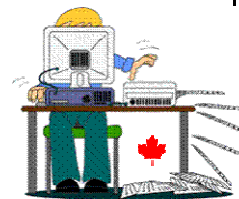


## Media Watch...

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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Compiled & Annotated by Barry R. Ashpole

Preventing hospital and nursing home admissions: Scroll down to [Specialist Publications](#) and 'Home health agency work environments and hospitalizations' (p.13), in *Medical Care*.

## Canada

### Five ways Canada can fix end-of-life care

*THE GLOBE & MAIL* | Online – 18 September 2014 – It's one of the trickiest policy questions in health care... <http://www.theglobeandmail.com/search/?q=end+of+life+care>

**N.B.** Access to this article requires a subscription.

### Rona Ambrose says Canada needs better palliative care

CBC NEWS | Online – 15 September 2014 – Federal Health Minister Rona Ambrose says Canada has to do better when caring for people who are dying – and she wants to make that a priority. Ambrose ... spoke of her first-hand experience finding the best possible care for family members. "I know, in my family, my grandma had really good palliative care. And that made a huge difference to our family," Ambrose said. And, she says, as the debate around end-of-life care heats up again this fall, she will keep that in mind. "I think the starting point for me is that we still don't have the best elderly care and palliative care yet," Ambrose said. "So let's talk about making sure we have the best end-of-life care before we start talking about assisted suicide and euthanasia." Others are talking about suicide and euthanasia, though. Next month, the Supreme Court of Canada will hear an appeal by the B.C. Civil Liberties Association that could grant termi-

nally ill Canadians the right to assisted suicide. The Quebec government passed legislation in June that will allow for assisted suicides in some cases. It will take a year and a half to develop the regulations before the bill is formally law at the end of 2015. And the Canadian Medical Association passed a resolution last month allowing doctors to follow their conscience if they are asked to help a terminally ill patient to die, as long as they are in a province where it's legal. <http://www.cbc.ca/news/politics/rona-ambrose-says-canada-needs-better-palliative-care-1.2764813>

#### End-of-life care in Canada

Several reports, published between 1995 and 2012, on end-of-life care in Canada are listed in Media Watch of 3 March 2014, #347 (p.2).

Cont.

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

- *THE GLOBE & MAIL* | Online – 10 June 2014 – '**Canada needs national palliative care plan, Canadian Medical Association urges.**' The Canadian Medical Association is calling for the creation of a national palliative care strategy to ensure people across the country have access to a high-quality, dignified end-of-life experience. The association made the call in a new national end-of-life report created after speaking to Canadians across the country about their opinions on such highly charged as physician-assisted dying and palliative care.<sup>1</sup> <http://www.theglobeandmail.com/life/health-and-fitness/health/canada-needs-national-palliative-care-plan-cma-urges/article19088848/>

1. 'End-of-life care: A national dialogue,' Canadian Medical Association, based on five town-hall meetings held across Canada conducted in conjunction with *Maclean's*, June 2014. [http://www.cma.ca/multimedia/CMA/Content/Images/CMAAdvocacy/EOL\\_townhall\\_report\\_FINAL.pdf](http://www.cma.ca/multimedia/CMA/Content/Images/CMAAdvocacy/EOL_townhall_report_FINAL.pdf)

Noted in Media Watch, 2 June 2014, #360 (p.1):

- *THE GLOBE & MAIL* | Online – 28 May 2014 – '**New Democratic Party palliative-care motion gets through Commons, now up to Tories to respond.**' The House of Commons passed an Opposition [non-binding] motion that calls on the federal government to come up with a national strategy on palliative care. And while not promising to launch a formal effort to create such a strategy, Health Minister Rona Ambrose says she supports the call. <http://www.theglobeandmail.com/news/politics/ndp-palliative-care-motion-gets-through-commons-now-up-to-tories-to-respond/article18902276/>

