliative care have a future in the emergency department? Discussions with attending emergency physicians.'** http://www.jpsmjournal.com/article/S0885-3924(11)00272-7/abstract

Young doctors flock toward new specialty in end-of-life care

CALIFORNIA | *San Jose Mercury News* – 6 February 2012 – As Daniel Shaine approaches the end of his battle with terminal cancer, he is no longer surprised to find a troop of young doctors, some with pregnant bellies or sparkling engagement rings, at his side at the Palo Alto Veteran's Affairs hospital. "Sometimes I muse to myself, I'm old enough to be this person's father," said Shaine, 67. "I try to push that away." Increasingly, patients at the end of their lives are talking about end-of-life decisions and do-not-resuscitate orders with doctors on the brink of giving birth. These freshly minted physicians are among a new wave of specialists in the growing field of palliative medicine. Since medical boards only started recognizing the treatment of pain and end-of-life care as an official sub-specialty four years ago and new rules effectively bar older physicians from getting certified, the cohort of doctors spearheading palliative care departments across the country are increasingly in their early- to mid-30s. The stark generational differences are showing up at hospitals across the U.S. http://www.mercurynews.com/health/ci_19899121

Teaching doctors how to close life's last door

MASSACHUSETTS | *Boston University Today* – 6 February 2012 – Mathew Russell says end-of-life needs weren't part of the curriculum during his medical training in the 1990s. A 2007 study of 51 oncologists by Duke University's Center for Palliative Care[1] ... found that even when cancer patients did open up about their sorrows, fears, or anger, the discomfitted docs doused the discussion three-quarters of the time. That's changing. http://www.bu.edu/today/2012/teaching-doctors-how-to-close-lifes-last-door/

1. 'Oncologist communication about emotion during visits with patients with advanced cancer,' *Journal of Clinical Oncology*, 2007;25(36):5748-5752. http://jco.ascopubs.org/content/25/36/5748.abstract

From Media Watch dated 16 January 2012:

- *THE CLINICAL TEACHER*, 2012;9(1):9-13. **'Medical students talking to hospice patients.'** Medical students have increasing opportunities to learn about palliative care from talking to patients in a hospice. This resource is not fully utilised, in part because of concerns about patient and student welfare. http://onlinelibrary.wiley.com/doi/10.1111/j.1743-498X.2011.00513.x/full

Cont.

Of related interest:

- MISSOURI | *Ozarks First* (Springfield) – 6 February 2012 – **'Mizzou Professor and Drury grad documents the end of his life.'** Imagine spending a career teaching students about end-of-life medical care, only to be diagnosed with a terminal illness yourself. That's what happened to Mizzou professor David Oliver. In October, he was diagnosed with a rare form of nasal cancer. It's stage four and cannot be cured. Now Oliver's using his situation to find teachable moments in a very public lesson. http://ozarksfirst.com/fulltext?nxd_id=599222

The cost of dying: It's hard to reject care even as costs soar

CALIFORNIA | *San Jose Mercury News* – 6 February 2012 – Every night before putting on his pyjamas, Dad emptied the coins from his pockets. The special ones he placed in an album, but most went into a jar to be saved. So how could the hospital bill for the final days of this frugal man – with carefully prepared end-of-life instructions – add up to $323,000 in just 10 days? That's the price of a home for a struggling family. Enough to put a future doctor through medical school. Hundreds of prenatal visits. Thousands of vaccinations. My father's story – the final days of a frail 88-year-old with advancing dementia at the end of a long and rewarding life – poses a modern dilemma: Just because it's possible to prolong a life, should we? It's a story of people doing their best in a system that's built to save our loved ones. And it's a reminder of the impossibility, during a crisis, to assess costs and benefits that aren't at all obvious. This was the lesson of my father's passing: It is easy to get quick access to world-class treatment. It's much harder to reject it. http://www.mercurynews.com/health/ci_19898736?source=rss

From Media Watch dated 19 December 2011:

- *NEW YORK TIMES* | Online OpEd – 12 December 2011 – **'When care is worth it, even if end is death.'** http://www.nytimes.com/2011/12/13/health/policy/when-care-is-worth-it-even-if-end-is-death.html

Prisons must cope with surge in elderly inmates

MINNESOTA | *Star Tribune* (Minneapolis) – 6 February 2012 – In the mid-1990s, there was a mini-wave of "granny dumping." Elderly people, abandoned by families, showed up at hospitals and Salvation Army facilities, often with a note to the effect: "Please take care of her. We no longer can." That cold-hearted solution is not available to a U.S. prison system bracing for the time when it is increasingly running geriatric facilities behind bars for prisoners too ill, infirm or incompetent to be left to themselves. For the moment, the numbers aren't terribly large – 124,000 federal and state prisoners 55 and older, including 26,200 who are 65 and older – but the growth rates are alarming. A recent Human Rights Watch report[1] shows the number of prisoners older than 55 is growing at a rate six times that of the rest of the prison population. The number of prisoners 65 and older increased 63% from 2007 to 2010, while the total prison population rose just 0.7%. http://www.startribune.com/opinion/otherviews/138793949.html

