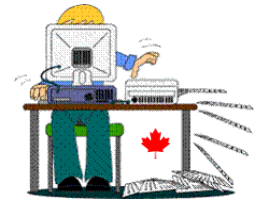


Media Watch...

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

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

Compiled & Annotated by Barry R. Ashpole

Family caregiver-patient ratio: Scroll down to [Specialist Publications](#) and 'Universality of ageing: Family caregivers for elderly cancer patients' (p.11), in *Frontiers in Psychology*.

Canada

Local palliative care for cancer patients found lacking

ONTARIO | *The Hamilton Spectator* – 26 June 2014 – The number of cancer patients in Hamilton and area who didn't get a palliative assessment within a year before their death was much larger than the Ontario average, according to a report rating the quality of cancer care.¹ A key recommendation in the Cancer System Quality Index report urges that all patients at the end of life "be referred to palliative care services earlier," and says they "may not have adequate access to the resources and supports they need to live and die in the setting of their choice." It also found that earlier access to palliative care would reduce hospital use near the end of life. The rating showed the Hamilton Niagara Haldimand Brant Local Health Integration Network [LHIN] had a higher rating than the Ontario average when it comes to keeping cancer patients out of the emergency department and from being admitted to hospital. The stats surprised long-time palliative care advocate and Hamilton doctor Scott Wooder. "You would think there are advantages built in (to being in or near a large urban centre like Hamilton)," he said. "There are some excellent palliative resources in Hamilton." He also said palliative care should be considered "early on while providing care for cancer patients," and that more resources are needed for in-home and hospice care. McMaster-trained palliative care physician Denise Marshall said part of the reason the LHIN was rated worse than average in providing such services is that until recently there haven't been "system-wide" approaches or a unified system – only great components, like the region's hospices. <http://www.thespec.com/news-story/4599129-local-palliative-care-for-cancer-patients-found-lacking/>

1. 'Cancer System Quality Index 2014,' Cancer Quality Council of Ontario, June 2014. <http://www.csqi.on.ca/>

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.

Give family caregivers a break

THE GLOBE & MAIL | Online – 23 June 2014 – Should Canadian employers be doing more to retain experienced employees who are burdened with the long-term care of aging, chronically ill or disabled family members? The Harper government thinks so, and has set up a blue-ribbon panel of private-sector executives to examine the issue, calling it the Canadian Employers for Caregivers Plan. At this point, however, it's less of a plan and more of a plan to come up with a plan. More than 6.1 million working Canadians are providing various levels of full-time care to loved ones. According to Statistics Canada, close to half of these people have reported the need to arrive at work late and leave early; 40% have taken less demanding jobs; and, 10% passed up promotions or new jobs. The federal government recognizes that, while people who care for loved ones take pressure off the health-care system, they also hurt productivity and may end up falling out of the labour market. <http://www.theglobeandmail.com/globe-debate/editorials/give-family-caregivers-a-break/article19301566/>

Noted in Media Watch, 16 June 2014, #362 (p.1):

- CANADIAN HUMAN RIGHTS COMMISSION | Online – 11 June 2014 – '**Balancing work and caregiving obligations: New guide walks you through it.**' The Commission has released its *Guide to Balancing Work and Caregiving Obligations: Collaborative Approaches for a Supportive and Well-performing Workplace*. The guide offers employers and employees practical tips on what to do when an employee's family caregiving and work responsibilities come into conflict. http://www.chrc-ccdp.gc.ca/sites/default/files/a_guide_to_balancing_work.pdf

Noted in Media Watch, 24 June 2013, #311 (p.8):

- *BEREAVEMENT CARE*, 2013;32(1):4-10. '**Building a compassionate community: Developing an informed and caring workplace in response to employee bereavement.**' When an employee suffers a bereavement, the responses of colleagues and line managers can have long lasting effects. <http://www.tandfonline.com/doi/full/10.1080/02682621.2013.779819>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE GLOBE & MAIL* | Online (Commentary) – 25 June 2014 – '**Right to die: An open discussion, a free vote.**' Quebec Health Minister Gaétan Barrette was likely right when he observed that "Canada will not be spared this (right-to-die) debate. At some point, they will have to face it. But I believe that support for an initiative like this one will not be uniform across the country." In fact, Canada has faced the question of doctor-assisted death before, and politically and legally decided against it. But Dr. Barrette is correct that the rest of the country will not be spared another debate. Indeed, it's already upon us. Canada can debate the issue through a government initiative, but that will not happen while Stephen Harper's Conservatives govern, because the party is completely satisfied with the current law, which prohibits doctor-assisted death. Even if one of the two private-member bills recommending overturning that offence are debated, the government majority will be instructed to kill them. That would be too bad for the bills' sponsor, Conservative MP Steven Fletcher, but that's the way things go when a government takes an entrenched position. So, it will be for the Supreme Court to decide. It has done so once, in 1993, when it turned down Sue Rodriguez's plea for the right to die with the assistance of physicians. Now, it confronts another appeal in a case from British Columbia. There are new judges on the court now, but will they overturn the court's previous ruling that charter rights are not violated by the criminal-law prohibition of doctor-assisted death? <http://www.theglobeandmail.com/globe-debate/right-to-die-an-open-discussion-a-free-vote/article19316534/>

Cont.