### **Light in the dark: What if vegetative patients are actually conscious?**

*MACLEAN'S* | Online – 15 September 2014 – Vegetative patients were long believed to lack any consciousness at all. Unlike patients in a coma, they wake up and fall asleep, and retain basic reflexes; yet their eyes rove around the room, fixating on nothing. They're unable to communicate or follow basic commands, such as squeezing a doctor's hand to demonstrate awareness. Patients can live like this for years. Some families make the wrenching decision to end life support, or else find themselves pitched in legal battles over care, as happened in the cases of Terri Schiavo ... and Hassan Rasouli... After an infection left Rasouli brain-damaged, doctors wanted to end treatment; his family refused. Ultimately, the Supreme Court ruled with the family. It was in 2006 that Owen, then at the University of Cambridge, launched his first real challenge to the notion that all vegetative patients are unconscious. Owen [now based at University of Western Ontario] and his team have shown that almost one in five vegetative patients retains some awareness, and can follow commands by fluctuating brain activity... Still, the "playing tennis" technique is far from perfect, he acknowledges: It could be missing patients who aren't able to picture themselves darting around a tennis court, or simply feel tired or confused at the time of the scan. <http://www.macleans.ca/society/health/light-in-the-dark-what-if-vegetative-patients-are-actually-conscious/>

**N.B.** The *Maclean's* article refers to 'A common neural code for similar conscious experiences in different individuals,' published in the *Proceedings of the National Academy of Sciences*, 11 September 2014. <http://www.pnas.org/content/early/2014/09/11/1407007111>

Noted in Media Watch, 8 September 2014, #374 (p.8):

- *CANADIAN JOURNAL OF ANESTHESIA* | Online – Accessed 2 September 2014 – '**The future of decision-making in critical care after *Cuthbertson v. Rasouli*.**' The Supreme Court of Canada ruling on *Cuthbertson v. Rasouli* has implications for all acute healthcare providers. The authors' objective in writing this article is to clarify the implications of this ruling on the care of critically ill patients. <http://link.springer.com/article/10.1007/s12630-014-0215-9>

## Too many vulnerable Canadians are denied home care: Editorial

ONTARIO | *The Toronto Star* – 15 September 2014 – It comes as no surprise that people are falling through the cracks in Canada's home care system. The shock is just how many. According to a new study, more than 790,000 Canadians report that their need for home care is going entirely unmet, or is only being partially addressed. They are among the most vulnerable members of society: the aged, the disabled and those suffering from a long-term illness. And that their treatment is inexcusable. Demand for home care is soaring as hospitals cut costs by discharging patients "sicker and quicker," sending them home instead of occupying expensive acute care beds. This wouldn't be a problem if home care services kept pace with rising demand, but that just isn't happening. People are being sent home to suffer without professional help. Meanwhile, overall need for home care is set to get a whole lot worse with the number of Canadians 65 and older expected to double over the next 20 years... Some can expect bigger trouble than others. [http://www.thestar.com/opinion/editorials/2014/09/15/too\\_many\\_vulnerable\\_canadians\\_are\\_denied\\_home\\_care\\_editorial.html](http://www.thestar.com/opinion/editorials/2014/09/15/too_many_vulnerable_canadians_are_denied_home_care_editorial.html)

1. 'Study: Canadians with unmet home care needs, 2012,' Statistics Canada, September 2014. [Noted in Media Watch, 15 September 2014, #375 (p.2)] <http://www.statcan.gc.ca/daily-quotidien/140909/dq140909a-eng.htm?HPA>

Of related interest:

- BRITISH COLUMBIA | 24 Hour News (Vancouver) – 16 September 2014 – **'Minister defends home care hours.'** B.C. government has increased the number of subsidized home care support hours to 7.37 million as part of a strategy to free up hospital and residential care beds. [Provincial] Health Minister Terry Lake told 24 Hours [News] the increase represents a 23% growth in the number of hours performed since 2009-2010. He made the comments after criticism from a seniors' group that B.C. wasn't doing enough to boost services at home. <http://vancouver.24hrs.ca/2014/09/16/minister-defends-home-care-hours>
- *THE GLOBE & MAIL* | Online – 16 September 2014 – **'Home care's where the heart is.'** In Canada, we talk incessantly about the impact of our aging population – especially the financial impact – and about the need to shift health-care resources into the community, into programs like home care. The new data [from Statistics Canada] are a stark reminder that we're all talk. <http://www.theglobeandmail.com/globe-debate/home-cares-where-the-heart-is/article20607231/>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MANITOBA | *The Winnipeg Free Press* – 16 September 2014 – **'Fletcher to take suicide bill to Senate: Issue not on Parliament's agenda.'** Physician-assisted suicide will be a reality in Canada no matter what the federal government wants, Manitoba Conservative MP Steven Fletcher said. Fletcher was reacting to comments from Health Minister Rona Ambrose, who said in an interview ... with CBC that assisted suicide is not her priority. "The starting point for me is we still don't have the best elderly care and palliative care yet," said Ambrose. "I want to see us strive to be the best in the world for palliative care before we lead to this discussion." She pointed to a 2010 debate on an ultimately defeated Bloc Québécois bill for assisted suicide as a sign Parliament doesn't want to go down that road at this time, and suggested the issue isn't on Parliament's agenda. <http://www.winnipegfreepress.com/local/fletcher-to-take-suicide-bill-to-senate-275245651.html>