1. 'The Aging Prison Population in the U.S.,' Human Rights Watch, January 2012 (noted in Media Watch dated 30 January 2012). http://www.hrw.org/reports/2012/01/27/old-behind-bars

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- GEORGIA | *New York Times* – 6 February 2012 – **'Georgia court rejects law aimed at assisted suicide.'** The Georgia Supreme Court ... ruled that a law aimed at controlling assisted suicide was unconstitutional, a decision that is likely to help shape the national debate over the practice. On its face, the unanimous ruling was more about free speech than about whether helping people kill themselves should be legal. http://www.nytimes.com/2012/02/07/us/assisted-suicide-law-is-overturned-by-georgia-supreme-court.html?_r=1

International

More Singaporeans signing up for 'living wills'

SINGAPORE | *Straits Times* – 13 February 2012 – A growing number of Singaporeans are making the difficult decision not to be put on life support when the end comes. By last December, about 15,000 had signed up for 'living wills,' which aim to minimise suffering by instructing doctors not to use artificial means, such as respirators, to keep them alive ... an increase from the 10,100 Advance Medical Directives made by 2008. The rise may be due to an increased awareness of living wills, said Dr Lam Pin Min, chairman of the Government Parliamentary Committee for Health. http://www.straitstimes.com/BreakingNews/Singapore/Story/STIStory_766049.html

Hospice ordered to leave Kenyatta National Hospital

AFRICA (KENYA) | *Daily Nation* (Nairobi) – 10 February 2012 – Anxiety has gripped patients and health officers at the Nairobi Hospice after Kenyatta National Hospital gave them a two-month notice to vacate their premises inside the hospital's compound. The hospice, which offers palliative care to about 5,000 cancer patients every month, said that the decision was going to have serious implications on patients and delivery of services across the country. According to a letter written by Kenyatta National Hospital chief executive Richard L. Lesiyampe, the hospital needs the space for expansion. http://allafrica.com/stories/201202120072.html

China faces shortage on hospice care

CHINA | Channel News Asia (Beijing) – 9 February 2012 – With over 400 patients, Song Tang hospice is one of the oldest and biggest hospices in China. Apart from looking after patients' daily needs, the hospital also offers medical assistance and prescripttions for both the terminally-ill and the elderly. But the 24-year-old hospice had to move seven times in the past 2 decades, due to traditional notions and biases associated with death and dying. Li Wei, director, Beijing Song Tang Hospice, said: "We were driven away each time as people living near the hospice said we are a hospital for the dead, and the last stop before the cemetery. They said that it's unlucky to be surrounded by dead people, and that they'd never be prosperous." But over the past decade, there has been a perceptible change in mindset with the concept of ageing and dying, and that's mainly due to a change in family and social structure, as well as a rapidly aging society." http://www.channelnewsasia.com/stories/southeastasia/view/1181930/1/.html

Specialist Publications

Of particular interest:

'End-of-life care in Hong Kong' (p.8), published in the *Asian Journal of Gerontology & Geriatrics.*

'Researching "good death" in a Hong Kong palliative care program: A clinical data-mining study' (p.8), published in *Omega – Journal of Death & Dying.*

Bereaved hit for €200 by hospital embalming ban

IRELAND | *Independent* (Dublin) – 7 February 2012 – Bereaved families face the prospect of an increase of up to €200 in funeral prices after a decision to no longer allow embalming of the dead in HSE [Health Services Executive] run hospitals. Permission for undertakers to carry out embalming in some hospital mortuaries was customary in several HSE run community hospitals. However, this is ending due to a number of factors, including concerns about insurance, lack of supervision of embalmers and questions over consent to the procedure from relatives. It means part-time funeral directors who rely on the hospital service will have to secure other facilities, which could add €100 to €200 to the funeral bill. http://www.independent.ie/national-news/bereaved-hit-for-200-by-hospital-embalming-ban-3011371.html

Report raises questions over equality of access to end of life care community services

U.K. | National End of Life Care Intelligence Network online report – 7 February 2012 – People who live in deprived areas are more likely to die in hospital than those living in affluent areas, research suggests. The report reveals that 61% of deaths amongst people living in the most deprived quintile (the poorest 20% of areas) occurred in hospital – compared to 54% amongst the two least deprived quintiles. The report concludes that the gap is not solely accounted for by factors such as differences in the causes of death between the social groups. Surveys consistently show that most people would choose to die at home or in a community setting such as a hospice. Reducing the percentage of deaths that occur in hospital is a key goal of the Department of Health's 2008 national End of Life Care Strategy. The report, *Deprivation & death: Variations in place and cause of death*, offers some evidence that the National Health Service and its partners are making progress in delivering on that goal: the percentage of deaths taking place in hospital across all population groups fell from 58% in the period 2005–07 to 57% between 2007and 2009. http://www.endoflifecare-intelligence.org.uk/resources/publications/deprivation_and_death.aspx