- QUEBEC | *The Toronto Star* (Ontario) – 20 June 2014 – **'Right-to-die already weighing on Quebec's conscience.'** With a massive provincial deficit, public institutions bracing for budget cutbacks and the population aging rapidly, there isn't any expectation that the quality of palliative care in Quebec will improve or that more people will have access to such specialized services when they reach the end. That troubling sum at the bottom of Quebec's balance sheets isn't doing anything to ease the moral burden that doctors and nurses are already confronting ahead of the first requests for euthanasia from dying patients, which could begin as early as mid-2015. Many hospitals have started the long process of consulting their doctors and nurses, educating staff about the new obligations they could face under Bill 52 and gauging just how many of their doctors would be willing to administer a lethal needle if asked. The law allows for physicians to refuse a request from a dying patient if it goes against their conscience. http://www.thestar.com/news/insight/2014/06/20/righttodie_already_weighing_on_quebecs_conscience.html

U.S.A.

Is that hospice safe? Infrequent inspections mean it may be impossible to know

ALABAMA | *The Washington Post* – 26 June 2014 – Inspectors showed up at a hospice agency here in March 2012, and then issued what amounted to a 161-page catalogue of end-of-life neglect. In all, the state health inspectors found treatment problems in the records for nine of 14 patients from early 2012. The discoveries at the hospice, known as Expect Care, highlight how weaknesses in the inspection system can allow agonizing lapses in care for the terminally ill. The typical hospice in the U.S. undergoes a full government inspection about once every six years, according to federal figures, making it one of the least-scrutinized areas of U.S. health care – even though about half of older Americans receive hospice care at the ends of their lives. By contrast, nursing homes are inspected about once a year, and

home health agencies every three years. http://www.washingtonpost.com/business/economy/is-that-hospice-safe-infrequent-inspections-means-it-may-be-impossible-to-know/2014/06/26/e258e880-aaa4-11e3-b98c-72cef4a00499_story.html

Extract from *The Washington Post* article

Even as the U.S. hospice industry has grown rapidly, caring for some of society's most vulnerable, the companies that provide hospice services are rarely reviewed for competency. It is impossible to say precisely how many hospice companies might be cited for violations if there were more scrutiny, but a significant portion of them appear to be providing scant care, Medicare statistics and interviews show.

N.B. See 'Oversight of hospice facilities,' *The Washington Post* graph/table, 26 June 2014. http://www.washingtonpost.com/business/economy/oversight-of-hospice-facilities/2014/06/26/15c7a618-fd4a-11e3-8176-f2c941cf35f1_graphic.html



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>

15 years after landmark court ruling, progress to home care for aged, disabled is checkered

GLOBAL POST | Online – 26 June 2014 – Fifteen years after a landmark Supreme Court ruling that the disabled should be given the choice to live outside nursing homes, mental hospitals and other institutions, its legacies are dueling. Progress has been made in every state to keep more aged and disabled people in their homes and communities, but only half of Medicaid spending goes to such care, with the services routinely denied by a system that favours institutions even though they're typically more expensive to taxpayers. In the 22 June 1999, decision in *Olmstead v. L.C.*, the justices ruled that unnecessarily segregating people with disabilities in institutions amounts to discrimination under the Americans with Disabilities Act if they can be cared for in more home-like settings. Advocates for the mentally ill, older people and the physically disabled regularly cite the ruling, but it has limitations. It says individuals should be "reasonably accommodated," specifically noting "the resources available to the state," caveats that have made it difficult to assess compliance and that have fueled widely different outcomes around the country. <http://www.globalpost.com/dispatch/news/the-canadian-press/140626/15-years-after-landmark-court-ruling-progress-home-care-aged>

Of related interest:

- VIRGINIA | Associated Press – 26 June 2014 – **'In years since landmark court ruling, Virginia has increased spending on home care for disabled.'** Virginia has increased the amount it spends to allow the disabled to live outside institutions in the years since a landmark Supreme Court ruling. In 2002, Virginia spent ... 27% of Medicaid funds on such services. In 2012, the figure was more than 52%. Nationally in 2012, states devoted an average of 49.5% of Medicaid long-term care funding for home settings, compared to 31.1% a decade earlier. <http://www.greenfieldreporter.com/view/story/1d08235dbc7d453c81dc064f44f794e3/VA--Home-Care-Virginia>

New drug policy too burdensome, hospices say

REUTERS | Online – 26 June 2014 – The Centers for Medicare & Medicaid Services [CMS] met with 30 hospice and healthcare organizations after outcry over a new rule. The rule was designed to help avoid duplicate payments for hospice medications but may be having unintended consequences. More than 40 organizations called for the rule's suspension in a letter this week to CMS. Signed by the American Medical Association, the American Society of Clinical Oncology and the American Geriatrics Society, it argues the policy places "undue burden" on beneficiaries – requiring "dying patients to navigate payer disputes." Previously, hospices paid only for the drugs patients needed for symptom management, and Medicare Part D drug policies covered drugs for hospice patients' unrelated conditions. Under the new rule, CMS now requires a prior authorization process for hospices and Part D providers to determine responsibility of drug coverage, and hospices must cover medications not related to the hospice diagnosis. The Office of the Inspector General recommended the policy to minimize mistakes in which Part D plans covered hospice drugs, but many hospice providers say they now face financial burdens that are not theirs to bear. <http://www.reuters.com/article/2014/06/26/us-cms-hospices-drug-costs-idUSKBN0F11R020140626>