### [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.18.

## U.S.A.

### Terminally ill, but constantly hospitalized

*THE NEW YORK TIMES* – 21 September 2014 – It turns out that in the New York metropolitan region, patients opt for aggressive treatment much more often than other Americans. "New York City continues to lag in serious ways with regards to providing patients with the environment that they want at the end of life," says Dr. David Goodman, who studies end-of-life care at Dartmouth College's Geisel School of Medicine. The reasons they do this are many, but most experts agree that it has less to do with the unique characteristics and desires of people in New York and New Jersey than the health care system and culture that has evolved here. At the end of life, all this translates to more people dying in the hospital, often in an intensive care unit on a ventilator or feeding tube; more doctor visits leading to tests, treatments and drug prescriptions; and more money being spent by the government, private insurers and patients themselves. Specialists at the Dartmouth Healthcare Atlas maintain that one of the main drivers of this phenomenon is quantity: People end up in hospitals here so often, they say, because this region simply has a lot of hospital beds. "One of the truisms of health care is that whatever resources are available, or whatever beds are built, they tend to get filled," Goodman says. A second driver is that every region has its own medical "culture," and the one in New York is built around highly trained specialists and sub-specialists who see it as their job to cure illness. <http://www.npr.org/blogs/health/2014/09/21/349585612/terminally-ill-but-constantly-hospitalized>

Of related interest:

- *THE NEW YORK TIMES* | Online OpEd – 18 September 2014 – **'When medicine is futile.'** My father would have been thrilled to read 'Dying in America' ... that argues that we subject dying patients to too many treatments, denying them a peaceful death. But he would have asked what took us so long. A physician from the late 1950s to the late 1990s, my dad grew increasingly angry at how patients died in this country, too often in hospitals and connected to machines and tubes he knew would not help them. He placed some of the blame for the situation at the feet of bioethics and patients' rights, two movements that I, as a young physician, had fiercely advocated. Doctors, he believed, had abrogated their duties in preventing – and, if necessary, thwarting – patients from pursuing inappropriate end-of-life interventions. [http://www.nytimes.com/2014/09/19/opinion/when-medicine-is-futile.html?\\_r=0](http://www.nytimes.com/2014/09/19/opinion/when-medicine-is-futile.html?_r=0)

### Dying in America is harder than it has to be, Institute of Medicine advises

*KAISER HEALTH NEWS* | Online – 17 September 2014 – It is time for conversations about death to become a part of life. That is one of the themes of a 500-page report ... by the Institute of Medicine [IOM].<sup>1</sup> The report suggests that the first end-of-life conversation could coincide with a cherished American milestone: getting a driver's license at 16, the first time a person weighs what it means to be an organ donor. Follow-up conversations with a counselor, nurse or social worker should come at other points early in life, such as turning 18 or getting married. The idea ... is to "help normalize the advance care planning process by starting it early, to identify a health care agent, and to obtain guidance in the event of a rare catastrophic event." The 21-member IOM committee that authored the report grappled with the fact that most Americans have not documented their wishes for end-of-life care. <http://www.kaiserhealthnews.org/Stories/2014/September/17/institute-of-medicine-says-dying-in-america-is-harder-than-it-has-to-be.aspx>

1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine, Washington, September 2014. <http://www.iom.edu/~media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf>