Assisted (or facilitated) death

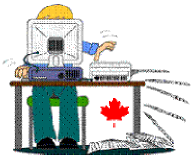
Representative sample of recent news media coverage:

- THE NETHERLANDS | *Daily Mail* (U.K.) – 10 February 2012 – **'Go-ahead for world's first mobile euthanasia unit that will allow patients to die at home.'** The world's first mobile team to administer euthanasia in patients' homes will be launched next month. Units will be dispatched when family doctors refuse to administer lethal drugs on 'ethical' grounds. They are expected to send the number of euthanasia cases in Holland soaring, with pro-campaigners claiming they will end the lives of an additional 1,000 patients a year. http://www.dailymail.co.uk/news/article-2099089/Go-ahead-worlds-mobile-euthanasia-unit-allow-patients-die-home.html?ito=feeds-newsxml

- U.K. (SCOTLAND) | *Scotsman* (Edinburgh) – 7 February 2012 – **'Poll support for assisted suicide move.'** A Panelbase survey of 1,000 voters found 69% of the public are in favour of allowing sufferers of diseases such as multiple sclerosis and cancer to get medical help to end their lives. http://www.scotsman.com/news/health/poll_support_for_assisted_suicide_move_1_2099794

- U.K. | BBC News – 6 February 2012 – **'Assisted suicide cases guidelines issued by GMC.'** The General Medical Council [GMC] is launching its first ever guidelines on assisted suicide.[1] The new guidelines will help the GMC decide if doctors should face a disciplinary panel if they are alleged to have encouraged or assisted suicide. A draft version is to be subject to a three month public consultation period. The GMC's chief executive, Niall Dickson said "the main message is that assisting suicide is illegal and doctors should have no part of it". The GMC, which is the regulatory authority for doctors, decided to produce the guidelines after the case of a severely paralysed man, which was highlighted by the BBC last summer. http://www.bbc.co.uk/news/uk-16914285

[1] 'Guidance for the Investigation Committee and case examiners when considering allegations about a doctor's involvement in encouraging or assisting suicide,' General Medical Council, January 2012. http://www.gmc-uk.org/Assisted_suicide_consultation_version_3_pub_0001.pdf_47681132.pdf



Barry R. Ashpole

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

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

Influences on decision making identified by parents of children receiving pediatric palliative care

AMERICAN JOURNAL OF BIOETHICS: PRIMARY RESEARCH, 2012;3(1):1-7. [In this study] four dominant interrelated themes permeated parents' discussions about the decisions they were making for their children and the process of decision making. First, orientation and direction (including the sub-themes of goals and hopes, spirituality and meaning, and purposeful effort) connotes the parents' effort to establish and clarify the broad context of decision making. Second, defining what is good for the child (including the sub-themes of quality of life and suffering, and normalcy and normalization) conveys how the parents posed questions and pondered what decisions would be in the child's best interests. Third, the entwined theme of relationships, communication, and support reflects how parents reported the social and interactive nature of decision making. Fourth, the theme of feelings and personal accountability focuses inward as parents report efforts to deal with their emotional responses and self-judgments. http://www.tandfonline.com/doi/abs/10.1080/21507716.2011.638019

Families of seriously ill children struggling to navigate complex health and social care system, says new report

TOGETHER FOR SHORT LIVES (U.K.) | Online posting – 7 February 2012 – A [new] report highlights the daily battles faced by thousands of families of life-limited children and young people as they struggle to get the health, education and social care support they need. The report, published by the charity Together for Short Lives, pulls together the findings from an innovative and exciting national listening tour of 42 events held across England, Scotland and Northern Ireland. These unique events – called 'Square Tables' to symbolise the equal weight and importance of all those who took part – were held throughout 2011 and culminated in a UK wide event in November. http://www.act.org.uk/news.asp?itemid=1857&itemTitle=Families+of+seriously+ill+children+struggling+to+navigate+complex+health+and+social+care+system%2C+says+new+report&section=94&sectionTitle=News

Of related interest:

- *HOME HEALTHCARE NURSE*, 2012;30(2):126-131. **'Research in advancing pediatric palliative care.'** Approximately 53,000 children die each year in the U.S. and more than 400,000 are living with life-threatening or life-limiting illnesses. Many providers lack the education and resources needed to provide safe, quality pediatric palliative care. The authors summarize published research related to pediatric palliative care that describes some of the ongoing barriers in this area and innovative programs working toward reaching more people in need of these services. http://journals.lww.com/homehealthcarenurseonline/Abstract/2012/02000/Research_in_Advancing_Pediatric_Palliative_Care.11.aspx

Negotiating the boundary between paid and unpaid hospice workers: A qualitative study of how hospice volunteers understand their work

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 5 February 2012 – The nature and dynamics of the relationship between nursing staff and volunteers [i.e., study participants] within the day hospice were characterized by increasing formality and changes in the division of labor, which challenged smooth working relationships. Volunteers see their role as becoming increasingly formalized partly as a response to increasing administrative demands on hospice nurses. The willingness of volunteers to take on new roles is variable. For volunteers to feel secure and valued and working relationships to remain strong, the process of how boundaries between paid and unpaid workers are negotiated needs to be transparent. http://ajh.sagepub.com/content/early/2012/01/23/1049909111435695.abstract

Cont.