[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>

When advance directives are ignored

THE NEW YORK TIMES | Online – 24 June 2014 – Health care professionals, ethicists and advocates continually urge older people to document their preferences about end-of-life medical decisions, and a growing proportion do. A recent large national study, tracking more than 6,000 people over age 60 who died between 2000 and 2010, found that the proportion with advance directives climbed to 72% from 47%.¹ But how much does it matter? How often are people's advance directives ignored or overridden? Do they really ensure that the elderly get the care they want or ward off procedures they don't? That large national study concluded that having advance directives had little effect on whether people were hospitalized and how often, or whether they died in hospitals. Yet where someone dies has considerable impact on how. "I don't want to demean advance directives," said Susan Tolle, director of the Center for Ethics in Health Care at Oregon Health & Science University. "They lift an emotional burden from family members. Appointing a person to make decisions on your behalf really does have benefits." But when it comes to end-of-life wishes, Dr. Tolle said, citing Dartmouth Atlas findings, patient preferences aren't the dominant factor.² http://newoldage.blogs.nytimes.com/2014/06/24/when-advance-directives-are-ignored/?_php=true&_type=blogs&_r=0

1. 'Advance directive completion by elderly Americans: A decade of change,' *Journal of the American Geriatrics Society*, 2 April 2014. [Noted in Media Watch, 7 April 2014, #352 (p.9)] <http://onlinelibrary.wiley.com/doi/10.1111/jgs.12736/abstract>
2. *Trends and Variation in End-of-Life Care for Medicare Beneficiaries with Severe Chronic Illness*, A report of the Dartmouth Atlas Project, Dartmouth Institute for Health Policy & Clinical Practice, Hanover, New Hampshire, April 2011. [Noted in Media Watch, 18 April 2011, #197 (p.3)] http://www.dartmouthatlas.org/downloads/reports/EOL_Trend_Report_0411.pdf

Noted in Media Watch, 1 July 2013, #312 (p.8):

- *BIOEDGE* | Online – 29 June 2013 – '**Advance directives are often not honoured.**' Advance directives give peace of mind to patients and their loved ones because they can be sure that their health care wishes will be followed even if they are not able to communicate. At least that's the theory. In practice, the situation is different, according to Susan P. Shapiro, a sociologist with the American Bar Association. After observing a thousand interviews of doctors with families in two intensive care units, she found that what happens is far more complicated. http://www.bioedge.org/index.php/bioethics/bioethics_article/10579

Most people short on money for nursing home care

USA TODAY | Online – 24 June 2014 – More than half of people in the USA underestimate the cost of nursing home care, and almost 40% have nothing set aside to pay for assisted living or nursing home care, a new survey shows.¹ Nursing home costs vary greatly across the country, but the price averages about \$81,000 a year. Yet, 57% of people believe it costs less than \$75,000 a year, according to the survey of 2,000 adults, ages 25 and older. About two-thirds (67%) of respondents have less than \$75,000 saved for elder care expenses, and 50% of women and 31% of men have nothing put aside. <http://americasmarkets.usatoday.com/2014/06/24/most-people-short-on-money-for-nursing-home-care/>

1. 'Survey: Most Americans underestimate nursing-home costs,' MoneyRates.com, June 2014. <http://www.money-rates.com/research-center/americans-underestimate-nursing-home-costs.htm>

At these hospitals, recovery is rare, but comfort is not

THE NEW YORK TIMES | Online – 23 June 2014 – Propped up in a hospital bed, a 75-year-old man with amyotrophic lateral sclerosis ... must make an agonizing decision. Should he keep struggling until the illness inevitably kills him, dependent on a ventilator, unable to walk or eat or move? Or should he choose a day and a time to have the ventilator disconnected, and die? The man ... was a patient at the Hospital for Special Care here, one of 400 long-term acute care hospitals in the U.S. These are no ordinary hospitals: critically ill patients, sometimes unresponsive or in comas, may live here for months, even years, sustained by respirators and feeding tubes. Some ... eventually will leave. Others will be here for the rest of their lives. These facilities often are tucked out of sight, and even many doctors do not know they exist. This one [in New Britain, Connecticut] sits on the edge of a decaying industrial town. "People don't want

to think about us," said Dr. Paul Scalise, chief of medicine at the Hospital for Special Care. "I don't want to think about us, either." But more experts and policy makers are likely to have to start thinking about them soon. The cost of long-term acute care is substantial, about \$26 billion a year in the U.S., and by one estimate the number of patients in these facilities has more than tripled in the past decade to 380,000. <http://www.nytimes.com/2014/06/24/health/life-goes-on-at-long-term-acute-care-hospitals.html?ref=health&r=0>

Specialist Publications

'Creating a fabric for palliative care in safety net hospitals: End-of-life nursing education consortium for public hospitals' (p.14), in *Journal of Hospice & Palliative Nursing*.