## Congress approves tighter scrutiny of hospices

*THE WASHINGTON POST* | Online – 19 September 2014 – Hospice agencies must subject themselves to government inspections at least once every three years under new legislation approved by Congress, part of a measure that addresses concerns about substandard operators in the booming industry. Approved by the House earlier this week and by the Senate late Thursday night, the bill requires more frequent inspections of hospices and closer scrutiny of hospices at which a large percentage of patients live longer than six months - a sign to regulators that a hospice may be intentionally enrolling people who are not near death. As the hospice industry has grown in recent decades, evolving from a movement of non-profit organizations into a significant piece of the healthcare industry, critics have noted that some of the new hospices may not be living up to the original ideals. [http://www.washingtonpost.com/business/economy/congress-approves-tighter-scrutiny-of-hospices/2014/09/19/94f8e218-4010-11e4-b03f-de718edeb92f\\_story.html](http://www.washingtonpost.com/business/economy/congress-approves-tighter-scrutiny-of-hospices/2014/09/19/94f8e218-4010-11e4-b03f-de718edeb92f_story.html)

## New York among worst states for nursing home care

NEW YORK | WSYR-TV (Syracuse) – 15 September 2014 – New York's nursing-home care is among the nation's worst, according to an advocacy group. Families for Better Care gave the Empire State's nursing-home care an "F," and ranked the state No. 45 overall. Families for Better Care executive director Brian Lee said one of the main problems was limited staff levels. "Inadequate staffing levels continue to fuel widespread neglect and abuse," said Lee. [http://www.localsyr.com/story/d/story/new-york-among-worst-states-for-nursing-home-care/31635/H\\_SD\\_wxOzEKvOQ1xgUGdNg](http://www.localsyr.com/story/d/story/new-york-among-worst-states-for-nursing-home-care/31635/H_SD_wxOzEKvOQ1xgUGdNg)

### Specialist Publications

'Site of death among nursing home residents in the U.S.: Changing patterns, 2003-2007' (p.15), in *Journal of the American Medical Directors Association*.

**N.B.** Interactive rating of each state: <http://nursinghomereportcards.com/>

## A third of family caregivers spend over \$10K a year

*USA TODAY* | Online – 15 September 2014 – About a third of family caregivers spend more than 30 hours a week on caregiving tasks, a new survey shows.<sup>1</sup> And about a third spend more than \$10,000 a year on caregiving expenses, such as medications, medical bills, in-home care, and in some cases senior housing. The survey found that 46% of family caregivers spend more than \$5,000 a year on out-of-pocket caregiving expenses; 32% spend less than \$5,000; and, 21% don't know how much they spend. About 7% spend \$50,000 or more a year. About half of the caregivers in the survey are retired; 39% are working full time, part time or are self-employed. Of those who are working, 60% say their duties have had a negative impact on their jobs; 17% say they have had to miss a significant amount of work because of those caregiving duties. <http://www.usatoday.com/story/money/personalfinance/2014/09/15/family-caregiving-time-costs/15456771/>

1. Senior Care Cost Index, September 2014, Caring.com. <http://www.caring.com/research/senior-care-cost-index-2014>

Of related interest:

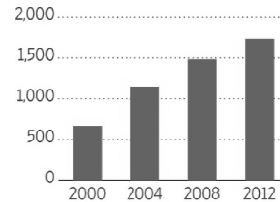
- *FORTUNE* | Online – 15 September 2014 – 'The worst paying fastest-growing job in America.' Historical discrimination, demographics, and public funding have left home care workers at the very bottom of the American work hierarchy. <http://fortune.com/2014/09/15/home-care-workers/>

## Straight talk about palliative care: What everyone should know

*THE WALL STREET JOURNAL* | Online – 14 September 2014 – The U.S. health-care system is in enormous flux between the old fee-for-service, or paying-for-volume, model and the emerging payment model based on paying for quality of care and good clinical outcomes. Palliative care will be embraced because it improves quality so much that it reduces need for crisis hospitalizations, which are not only difficult for patients and families, but are by far the costliest setting for medical care. Because better medical care means people can remain safely in their homes and communities, it's better for patients and it saves the taxpayers a lot of unnecessary and burdensome health-care spending. It's less expensive not because we're stinting or withholding care, but because the quality is better. <http://online.wsj.com/articles/straight-talk-about-palliative-care-what-everyone-should-know-1410724839>

### On the Rise

Numbers of U.S. hospitals with 50 or more beds that offer palliative-care programs. The first and last numbers represent 24.5% and 61%, respectively, of all U.S. hospitals of this size.