From Media Watch dated 16 January 2012:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 12 January 2012 – **'Should I stay or should I go: A study of hospice palliative care volunteer satisfaction and retention.'** http://ajh.sagepub.com/content/early/2012/01/04/1049909111432622.abstract

From Media Watch dated 14 February 2011:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 10 February 2011 – **'Boundary issues for hospice palliative care volunteers: When to say "yes" and when to say "no."'** http://ajh.sagepub.com/content/early/2011/02/08/1049909110397926.abstract

End-of-life care in Hong Kong

ASIAN JOURNAL OF GERONTOLOGY & GERIATRICS, 2011;6(2):103-106. The Hong Kong government does not have a clear policy on developing high-quality end-of-life care services as a critical part of health care, nor on promoting dying in place, either at home or in a residential care home for the elderly. http://hkag.org/Publications/AJGG/V6N2/RA1_JKH%20Luk.pdf

Of related interest:

- *OMEGA – JOURNAL OF DEATH & DYING*, 2011-2012;64(3):203-222. **'Researching "good death" in a Hong Kong palliative care program: A clinical data-mining study.'** This study operationalizes and assesses the percentage of "good deaths" achieved among ... cancer patients in a palliative care program, the profile of these patients, the relationship between patients with a good death and psychosocial factors, and the differences in background factors, and physical and psychosocial conditions between patients who experienced a good death and those who did not. http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,2,5;journal,1,254;linkingpublicationresults,1:300329,1

From Media Watch dated 1 August 2011:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 27 July 2011 – **'Being aware of the prognosis: How does it relate to palliative care patients' anxiety and communication difficulty with family members in the Hong Kong Chinese context?'** Patients whose family members were less aware of the prognosis were more likely to experience difficulty communicating with family members. http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0099

Nursing care of the family before and after a death in the ICU: An exploratory pilot study

AUSTRALIAN CRITICAL CARE | Online article – 4 February 2012 – Participants [in this quailtative descriptive study]identified that their ICU training was inadequate in equipping them to address the complex care needs of families leading up to and following patient deaths, and they relied on peer mentoring and role-modelling to improve their care. Organisational constraints, practices and pressures impacting on the nurse made 'ideal' family care difficult. They also identified that a lack of access to pastoral care and social work after hours contributed to their concerns about family care. http://www.sciencedirect.com/science/article/pii/S1036731412000239

Palliative models of care for later stages of mental disorder: Maximizing recovery, maintaining hope, and building morale

AUSTRALIAN & NEW ZEALAND JOURNAL OF PSYCHIATRY, 2012;46(2):92-99. The concept of staging of disease in psychiatry has developed over the past years. A neglected component of this model pertains to people in the advanced stages of a mental illness, who remain symptomatic and functionally impaired despite treatment. These patients are often high service utilizers, receiving complex multimodal treatments where the balance of risk and benefit shifts perceptibly. In this paper, we argue the need to adopt 'palliative' models of care for some individuals, and consider changing the therapeutic goals to follow care pathways similar to those used in other chronic and refractory medical illnesses. http://anp.sagepub.com/content/46/2/92.short

Twenty-first century end-of-life issues in selected U.S. professional schools

ILLNESS, CRISIS & LOSS, 2012;20(1):19-32. Selected professional schools (medical, nursing, dental, child life, and veterinary) were surveyed to determine their emphasis on end-of-life issues. With the exception of dental schools over 96% offer "something" on end-of-life issues. The lecture format and interdisciplinary background of the instructtors frequently occur, with medical schools tending to be the most interdisciplinary. Topics covered vary, though attitudes toward death and dying, communication with the family and patient/owner of the animal, social and psychological contexts of dying, the experience of dying, and grief and bereavement are most often addressed. http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,3,10;journal,1,53;linkingpublicationresults,1:103734,1

From Media Watch dated 11 July 2011:

Veterinary medicine's perspective on end of life care

DVM NEWSMAGAZINE – July 2011 – **'Compassionate care survey probes end-of-life care practices.'** Almost half of the veterinarians surveyed are having end-of-life discussions with pet owners more than 11 times per month. http://veterinarynews.dvm360.com/dvm/Veterinary+news/Virbacs-compassionate-care-survey-probes-end-of-li/ArticleStandard/Article/detail/729103

Law Reform Commission

Public register urged for home carers

IRISH MEDICAL TIMES | Online report – 8 February 2012 – All professional home carers should be registered and a register made available for public examination, according to a Law Reform Commission report[1] on regulating private companies who provide professional homecare services. The report states that HIQA [Health Information & Quality Authority] should now be given powers to regulate the sector. Professional home care should be defined as services which are required to ensure that an adult person can continue to live independently in their own home, the report said. This may include the services of nurses, home care attendants, home helps, various therapies and personal care. The Commission also recommended that palliative care be included in the definition of professional home care. The Commission added that HIQA's forthcoming 'National Standards for Professional Home Care' should form the basis for the individual contract of care between the professional care provider and the care recipient. http://www.imt.ie/news/latest-news/2012/02/public-register-urged-for-home-carers.html

Extract from the Law Reform Commission's report

The Commission is of the opinion that palliative care is an important aspect of end-of-life care. The Commission also notes that many people wish to die at home. To ensure that this wish can be met, the Commission is of the opinion that palliative care must come within the definition of professional home care. The Commission thus recommends that palliative care be included in the definition of professional home care.