International

End-of-life care in Ireland

Report calls for improved end-of-life care

IRELAND | *The Irish Times* (Dublin) – 27 June 2014 – End-of-life care could be improved through better communication with patients and their family and friends, a new report suggests.¹ The report by Ombudsman Peter Tyndall makes a series of recommendations for improving end-of-life care. The report picks up on some of the common themes in complaints ... about end-of-life care. These include the management of complaints, the return of deceased people's belongings, issues around post mortems, support for families and friends, and specialised palliative care. Almost all of the complaints made to the Ombudsman about end-of-life care arise because of poor communication and a lack of clarity about the duties and rights of doctors, nurses, patients and

families, according to the report. <http://www.irishtimes.com/news/health/report-calls-for-improved-end-of-life-care-1.1847516>

Hospital staff asked grieving family if their dead father wanted dinner – report

IRELAND | *The Independent* (Dublin) – 27 June 2014 – A family forced to publicly grieve over their father's death in a busy hospital ward were asked if he wanted dinner, a report on dying in Ireland reveals. <http://www.independent.ie/irish-news/health/hospital-staff-asked-grieving-family-if-their-dead-father-wanted-dinner-report-30389878.html>

1. 'A Good Death: A Reflection on Ombudsman Complaints about End of Life Care in Irish Hospitals,' Office of the Ombudsman/Oifig an Ombudsman (of Ireland), June 2014. <http://www.ombudsman.gov.ie/en/Publications/Investigation-Reports/Health-Service-Executive/A-Good-Death/A-Good-Death-Report.pdf>

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

Families must get a say on "dying patients" care

U.K. (England) | *The Daily Mail* – 25 June 2014 – Families will be given a say over the treatment of patients who are thought to be near death, ministers promised. They said loved ones must be "involved in decisions" in National Health Service hospitals to ensure the "horrific" abuses and "tick-box" culture created by the discredited Liverpool Care Pathway [LCP] never happen again. And hospital managers or doctors who try to cover up the circumstances of a patient's death will be subject to criminal prosecutions and heavy fines in court. The radical rights for families are part of a new protection package for the dying that ministers say will mean an end to the "protocols and processes" that led to the LCP scandal. New rules for the care of patients thought to be near the end of their lives will forbid hospitals from deciding that someone is dying and then speeding their end by drugging them and removing tubes giving them food and water. Instead, there must be regular reviews of treatment in all cases, dying patients and their families must be kept informed and involved in decisions, and treatment will be "tailored to the individual." Hos-

pitals will be told to appoint independent assessors to decide on complaints in "serious or untoward incidents." The new rules on care for the dying ('Priorities of Care') were announced by Care Minister Norman Lamb. http://www.dailymail.co.uk/news/article-2670036/Families-say-dying-patients-care-Victory-Mail-aftermath-Liverpool-Care-Pathway-scan-dal.html?ITO=1490&ns_mchannel=rss&ns_campaign=1490

Specialist Publications

'Trends in death and end-of-life costs in the U.K.,' (p.10), in *British Journal of Healthcare Management*.

'Is discussing futile treatments really best for dying patients?' (p.10), in *British Medical Journal*.

'Liverpool Care Pathway successor "clarifies GP role," says Royal College of General Practitioners' (p.11), in *GP*.

N.B. The 'Priorities of Care' are based on 'One chance to get it right: Improving people's experience of care in the last few days and hours of life,' Leadership Alliance for the Care of Dying People, June 2014. <https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations>

Of related interest:

- U.K. (England) | *The Guardian* – 27 June 2014 – **'Anyone can die alone – not just the lonely.'** Dying alone, unloved, and missed by no one is surely everyone's not-so-secret fear. And it's not just academic. Latest figures published by the Office for National Statistics give Britain the dubious distinction of being the loneliest place in Europe. In the U.K. we are less likely overall to know our neighbours or have strong friendships than people living anywhere else in the EU. http://www.theguardian.com/commentisfree/2014/jun/27/anyone-can-die-alone-isolated-age-uk-loneliest-country?CMP=tw_t_gu
 - U.K. | *The Guardian* – 26 June 2014 – **'The government is still failing its ageing population.'** More than a year after a powerful report warned that the U.K. was "woefully underprepared" for the consequences of its ageing population, there are few signs that the scale and urgency of the challenge have been truly understood. Reforms may have begun to address the pressures on the pension and long-term care systems, but there is scant evidence that policy-makers have grasped the need to adapt public services across the board. <http://www.theguardian.com/society/2014/jun/26/government-failing-ageing-population>
1. 'Report: Ready for ageing?' Lords Select Committee on Public Service & demographic Change, June 2013. <http://www.parliament.uk/business/committees/committees-a-z/lords-select/public-services-committee/report-ready-for-ageing/>

Cont.

- U.K. | OPM Research – Accessed 24 June 2014 – ***How could free social care at end of life work in practice?*** The authors of this report looked at a range of service models throughout the course of the research. They found considerable variation in: definitions of "end of life"; drivers for the development and provision of free social care at end of life; who can access services; who can refer into services; time periods over which services are available; the capacity and capability of providers; and, the quality of care available. Not only is there considerable variability between the different services models, there is also significant variability within individual service models. <http://www.opm.co.uk/wp-content/uploads/2014/06/How-could-free-social-care-at-end-of-life-work-in-practice1.pdf>

End-of-life care in Australia

Palliative care cutback

AUSTRALIA (Victoria) | *The Sunraysia Daily* – 24 June 2014 – Around-the-clock in-home palliative care in Mildura has been cut with patients told to phone a medical advice line after hours. Sunraysia Community Health Services service delivery general manager Ruth Fox said the hours of availability for palliative care nurses had been reduced due to concerns about the occupational health and safety and well-being of nurses. Ms. Fox said that before April, palliative care support was available to Mildura patients 24 hours a day, seven days per week, however nurses were now rostered from 8.30am until 8.30pm, seven days a week. If patients need support outside this time they are encouraged to telephone the Victorian Government 'Nurse on Call' line where they can access immediate over-the-phone advice from a registered nurse or doctor. The nurse or doctor will then determine whether a patient needs further assistance and will direct them to hospital if needed. <http://www.sunraysiadaily.com.au/story/2370763/palliative-care-cutback/?cs=1511>