Source: Center to Advance Palliative Care  
The Wall Street Journal

Noted in Media Watch, 15 September 2014, #375 (p.4):

- CENTER TO ADVANCE PALLIATIVE CARE | Online – 2 September 2014 – **'National Palliative Care Registry Annual Survey Summary: Results of the 2012 National Palliative Care Registry Survey, as of July 2014.'** Palliative care [PC] in U.S. hospitals continues to increase... The prevalence of hospitals (50 or more beds) with a PC team increased from 658 (24.5%) to 1,734 (61%), a 163.5% increase from 2000-2012. In 2000, less than one-quarter of these hospitals (658) had a PC program, compared with more than two-thirds (1,734) in 2012. [https://registry.capc.org/cms/portals/1/Reports/National\\_Palliative\\_Care%20Registry\\_Annual\\_Survey\\_Summary\\_9.2.2014.pdf](https://registry.capc.org/cms/portals/1/Reports/National_Palliative_Care%20Registry_Annual_Survey_Summary_9.2.2014.pdf)

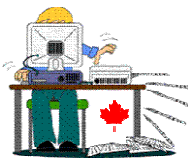
## International

### Cost of dying in Wales

#### **Pauper's funeral for 18-year-old among 500 in Wales**

U.K. (Wales) | BBC News – 18 September 2014 – More than 500 people have had pauper's funerals in Wales in the last five years, costing more than £500,000. The funerals are carried out when a person died without relatives or the family is unable to pay. A simple service is followed by cremation or burial in an unmarked grave which could potentially be reused three or four times. Officially known as public health funerals, the cost is met by local councils or the National Health Service, with such funerals set to put an "increasing strain" on the public purse, according to councils. BBC Wales asked every council in Wales how many public health funerals they arranged between 2009-2010 and 2013-2014 in a Freedom of Information request, and how much they cost. <http://www.bbc.com/news/uk-wales-29241746>

Cont. next page



### 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>

Noted in Media Watch, 5 May 2014, #356 (p.6):

- U.K. (England) | *The Plymouth Herald* – 28 April 2014 – '**431 pauper's funerals in 2013 as figure doubles in five years.**' The number of people given a "pauper's funeral" has doubled in the South West over the past five years. The South West recorded the biggest surge over the 5-year period of nine English regions... <http://www.plymouthherald.co.uk/431-pauper-s-funerals-2013-figure-doubles-years/story-21023434-detail/story.html>

#### End-of-life care in Scotland

### **National Health Service figures reveal an increase in the number of Lanarkshire residents spending the last six months of their lives at home or in a community setting**

U.K. (Scotland) | *The Scottish Daily Record* (Glasgow) – 17 September 2014 – New statistics reveal an increase in the number of people across Lanarkshire spending the last six months of their lives at home or in a community setting. The official National Health Services Scotland [NHSS] figures ... are just below the Scottish average. In Lanarkshire, 90.6% of people spent the last six months of their lives at home or in a community setting during 2012-2013. The figure for 2011-2012 was 90%, 2010-2011 was 89.6, 2009-2010 was 89.5% and 2008-2009 was 89.5%. The official report from Information Services Division ... says that the proportion of time spent at home or in a community setting towards the end of life provides a high level indication of progress in implementation of the national action plan.<sup>1</sup> <http://www.dailyrecord.co.uk/news/local-news/nhs-figures-reveal-increase-number-4273808>

1. 'Living & Dying Well: National Action Plan for Palliative and End-of-Life Care in Scotland,' The Scottish Government, 2008: <http://www.scotland.gov.uk/Resource/Doc/239823/0066155.pdf>

**N.B.** 'Preferred Place of Care: Palliative Care Audit,' National Health Service Lanarkshire, 2010. <http://www.nhslanarkshire.org.uk/Services/PalliativeCare/Documents/PPC%20Audit%20Final.pdf>