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1. Legal Aspects of Professional Home Care, Law reform Commission, January 2012. http://www.lawreform.ie/_fileupload/Reports/r105Carers(1).pdf

American Society of Clinical Oncology (ASCO) provisional clinical opinion

Palliative care: A lifeline to quality of life

JOURNAL OF CLINICAL ONCOLOGY | Online article – 7 February 2012 – Promoting quality of life and preventing suffering are essential aspects of practice for clinicians whose ambition it is to deliver high-quality cancer care. ASCO's Provisional Clinical Opinion (PCO)[1] offers the opportunity to bring clinicians a significant step forward in delivering truly patient-centered, family-focused care that can make a difference [see sidebar right]. The PCO also identifies critical research areas that require intense focus to make best use of limited federal and philanthropic support. Treating the whole patient –not only the disease but also the physical and psychological consequences of treatment – is the key to both extending life and enhancing the quality of the time gained. Despite these benefits, palliative care remains a mystery to many laypersons. Recent public opinion research shows that a majority (70%) of Americans are "not at all knowledgeable" about palliative care. Yet the survey also revealed that once consumers understand palliative care as an increased emphasis on relief of symptoms, pain, and stress that is appropriate at any stage of serious illness, a large majority (92%) would be likely to consider it for themselves or their families and think it should be available in hospitals nationwide.http://jop.ascopubs.org/content/early/2012/02/07/JOP.2011.000530.full.pdf+html

Steps clinicians can take

Ask patients about quality of life routinely. For example, "How are your spirits?" and/or "Are you able to do the things you need to do?"

Consider a referral for early palliative care if you have access to an outpatient consultation service; if you do not have access, tell your health system or administrator that you need it.

Talk about palliative care as "an extra layer of support" that is helpful "at every point in cancer care."

Make discussions about the future a routine part of your practice. Ask (more than once) whether patients want to talk about their prognosis.

Encourage patients to prepare for sudden problems that might occur when they are too sick to make decisions. Establish a medical durable power of attorney.

Help patients and families prepare for end of life care, and encourage them to consider this earlier than they think they will need it. Consider a hospice information visit early.

1. 'American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care,' *Journal of Clinical Oncology*, published online 6 February 2012. http://jco.ascopubs.org/content/early/2012/02/06/JCO.2011.38.5161.abstract

Of related interest:

- *ANNALS OF INTERNAL MEDICINE* | Online article – 7 February 2012 – **'End-of-life care discussions among patients with advanced cancer.'** National guidelines recommend that physicians discuss end-of-life (EOL) care planning with patients with cancer whose life expectancy is less than 1 year. http://www.annals.org/content/156/3/204.abstract

  N.B. The *Annals of Internal Medicine* publish 'Summaries for Patients' to help demystify the language of modern medicine. 'End-of-Life care discussions between patients with advanced cancer and doctors' explains the findings of the study above: http://www.annals.org/content/156/3/I-34.full.pdf

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 5 February 2012 – **'Integrative palliative care, advance directives, and hospital outcomes of critically ill older adults.'** http://ajh.sagepub.com/content/early/2012/01/23/1049909111435813.abstract

The quality of informed consent: Mapping the landscape. A review of empirical data from developing and developed countries

JOURNAL OF MEDICAL ETHICS | Online article – 7 February 2012 – This review shows that the assertion that informed consent is worse in developing countries than in developed countries is a simplification of a complex picture. Despite the limitations of comparison, the data suggest that: 1) comprehension of study information varies among participants in both developed and developing countries, and comprehension of randomisation and placebo controlled designs is poorer than comprehension of other aspects of trials in both settings; and, 2) participants in developing countries appear to be less likely than those in developed countries to say they can refuse participation in or withdraw from a trial, and are more likely to worry about the consequences of refusal or withdrawal. http://jme.bmj.com/content/early/2012/02/06/medethics-2011-100178.abstract

Of related interest:

- *JOURNAL OF MEDICAL ETHICS* | Online article – 8 February 2012 – **'Forced to be free? Increasing patient autonomy by constraining it.'** In the present work, it is argued that evidence from psychology shows that human beings are subject to a number of biases and limitations as reasoners, which can be expected to lower the quality of their decisions and which therefore make it more difficult for them to pursue their most important goals by giving informed consent. It is further argued that patient autonomy is best promoted by constraining the informed consent procedure. http://jme.bmj.com/content/early/2012/02/09/medethics-2011-100207.abstract

Media Watch Online

The weekly report can be accessed at several websites, among them:

Canada

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network:
http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx (Click on 'Current Issue' under 'Media Watch')

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

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

New Link

ONTARIO | Palliative Care Consultation Program (Oakville):
http://www.palliativecareconsultation.ca/?q=mediawatch

U.S.A.