Media Watch: Editorial Practice

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

Distribution

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

Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (West Australia) | *PerthNow* – 28 June 2014 – **'WA Speaks survey shows 83% of West Australians support voluntary euthanasia.'** Most West Australians [WA] support voluntary euthanasia. Yet just 11 of WA's 95 politicians this week said they would back new state-based laws to make it legal. The WA Speaks Survey of more than 6000 people found 83% support voluntary euthanasia. The survey, conducted by *PerthNow*, *The Sunday Times* and *Nine News*, was the biggest of its kind and was analysed by respected pollster Galaxy Research. <http://www.perthnow.com.au/news/western-australia/wa-speaks-survey-shows-83-per-cent-of-west-australians-support-voluntary-euthanasia/story-fnhocxo3-1226970008845?nk=298e7e53de4edf0c8cba424897ba3799>

Of related interest:

- AUSTRALIA | *The West Australian* – 25 June 2014 – **'Limits in draft euthanasia law.'** Three doctors would need to approve before a terminally ill person could take their own life under proposed national euthanasia laws. The draft "dying with dignity" laws also say euthanasia would be limited to adults and Australian residents. The Senate agreed to set up a four-month long inquiry into the draft of Greens health spokesman Richard Di Natale's private member's Bill. <https://au.news.yahoo.com/thewest/national/a/24313055/limits-in-draft-euthanasia-law/>
- ASSOCIATED PRESS | Online – 25 June 2014 – **'Beyond cure? Europe euthanasia rulings sear debate.'** One French court acquitted a doctor of poisoning seven terminally ill patients while another ordered physicians to suspend treatment for a comatose man, while Britain's top court said the country's ban on assisted suicide may be incompatible with human rights. The decisions of the past few days are fueling the arguments of Europeans who say the duty of doctors is to end the suffering of those beyond treatment. But emotions run high on all sides around the issue of euthanasia and assisted suicide, as is shown by the bitter case of the comatose Frenchman, Vincent Lambert. Hours after the French court sided with his wife in ordering an end to treatment, the European Court of Human Rights blocked the move at the request of his parents, in a rare late-night ruling. The prosecution in France of Dr. Nicolas Bonnemaison was relatively unusual as well. The physician never denied giving seven terminally ill patients lethal injections, and some of their families testified on his behalf. Bonnemaison's lawyer said he hoped Wednesday's acquittal – and Tuesday's ruling in the case of Lambert — would force the government to update the law quickly. <http://www.kansascity.com/living/health-fitness/article612906.html>
- U.K. | BBC News – 24 June 2014 – **'Right-to-die: For and against assisted suicide.'** Lord Falconer's Bill on assisted dying is scheduled for debate in the House of Lords in the next three weeks. It differs from assisted suicide as it is not about stopping ongoing illness or disability with which you can live. His bill applies to terminally ill, mentally competent adults. It also requires the dying patient, after meeting strict legal safeguards, to self administer life-ending medication. <http://www.bbc.com/news/blogs-ouch-27922966>
- AUSTRALIA (Victoria) | *The Saturday Paper* (Collingwood) – 14 June 2014 – **'The language of euthanasia.'** The language used to describe ending one's life can hinder our ability to discuss the ethical issues. <http://www.thesaturdaypaper.com.au/opinion/topic/2014/06/14/the-language-euthanasia/1402668000>



World hospice &
palliative care day

11 October 2014

Who Cares? We Do!

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

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

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

Trends in death and end-of-life costs in the U.K.

BRITISH JOURNAL OF HEALTHCARE MANAGEMENT, 2014;20(6):298-299. From the viewpoint of health and social care the end of life tends to be the most expensive period in a person's lifetime costs... Acute admissions peak in the last year of life, while social and primary care costs start to rise slightly earlier... It is death (or nearness to death) not age *per se* that drives these costs. Interestingly the funding formula which distributes money to English Clinical Commission groups [CCG] implicitly assumes that age distributions predict death and hence end-of-life costs are assumed to be driven by age. If end-of-life is so important to the overall cost born by each CCG, why are the trends in death so poorly understood and their importance even more poorly communicated? http://www.hcaf.biz/2014/Trends_EOL_Costs.pdf

Is discussing futile treatments really best for dying patients?

BRITISH MEDICAL JOURNAL | Online – 24 June 2014 – The [recent Court of Appeal] judgment states that CPR is "potentially life-saving" and that therefore "there should be a presumption in favour of patient involvement" in a do not attempt cardiopulmonary resuscitation decision. Indeed, but does every decision not to offer ineffective treatment—organ transplant, chemotherapy, dialysis – need to become "patient informed" to absolve doctors from potential future blame? Should "badgering" be the norm? How informed must patients be? The judgment says that the words "slip away" were inadequate because they were not "fully understood." I too have used such words for the likely form of death without CPR. Should we now ensure that every patient whom we think is near death – and their relatives – understands in gritty detail that they will not be offered CPR even though it would be useless? <http://www.bmj.com/content/348/bmj.g4180>

Noted in Media Watch, 23 June 2014, #363 (p.6):

- U.K. (England) | BBC News – 17 June 2014 – '**Legal duty over resuscitation orders.**' Doctors now have a legal duty to consult with and inform patients if they want to place a do not resuscitate order on medical notes, the Court of Appeal in England ruled. The issue was raised by a landmark judgement that found doctors at Addenbrooke's Hospital, in Cambridge, had acted unlawfully. <http://www.bbc.com/news/health-27886265>