#### End-of-life care in England

### **Essex: Health groups launch new pathway for terminally ill patients**

U.K. (England) | EADT24 – 16 September 2014 – A new approach to supporting dying people is being implemented across north east Essex... The 'Individual Care Record For The Last Days Of Life' has been adopted by a number of health organisations working in partnership. It has been developed following the withdrawal of the Liverpool Care Pathway, which had been blamed for poor care in a Parliamentary review,<sup>1</sup> and is designed to provide tailored support to terminally ill patients at all times. It is based on five 'Priorities for Care,' created by a national coalition of organisations,<sup>2</sup> and will mean care is focused on dying people's wishes, rather than processes. Priorities for care include guidance about food and drink, stating that patients should be supported to eat and drink for as long as they wish to do so, and also stresses the importance of clear and sensitive communication between staff, the person who is dying, and their family and friends. [http://www.eadt.co.uk/news/essex\\_health\\_groups\\_launch\\_new\\_pathway\\_for\\_terminally\\_ill\\_patients\\_1\\_3771911](http://www.eadt.co.uk/news/essex_health_groups_launch_new_pathway_for_terminally_ill_patients_1_3771911)

1. '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>
2. '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. [Noted in Media Watch, 30 June 2014, #364 (p.7)] <https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations>

## End-of-life care in Israel

### **Suspended between life and death**

ISRAEL | BBC News (U.K.) – 13 September 2014 – When [former Israeli Prime Minister] Ariel Sharon died in January this year, eight years after a stroke, he'd survived for longer than would probably be expected had he lived elsewhere in the world. Since 2005 it's been illegal in Israel to turn off ventilators when a person is dying or has no hope of recovery. The result is that large numbers of patients spend years on life support, many of them unconscious. The law in Israel was informed by Jewish tradition, but talking to families of other faiths in the hospital here, it seems to have become a cultural viewpoint too. Israel's position on keeping ventilated patients alive is particularly unusual when patients are not stable on a ventilator but dying on one. When a patient is dying decisions have to be made, both by the medical team and the family, about what treatment they receive. The Jewish faith draws a clear distinction between withholding and withdrawing. Any act that hastens death is prohibited; so it follows that it is illegal to turn a ventilator off when a patient is dying, even if this would ease his suffering. <http://www.bbc.com/news/health-29132303>

## Elder and home care in the U.K.

### **"Cuts forcing English councils to limit social care"**

U.K. (England) | BBC News – 13 September 2014 – Almost 90% of councils in England no longer offer social care to people whose needs are ranked low to moderate, the Association of Directors of Adult Social Services (Adass) has said. The group is warning cuts are making the care system "unsustainable." The government says councils have been given an extra £1.1bn to help protect social care this year. But charities say hundreds of thousands of people are struggling without help. When someone applies for social care, their needs are determined as critical, substantial, moderate or low. In recent years the number of councils able to help those at the lower end of the scale has gone down as they struggle to balance their budgets. In 2010-2011, Adass says 72% of councils in England only offered help with care to adults with substantial or critical needs. The association says that figure has now risen to 89%. <http://www.bbc.com/news/health-29135042>

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

### **Death: Foe to be conquered? Questioning the paradigm**

*AGE & AGEING* | Online – 16 September 2014 – People living in most developed countries today can expect to survive to an advanced age and die in hospital rather than at home as in the past. Owing to these and other historical, cultural and social factors, our views on death have been skewed. Medical technology provides an arsenal of weapons to launch against death and the "war against disease" has entrenched itself in medical philosophy. We now primarily experience death through the lens of a camera. Representations of "death as spectacle" distort our perceptions and leave us ill-prepared for the reality. Additionally, death as a natural consequence of life has become much less visible than it was in the

past due to our longer life expectancies and lack of infectious disease. The continued thrust for treatment, wedded with a failure to recognise the dying process, can rob individuals of a peaceful, dignified death. <http://ageing.oxfordjournals.org/content/early/2014/09/14/ageing.afu116.abstract>

#### **Extract from *Age & Ageing* article**

Progress being made in advance care planning and palliative care is limited by the existing paradigm of death as a "foe to be conquered." It is time for a shift in this paradigm.