Prison Terminal: http://www.prisonterminal.com/news%20media%20watch.html

Europe

HUNGARY | Hungarian Hospice Foundation: http://www.hospicehaz.hu/en/training/ (Scroll down to 'Media Watch')

U.K. | Omega, the National Association for End of Life Care: http://www.omega.uk.net/news.htm (Scroll down to 'International End of Life Roundup')

International

Australasian Palliative International Link: http://www1.petermac.org/apli/links.htm (Scroll down to 'Media Watch')

Palliative Care Network Community: http://www.pcn-e.com/community/pg/file/owner/MediaWatch

International Palliative Care Resource Center: http://www.ipcrc.net/archive-global-palliative-care-news.php

Palliative care registers: Infringement on human rights?

JOURNAL OF MEDICAL ETHICS | Online commentary – 7 February 2012 – A personal view made in light of the recent news article regarding a husband wanting to sue Addenbrooke's hospital over a Do Not Attempt Resuscitation decision. This article aims to highlight how the rolling out of cross boundary palliative care registers may be more at risk of infringing human rights. http://jme.bmj.com/content/early/2012/02/06/medethics-2011-100310.abstract

From Media Watch dated 29 August 2011:

- U.K. | *The Guardian* – 26 August 2011 – **'Do not resuscitate: Final word is with medical staff, whatever patient feels.'** http://www.guardian.co.uk/society/2011/aug/26/do-not-resuscitate-medical-patient

Research into end-of-life cancer care – investment is needed

THE LANCET, 2012;379(9815):519. The vast sums spent on caring for cancer patients in their last weeks of life belie the extraordinarily small proportion of research funds allocated to palliative and end-of-life care. Data on U.K. research funding by National Cancer Research Institute partners in 2010 show that, of the £508 million awarded for research into cancer, just 0·24% (£1,219,349) was allocated to palliative and end-of-life care research. Similarly, in the U.S., of the National Cancer Institute's total appropriation for 2010 of US$5 billion, only 1% was awarded to palliative care research. Most cancer patients are inadequately palliated at the end of life, with basic symptom control such as pain relief unmet. Early palliative care interventions have been shown to reduce symptoms, improve quality of life, and reduce the use of anti-cancer therapy while improving survival. A substantial investment in research into palliative and end-of-life care is urgently required to inform the transition from disease-directed to palliative care, to improve symptom control, and to ensure that choices at the end of life are offered and met. In the current economic climate, the cost saving potential of this strategy cannot be ignored. http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(12)60230-X/fulltext?rss=yes

Looking back, looking forward: The evolution of palliative and end-of-life care in England

MORTALITY | Online article – 2 February 2012 – Palliative and end-of-life care in England has undergone some remarkable transformations across the course of less than half a century and can be seen as a useful case study with which to understand international trends and challenges. This paper examines some of the long term influences which led to the emergence, for the very first time, of an End-of-Life Care Strategy in England. It revisits the critical contribution of Cicely Saunders to the development of a theoretical framework for palliative care before examining the gradual and as yet incomplete transformation of 'palliative care' into 'end-of-life care' which is occurring internationally. The paper examines two key challenges in contemporary end-of-life care, looking at how these are being addressed in England and forecasting the possible direction of travel in the future. http://www.tandfonline.com/doi/abs/10.1080/13576275.2012.651843

Defining the palliative care patient: A systematic review

PALLIATIVE MEDICINE | Online article – 6 February 2012 –The authors propose elements of the patients' health status (e.g., a progressive, life-threatening disease with no possibility of obtaining remission or stabilisation, or modifying the course of the illness) and the care delivered to them (e.g. a holistic interdisciplinary approach that focuses on supporting the quality of the end of life) to be included in the definition of a palliative care patient. They suggest considering the patients' readiness to accept palliative care and a vision of palliative care shared by the patient and all caregivers involved as potentially important elements in this definition. http://pmj.sagepub.com/content/early/2012/02/06/0269216311435268.abstract

Speaking of the dead

MORTALITY | Online article – 2 February 2012 – Many people think the reputations of the dead should be treated with respect, though this position is hard to defend if dead people are not only unconscious of what is said about them but also non-existent. The author examines unsuccessful arguments for holding that the dead are wronged by slander or denigration and ask what kind of civilised values are at issue when we speak about dead people. Subsequently he proposes an alternative account which identifies the ante-mortem person as the real subject of posthumous slander. One important implication of this view is that moral status does not decline with time, so that failing to respect a dead person's good name is equally wrong whether she is long-dead or only recently deceased. http://www.tandfonline.com/doi/abs/10.1080/13576275.2012.654710