Of related interest:

- *PALLIATIVE MEDICINE* | Online – 25 June 2014 – '**Physician-patient end-of-life care discussions: Correlates and associations with end-of-life care preferences of cancer patients: A cross-sectional survey study.**' Only 7.8% of respondents [to a cross-sectional survey] reported discussing end-of-life-care preferences with their physicians. Physicians were more likely to discuss end-of-life-care preferences with cancer patients who accurately understood their prognosis, but less likely to do so if patients were married or received care in a hospital with an inpatient hospice unit. Furthermore, physician-patient end-of-life-care discussions were significantly, positively associated with the likelihood of preferring comfort-oriented care and hospice care, but negatively associated with preferences for receiving cardiopulmonary resuscitation when life is in danger and aggressive life-sustaining treatments at end of life, including intensive care unit admission, cardiac massage, intubation, and mechanical ventilation support. <http://pmj.sagepub.com/content/early/2014/06/24/0269216314540974.abstract>

Universality of ageing: Family caregivers for elderly cancer patients

FRONTIERS IN PSYCHOLOGY | Online – 20 June 2014 – The world population is ageing, with the proportion of older people (65+ years) expected to reach 21% in 2050 and to exceed the number of younger people (aged 15 or less) for the first time in history. The estimated number of new cancer cases worldwide among people over 65 is expected to grow from about 6 million in 2008 to more than 11 million during the coming decade. By 2030, individuals over 65 are expected to account for 70% of all cancer patients in the Western world. Along with the increase in oncology patients, the number of older people caring for their ill spouses or other relatives is also growing, with the ensuing toll on these caregivers causing major concern, especially in western countries. <http://journal.frontiersin.org/Journal/104563/abstract>

Noted in Media Watch, 28 April 2014, #355 (pp.6-7):

- *BRITISH MEDICAL JOURNAL* | Online – 25 April 2014 – '**Demand for family caregivers will exceed supply by 2017, think tank predicts.**' The number of elderly people in England who need care will outstrip the number of adult children who are able to provide it for the first time in 2017 and will grow steeply after that, a think tank has predicted. Without concerted action to tackle this "family care gap," pressure on hospital emergency departments and inpatient beds is likely to increase as more older people slip into crisis without the day care they need, it warns. <http://www.bmj.com/content/348/bmj.g2938>

Liverpool Care Pathway successor "clarifies GP role," says Royal College of General Practitioners

GP (U.K.) | Online – 26 June 2014 – Five new 'Priorities for Care' ... will restructure the approach to caring for people nearing the end of their life, placing greater emphasis on the wishes of the dying person and communication with their family.¹ The priorities were created by the Leadership Alliance for the Care of Dying People, a coalition of 21 organisations formed in response to a 2013 report on the failings of the Liverpool Care Pathway, led by Baroness Julia Neuberger.² The alliance accepted recommendations for a named GP to take overall responsibility for the care of patients nearing the end of their lives in the community. Dr. Maureen Baker, chairwoman of the Royal College of General Practitioners, one of the Alliance bodies, said: "Today's announcement should provide much-needed clarity for doctors and, most importantly, much-needed reassurance for patients and their families and carers. By setting out clear principles of what is expected, it should increase the confidence of doctors, nurses and other health professionals in confronting sensitive issues around end-of-life care, as well as reducing the potential for confusion or misinterpretation." <http://www.gponline.com/liverpool-care-pathway-successor-clarifies-gp-role-says-rcgp/palliative-end-of-life-care/article/1300789?HAYILC=SHOWCASE>

The 'Priorities for Care' state that, when it is thought a person may die within the next few days or hours:

This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

Sensitive communication takes place between staff and the dying person, and those identified as important to them.

The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion

Cont.

1. *One chance to get it right: Improving people's experience of care in the last few days and hours of life*, Leadership Alliance for the Care of Dying People, June 2014. <https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations>
2. *Independent Report: Review of Liverpool Care Pathway for dying patients* [in England], Department of Health, July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

Can personal dignity be assessed by others? A survey study comparing nursing home residents' with family members', nurses' and physicians' answers on the MIDAM-LTC¹

INTERNATIONAL JOURNAL OF NURSING STUDIES | Online – 19 June 2014 – Although nursing home residents themselves are the preferred source of information about the factors that influence their dignity, they may not always be able to provide this. In these cases, information must be obtained from proxy informants such as family members or caregiver staff. Proxies generally rated the residents' dignity more negatively ... than residents did themselves. Reports from proxy-informants cannot simply be substituted for nursing home residents' reports of personal dignity. [http://www.journalofnursingstudies.com/article/S0020-7489\(14\)00164-3/abstract](http://www.journalofnursingstudies.com/article/S0020-7489(14)00164-3/abstract)

1. **Measurement Instrument for Dignity AMsterdam** – for Long Term Care facilities.