## Care planning

### **Dying well with dementia: Insights from qualitative studies of place of death and advance care planning**

*ALZHEIMER'S & DEMENTIA*, 2014;10(4):225. People with dementia often die badly, receiving end-of-life care of poorer quality than that given to the cognitively intact. Advanced care planning (ACP) has the potential to improve end-of-life care in dementia. Commonly ACP is completed in the last six months of life, in dementia there may be problems with this as decision-making capacity and ability to communicate necessarily decrease as the disease progresses. Choosing the right time to discuss ACP with people with dementia may be challenging given the duration of the illness... [http://www.alzheimersanddementia.com/article/S1552-5260\(14\)00444-0/abstract](http://www.alzheimersanddementia.com/article/S1552-5260(14)00444-0/abstract)

Noted in Media Watch, 8 September 2014, #374 (p.10):

- *DEMENTIA* | Online – 3 September 2014 – '**End-of-life care: The experiences of advance care planning amongst family caregivers of people with advanced dementia: A qualitative study.**' Family caregivers need encouragement to ask the right questions during advance care planning to discuss the appropriateness of nursing and medical interventions at the end of life. <http://dem.sagepub.com/content/early/2014/09/03/1471301214548521.abstract>

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 18 September 2014 – '**Managing end-of-life uncertainty: Applying problematic integration theory to spousal communication about death and dying.**' A significant number of Americans die in ways that do not reflect their preferences for end-of-life (EOL) care. For married individuals, the spouse often has the legal authority to make decisions at EOL. Many factors ... determine whether such communication is viable and a partner's wishes are respected. <http://ajh.sagepub.com/content/early/2014/09/17/1049909114550675.abstract>
- *JOURNAL OF CHRISTIAN NURSING*, 2014;31(4):220-225. '**Advance directives education: A critical need.**' Most older Americans do not have advance health care directives (AHCDs) while healthcare providers report limited knowledge for teaching about AHCDs. This article ... explores one method for assessing AHCD knowledge ... and utilizes adult learning theory to develop an AHCD educational in-service for nurses. Information and resources are provided. [http://journals.lww.com/journalofchristiannursing/Abstract/2014/12000/Advance\\_Directives\\_Education\\_A\\_Critical\\_Need.8.aspx](http://journals.lww.com/journalofchristiannursing/Abstract/2014/12000/Advance_Directives_Education_A_Critical_Need.8.aspx)
- *JOURNAL OF MEDICINE & PHILOSOPHY*, 2014;39(5):523-542. '**Love as a regulative ideal in surrogate decision making.**' Currently, there are two basic models of surrogate decision making for incompetent patients: the "substituted judgment" and the "best interests" model. The former draws on the value of autonomy and responds with respect; the latter draws on the value of welfare and responds with beneficence. It can be difficult to determine which of these two models is more appropriate for a given patient, and both approaches may seem inadequate... <http://jmp.oxfordjournals.org/content/39/5/523.abstract>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 September 2014 – '**Factors related to establishing a comfort care goal in nursing home patients with dementia: A cohort study among family and professional caregivers.**' Optimizing patient-family-physician communication upon admission may support the early establishing of a comfort care goal.. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0205>



World hospice &  
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11 October 2014

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

## **Consensus on quality indicators to assess the organisation of palliative cancer and dementia care applicable across national healthcare systems and selected by international experts**

*BMC HEALTH SERVICES RESEARCH* | Online – 17 September 2014 – As part of a European policy improvement program, quality indicators (QIs) have been developed to monitor and improve the organisation of palliative care for patients with cancer and those with dementia in various settings in different European countries. A multidisciplinary, international panel of professionals participated in a modified RAND Delphi procedure to compose a set of palliative care QIs based on existing sets of QIs on the organisation of palliative care. The procedure resulted in 23 useful QIs. These represent key elements of the organisation of good clinical practice, such as the availability of palliative care teams, the availability of special facilities to provide palliative care for patients and their relatives, and the presence of educational interventions for professionals. The final set also includes QIs that are related to the process of palliative care, such as documentation of pain and other symptoms, communication with patients in need of palliative care and their relatives, and end-of-life decisions. <http://www.biomedcentral.com/content/pdf/1472-6963-14-396.pdf>

## **Taking an "upstream" approach in the care of dying cancer patients: The case for a palliative approach**

*CANADIAN ONCOLOGY NURSING JOURNAL*, 2014;24(3):144-148. Advances in technology and drug therapy have resulted in cancer patients living longer with malignant disease. However, most of these patients will face the end of life much sooner than the general population. Adopting a "palliative approach" is one innovation that has the potential to promote anticipatory planning and promote enhanced end-of-life care. Yet, in much of the western world, this upstream orientation has rarely been achieved. An emphasis on providing palliative care late in the illness trajectory has resulted in many challenges for the care of people with advanced cancer. The authors highlight ... the Initiative for a Palliative Approach in Nursing: Evidence & Leadership that aims to develop evidence to inform the integration of a palliative approach into the care of people with advancing chronic life-limiting conditions. [http://cano.malachite-mgmt.com/?page=CONJ\\_24\\_3](http://cano.malachite-mgmt.com/?page=CONJ_24_3)