New guide to manage last days of life in Parkinson's disease

NATIONAL COUNCIL FOR PALLIATIVE CARE (U.K. | Online posting – 6 February 2012 – *Parkinson's and the last days of life* has been developed by the Neurological Conditions Group following a survey of Parkinson's disease experts which expressed concerns about diagnosing dying, excluding reversible causes, withdrawing medications and symptom control. Parkinson's is one of the most common neurodegenerative conditions. 9 out of 10 people with Parkinson's die either in hospital or in care homes, with disproportionately higher numbers dying in care homes (41%) compared to the national average (18.5%). Nearly half (49%) of people with Parkinson's die in hospital. The guidance arrives amidst new projections that the number of people living with Parkinson's in the UK is set to rise by 28% by 2020, from 127,000 to 162,000. This further emphasises the need to get care right for this group, including, when the time comes, access to high quality end of life care. http://www.ncpc.org.uk/news/83

From Media Watch dated 11 April 2011:

- *JOURNAL OF MULTIDISCIPLINARY HEALTHCARE*, 2011;2011(4):33-38. **'Parkinson's disease permanent care unit: Managing the chronic-palliative interface.'** A specially designed and staffed care unit for Parkinsonism patients seems to fill a need for patients and caregivers, as well as for social and health care authorities. This model is sensitive to the changing needs and capacities of patients, ensuring that appropriate services are available in a timely manner. There was a rather short duration of patient stay and remaining life span after admission to the unit. http://www.dovepress.com/parkinsonrsquos-disease-permanent-care-unit-managing-the-chronic-palli-peer-reviewed-article-JMDH

Validity of the bereavement exclusion to major depression: Does the empirical evidence support the proposal to eliminate the exclusion in DSM-5?

WORLD PSYCHIATRY, 2012;11(1):3-10. The DSM-5 [i.e., *Diagnostic & Statistical Manual of Mental Disorders-5*] major depression "bereavement exclusion" (BE), which recognizes that depressive symptoms are sometimes normal in recently bereaved individuals, is proposed for elimination in DSM-5. Evidence cited for the BE's invalidity comes from two 2007 reviews purporting to show that bereavement-related depression is similar to other depression across various validators, and a 2010 review of subsequent research. The authors examined whether the 2007 and 2010 reviews and subsequent relevant literature support the BE's invalidity. Findings were: a) studies included in the 2007 reviews sampled bereavement-related depression groups most of whom were not BE-excluded, making them irrelevant for evaluating BE validity; b) three subsequent studies cited by the 2010 review as supporting BE elimination did examine BE-excluded cases but were in fact inconclusive; and, c) two more recent articles comparing recurence of BE-excluded and other major depressive disorder cases both support the BE's validity. They conclude that the claimed evidence for the BE's invalidity does not exist. The evidence in fact supports the BE's validity and its retention in DSM-5 to prevent false positive diagnoses. The authors suggest some improvements to increase validity and mitigate risk of false negatives. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3266762/

Cont.

- *BRITISH MEDICAL JOURNAL* | Online report – 10 February 2012 – **'Critics attack DSM-5 for overmedicalising normal human behaviour.'** Although not due to be published until May 2013, the fifth edition of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is already provoking dissent among psychiatrists and psychologists in Britain. Critics claim it will make an already problematic diagnostic system worse and result in more people being labelled mentally ill. http://www.bmj.com/content/344/bmj.e1020

N.B. Proposed changes to DSM-5 have been the focus of many articles, reports, etc. See Media Watch dated 2 January 2012 (p.7); 12 September 2011 (p.8); 22 August 2011 (p.9); 2 May 2011 (1); 4 April 2011 (p.8); 7 March 2011 (p.12); 7 February 2011 (p.8).

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *AUSTRALIAN & NEW ZEALAND JOURNAL OF PSYCHIATRY*, 2012;46(2):84-86. **'Physician-assisted suicide: Saying what we mean and meaning what we say.'** Entering an arena where so many distinguished commentators have already slugged it out is a daunting task. So rather than attempting to weigh arguments for and against, this discussion will confine itself to analysing and elucidating some of the linguistic underpinnings of the debate – the ways in which the notion of physician-assisted suicide is framed. http://anp.sagepub.com/content/46/2/84.full
    - *AUSTRALIAN & NEW ZEALAND JOURNAL OF PSYCHIATRY*, 2012;46(2):80-83. **'Words and reasons: Psychiatry and assisted suicide.'** http://anp.sagepub.com/content/46/2.toc

- *BIOETHICS* | Online article – 2 February 2012 – **'Moral fiction or moral fact? The distinction between doing and allowing in medical ethics.'** Opponents of physician-assisted suicide (PAS) maintain that physician withdrawal-of-life-sustaining-treatment cannot be morally equated to voluntary active euthanasia. PAS opponents generally distinguish these two kinds of act by positing a possible moral distinction between killing and allowing-to-die, *ceteris paribus* 9all other things being equal]. While that distinction continues to be widely accepted in the public discourse, it has been more controversial among philosophers. Some ethicist PAS advocates are so certain that the distinction is invalid that they describe PAS opponents who hold to the distinction as in the grip of 'moral fictions.' http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2011.01944.x/abstract