Ageing prisoners' views on death and dying: Contemplating end-of-life in prison

JOURNAL OF BIOETHICAL INQUIRY | Online – Accessed 27 June 2014 – Rising numbers of ageing prisoners and goals on implementing equivalent health care in prison raise issues surrounding end-of-life care for prisoners. The paucity of research on this topic in Europe means that the needs of older prisoners contemplating death in prison have not been established. About half of the prisoners [i.e., study participants] reported having thought about dying in prison, with some mentioning it in relation with suicidal thoughts and others to disease and old age. Themes identified during data analysis included general thoughts about death and dying, accounts of other prisoners' deaths, availability of end-of-life services, contact with social relations, and wishes to die outside of prison. <http://link.springer.com/article/10.1007/s11673-014-9548-x>

Of related interest:

- *JOURNAL OF BIOETHICAL INQUIRY* | Online – Accessed 27 June 2014 – **'Expert perspectives on Western European prison health services: Do ageing prisoners receive equivalent care?'** The aim of this paper is to gain insight into the approaches used in the provision of equivalent health care to ageing prisoners and to confront the intuitive definition of equivalent care and the practical and ethical challenges that have been experienced by individuals working in this field. <http://link.springer.com/article/10.1007/s11673-014-9547-y>

N.B. The provision and delivery of end-of-life care in the prison system have been highlighted in Media Watch on a regular basis. A compilation of articles, reports, etc., on this critically important public health issues noted in the weekly report in recent years is available online at the Palliative Care Community Network website: <http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons>.

Bereavement china and edge-work

JOURNAL OF GRADUATE MEDICAL EDUCATION, 2014;6(2):393-394. Most hospital wards in the U.K. have a special tea set called the "bereavement china" or "bad news china." It is strictly reserved for patients and families who have lost a loved one or received a devastating diagnosis. The physician breaks the bad news, the patients and relatives cry, then someone is assigned to make tea, with the murmured aside: "use the special tea set." The logic behind this does not stand up to scrutiny; after hearing the worst news of your life, is your subsequent heartache alleviated one whit by the serving of tea in a nicely patterned china cup and slightly fancy teapot? Probably not, but it is something we do. It makes us feel better. Breaking bad news is actually a two-way process. The doctor is always affected somewhat by the encounter, although often in subtle and hidden ways. The "breaker" must enter a shared emotional space with the "breakee," which can feel discomfiting and exhausting. Even the thickest-skinned physician often feels an unpleasant flicker of anguish as they watch someone's life fall apart. The heterogenous group of physical reactions is varied and difficult to prepare for. Some patients explode outward, sobbing and keening; some seem to physically diminish in front of you,

collapsing in on themselves and becoming suddenly small and frail. Some move textbook-like through the Kübler-Ross model of grief; others merely become dazed and monosyllabic, their unseeing eyes focused on something horrible in the future. Most of us will have faced an actor in our medical school examinations, our clumsy attempts at delivering a ... diagnosis prompting a prolonged and rehearsed emotional reaction, while we squirmed with the awkwardness of it all. Perhaps, we should be awarding the top marks to the student who decides to boil the kettle and hunts down some teabags. <http://www.jgme.org/doi/full/10.4300/JGME-D-13-00455.1>

Extract from *Journal of Graduate Medical Education* article

People *deserve* to have their hearts broken and worlds turned upside down in a calm, sensitive, and professional manner. Edge-work doesn't look very dramatic or exciting; we are not wielding scalpels, administering medication, or pumping someone's chest. Edge-work, however, may be some of the most life-changing work we do; we will be burned into our listeners' memory for rest of their lives.

Of related interest:

- *INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY* | Online – 23 June 2014 – '**Primary care providers' bereavement care practices: Recommendations for research directions.**' Bereaved patients are often seen in primary care settings. Although most do not require formal support, physicians may be called upon to provide support to some bereaved, particularly those with bereavement-related mental health disorders like complicated grief and bereavement-related depression. Research evidence on physician bereavement care is scant. <http://onlinelibrary.wiley.com/doi/10.1002/gps.4157/abstract>
- *JOURNAL OF RELIGION & HEALTH* | Online – 17 June 2014 – '**Empathy and silence in pastoral care for traumatic grief and loss.**' This paper evaluates silence as a therapeutic practice in pastoral care for traumatic grief and loss. Informed by the history of attachment and mourning theory, its research considers the basic effect that empathy has upon the therapeutic relationship around psychic difference. The study appraises the potential resources and detriments that empathic language may have for the grief process. Offering clinical examples in hospice chaplaincy, it refutes the idea that silence is formulaic tool to be used. It instead offers silence as the acceptance of the limits of empathic language and the affirmation of psychological difference and theological wholeness. <http://link.springer.com/article/10.1007/s10943-014-9904-5>

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- *WORLD JOURNAL OF SURGERY* | Online – 21 June 2014 – **'Withholding tragic knowledge may lead to a tragic death: A palliative care perspective.'** I read with interest the article by Suri *et al* on the harms and benefits of sharing "tragic knowledge" with patients.¹ However, I want to clarify there have been no good studies to indicate unrealistically optimistic patients benefit at the end of life. Studies that have pointed to the psychological benefits of unrealistic optimism in cancer patients are flawed because they are overwhelmingly cross-sectional in their design and do not take into account the emotional distress of patients and families when death is imminent. As a palliative care physician, I have seen this last-minute realization be accompanied by the awareness that there is no longer the opportunity to put affairs in order or to engage in meaningful legacy work. <http://link.springer.com/article/10.1007/s00268-014-2676-y>
 1. 'Tragic knowledge: Truth telling and the maintenance of hope in surgery,' April 2014, *World Journal of Surgery*. Truth telling in surgery raises questions on the nature of truth itself, how much information ought to be shared, what information can be withheld, and how surgeons should share tragic knowledge with patients. [Noted in Media Watch, 5 May 2014, #356 (p.1)] <http://link.springer.com/article/10.1007/s00268-014-2566-3>

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

Creating a fabric for palliative care in safety-net hospitals: End-of-life nursing education consortium for public hospitals

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2014;16(5):312-319. As the numbers of medically uninsured rise, more and more Americans are depending on public/safety-net (P/SN) hospitals – hospitals responsible for the care of the uninsured and underinsured. The Center to Advance Palliative Care has found that far fewer P/SN hospitals report palliative care services, compared with similarly sized not-for-profit hospitals. This article describes the implementation and evaluation of the End-of-Life Nursing Education Consortium for Public Hospitals, a statewide initiative to enhance palliative care education and leadership in 16 (of 17) California P/SN hospitals. http://journals.lww.com/jhpn/Abstract/2014/07000/Creating_a_Fabric_for_Palliative_Care_in_Safety.11.aspx

Noted in Media Watch, 28 April 2014, #355 (p.10)::

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 20 April 2014 – **'Assessing challenges in end-of-life conversations with patients utilizing a public safety-net health care system.'** This study examined barriers to end-of-life care discussions as experienced by health care providers working in a public safety-net health care system where the majority of their patients were low-income and immigrant Latinos seeking medical treatment. <http://ajh.sagepub.com/content/early/2014/04/17/1049909114530550.abstract>

Dying with dignity in the intensive care unit

NEW ENGLAND JOURNAL OF MEDICINE | Online – 26 June 2014 – This review covers issues related to the end of life in the absence of discordance between the patient's family and caregivers. <http://www.nejm.org/doi/full/10.1056/NEJMra1208795>

Of related interest:

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 26 June 2014 – **'Where we die.'** Even as increasing numbers of Americans choose to die at home, ICU stays toward the end of life have increased. <http://www.nejm.org/doi/full/10.1056/NEJMp1404427>

Nurses' experiences providing palliative care to individuals living in rural communities: Aspects of the physical residential setting

RURAL & REMOTE HEALTH | Online – 24 June 2014 – Nurses described the characteristics of working in a rural community and how it influences their perception of their role, highlighting the strong sense of community that exists but how system changes over the past decade have changed the way they provide care. They also described the key role that they play, which was often termed a "jack of all trades," but focused on providing emotional, physical, and spiritual care while trying to manage many challenges related to transitioning and working with other healthcare providers. Finally, nurses described how the challenges of working within the physical constraints of a rural residential setting impeded their care provision to clients who are dying in the community, specifically related to the long distances that they travel while dealing with bad weather. <http://www.rrh.org.au/articles/printviewnew.asp?ArticleID=2728>

Representative sample of articles noted in past issues of Media Watch on the provision and delivery of end-of-life care in rural areas.

- *RURAL & REMOTE HEALTH* | Online – 14 May 2014 – '**Understanding the distinct experience of rural inter-professional collaboration in developing palliative care programs.**' Previous research on developing rural palliative care has created a four-phase capacity development model that included inter-professional rural palliative care teams; however, the details of rural team dynamics had not been previously explored and defined. [Noted in Media Watch, 19 May 2014, #358 (p.10)] <http://www.rrh.org.au/articles/subviewnew.asp?ArticleID=2711>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 19 March 2013 – '**Among neighbors: An ethnographic account of responsibilities in rural palliative care.**' Families, healthcare providers, and administrators work together in fluid ways to support high quality palliative care in their communities. The very fluidity of these responsibilities, however, can also work against high quality care. [Noted in Media Watch, 1 April 2013, #299 (p.15)] <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8869654>
- *RURAL & REMOTE HEALTH* | Online – 7 January 2013 – '**Comparing the experiences of rural and urban family caregivers of the terminally ill.**' Results of this study suggest that while there are commonalities to the caregiving experience regardless of setting, key differences also exist. [Noted in Media Watch, 14 January 2013, #288 (p.13)] <http://www.rrh.org.au/articles/showarticlenew.asp?ArticleID=2250>

"Right to try" laws bypass [U.S.] Federal Drug Administration for last-ditch treatments

SCIENCE, 2014;344(6190):13229. Several state legislatures, prodded by desperately ill patients and a libertarian think tank, are defying federal regulators to make experimental drugs available to terminally ill patients outside of clinical trials. The new laws, called "Right to Try," went on the books in two states last month and are being considered in several others. One company has already announced its plans to use the laws to offer its stem cell treatment well ahead of approval from the Food & Drug Administration. But skeptics say few companies will be willing to bear the costs and risks of offering a drug outside of its clinical trials, especially if it means defying federal law. <http://www.sciencemag.org/content/344/6190/1329.short>

Noted in Media Watch, 9 June 2014, #361 (p.4):

- U.S. (Louisiana) | Associated Press – 2 June 2014 – '**Bill expanding experimental treatments for the terminally ill in Louisiana signed into law...**' Terminally-ill patients will be able to use experimental drugs or treatments not approved by the Food & Drug Administration. It prohibits the Louisiana State Board of Medical Examiners from taking action against a doctor authorizing the experimental treatments and insurers would not be required to cover treatment. <http://www.therepublic.com/view/story/a417bf1ded714062a2f7398dc1663721/LA--Right-To-Try>

N.B. 'Right to Try' legislation exists in Arizona, Colorado, and Missouri.

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/5/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 | Central Regional Hospice Palliative Care Program: <http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1>

ONTARIO | Central West Palliative Care Network: http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1

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>

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>

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