- *EUROPEAN JOURNAL OF PUBLIC HEALTH*, 2012;22(1):19-26. **'The labelling and reporting of euthanasia by Belgian physicians: A study of hypothetical cases.'** Belgium legalized euthanasia in 2002. Physicians must report each euthanasia case to the Federal Control & Evaluation Committee. This study examines which end-of-life decisions (ELDs) Belgian physicians label 'euthanasia,' which ELDs they think should be reported and the physician characteristics associated with correct labelling of euthanasia cases, the awareness that they should be reported and the reporting of them. http://eurpub.oxfordjournals.org/content/22/1/19.abstract

- *JOURNAL OF MEDICAL ETHICS* | Online article – 19 January 2012 – **'What makes killing wrong?'** What makes an act of killing morally wrong is not that the act causes loss of life or consciousness but rather that the act causes loss of all remaining abilities. This account implies that it is not even *pro tanto* morally wrong to kill patients who are universally and irreversibly disabled, because they have no abilities to lose. Applied to vital organ transplantation, this account undermines the dead donor rule and shows how current practices are compatible with morality. http://jme.bmj.com/content/early/2012/01/19/medethics-2011-100351.abstract

    From Media Watch dated 7 February 2011:

    - *MEDICAL LAW REVIEW* | Online article – 31 January 2011 – **'End-of-life treatment of potential organ donors: Paradigm shifts in intensive and emergency care.'** This article details and comments upon the current critical and historic debate affecting the medical treatment of potential deceased organ donors in the last phase of their lives. The significance stems from the challenge to the legal and ethical paradigm that the end-of-life care of patients should not be dictated or even influenced by the needs of others or of society as a whole. This gives expression to both the notion that the value of the lives of individuals should not be weighed in utilitarian fashion and that ... one should not be used instrumentally purely as a means to the ends of others. http://medlaw.oxfordjournals.org/content/early/2011/01/30/medlaw.fwq032.full

Cont.

- *THE PERMANENTE JOURNAL*, 2011;15(4). **'Physician-assisted suicide and euthanasia: Can you even imagine teaching medical students how to end their patients' lives?'** The peer-reviewed literature includes numerous well-informed opinions on the topics of euthanasia and physician-assisted suicide. However, there is a paucity of commentary on the interface of these issues with medical education. This is surprising, given the universal assumption that in the event of the legalization of euthanasia, the individuals on whom society expects to confer the primary responsibility for carrying out these acts are members of the medical profession. Medical students and residents would inevitably and necessarily be implicated. http://www.thepermanentejournal.org/issues/2011/fall/50-commentary/4186-euthanasia.html
    - *AUSTRALIAN & NEW ZEALAND JOURNAL OF PSYCHIATRY*, 2012;46(2):87-91. **'What should we tell medical students and residents about euthanasia and assisted suicide?'** http://anp.sagepub.com/content/46/2.toc

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.

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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.

Worth Repeating

Death and dying in the curriculum of public schools: Is there a place?

JOURNAL OF EMERGING KNOWLEDGE ON EMERGING MARKETS, 2011;3: Article 29. Death and dying is not myth but a reality of life and living. Though some of us view death as a stranger and try to evade its existence as much as we can, death is inevitable. This paper proposes the inclusion of death and dying in the school curriculum and offers several ways of integrating death and dying in the curriculum for different grade levels. It argues that death has visited frequently on our school campuses and in national life over the past decades and there is always a sense of despair, panic and uncertainty about how to react to this visitor. From the moment we enter this world at birth the only other sure event in our lives is our death and our dying. This topic then seems of paramount importance in our lives and should be embraced more than our first day at school, graduation among other events. http://digitalcommons.kennesaw.edu/jekem/vol3/iss1/29/

Lesson in life and death: Pupils building teacher's coffin

AUSTRALIA | *The Age* – 14 February 2007 – A Dutch primary school teacher dying of cancer is overseeing one last class project: her pupils are making her coffin. Eri van den Biggelaar, 40, has just a few weeks to live after being diagnosed last year with an aggressive form of cervical cancer. She asked the woodwork teacher, a friend, to build a coffin for her. "Why don't you let the children make it?" replied Erik van Dijk. Although Miss van den Biggelaar can no longer teach, she has looked at sketches of the coffin and is being kept up to date about it by pupils, aged between four and 11, who visit her at home. "Life and death belong together," she said. "The children realised that when I explained it to them. I didn't want to be morbid about it, I wanted them to help me. I told them: 'Where I will go is much nicer than this world.'" None of the children considered it creepy or was afraid and nobody felt traumatised, she said. Parents of the children involved all gave their consent. http://www.theage.com.au/news/world/lesson-in-lifeand-death-pupils-build-dyingteachers-coffin/2007/02/13/1171128974213.html

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