Noted in Media Watch, 19 September 2011, #219 (p.1):

- CANADA (British Columbia) | *The Delta Optimist* (Ladner) – 15 September 2011 – **'New nursing research initiative helps at the end of life.'** According to a recent study ... three-quarters of the British Columbians who die do so without being identified as people who could benefit from the services associated with palliative care... That could soon change, thanks to ongoing research undertaken by some of the province's universities and health authorities. <http://www.delta-optimist.com/news/nursing+research+initiative+helps+life/5415348/story.html>

## **Integrating palliative care in the ICU**

*CURRENT OPINION IN CRITICAL CARE* | Online – 17 September 2014 – The need for palliative care for ICU patients is substantial. A large percentage of patients meet criteria for palliative care consultation and there is frequent use of intensive care and other non-beneficial care at the end of life. Overall, the consultative model of palliative care appears to have more of an impact on patient care. However, given the current workforce shortage of palliative care providers, a sustainable model of delivering palliative care requires both an effective integrative model, in which palliative care is delivered by ICU clinicians, and appropriate use of the consultative model, in which palliative care consultation is reserved for patients at highest risk of having unmet or long-term palliative care needs. Efforts focused on improving integrative models and appropriately targeting the use of palliative care consultants are needed. [http://journals.lww.com/criticalcare/Abstract/publishahead/Integrating\\_palliative\\_care\\_in\\_the\\_ICU\\_.99474.aspx](http://journals.lww.com/criticalcare/Abstract/publishahead/Integrating_palliative_care_in_the_ICU_.99474.aspx)

Cont.

Of related interest:

- *CRITICAL CARE* | Online – 9 September 2014 – '**Considering age when making treatment decisions in the ICU: Too little, too much, or just right?**' There are a number of studies providing evidence that age is associated with treatment decisions for critically ill adults. This study raises the important question about the contributors to this association, and the authors raise the possibility that physician or surrogate bias may be contributing to decisions for older patients. <http://ccforum.com/content/18/5/483/abstract>
- *CURRENT OPINION IN CRITICAL CARE* | Online – 12 September 2014 – '**Economic implications of end-of-life care in the ICU.**' The authors identified three studies assessing the impact of palliative care consultation on ICU admissions for patients with life-limiting illness; all demonstrate reduced ICU admissions for patients receiving palliative care consultation. Among 16 studies evaluating ICU LOS [length of stay] as an outcome, five report no change and 11 report decrease in LOS for patients receiving advance care planning or palliative care. [http://journals.lww.com/co-critical-care/Abstract/publishahead/Economic\\_implications\\_of\\_end\\_of\\_life\\_care\\_in\\_the.99475.aspx](http://journals.lww.com/co-critical-care/Abstract/publishahead/Economic_implications_of_end_of_life_care_in_the.99475.aspx)

### **Surgeons, intensivists, and discretion to refuse requested treatments**

*THE HASTINGS REPORT*, 2014;44(5):33-42. Physicians are expected to engage patients as partners in identifying the possible benefits and harms associated with treatment options and selecting from among medically appropriate treatment options, rather than simply dictating what treatments patients will and will not receive. This collaborative model reflects the recognition that citizens in multicultural societies have diverse values and are likely to have different views about whether the possible benefits of a medical intervention outweigh the possible harms. However, there are circumstances in which the collaborative process breaks down due to irresolvable disagreement. Especially challenging are cases in which patients are expected to die if they do not receive a treatment and either the patients or their surrogates insist on the treatment despite the physician's belief that providing it is ill advised. The source of disagreement is often differing appraisals of the risks and potential benefits. In such cases, physicians generally judge there is insufficient likelihood or magnitude of benefit to justify the burdens or expense of treatment... <http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=7027>

### **Brain death and total brain failure**

*JOURNAL OF CLINICAL ETHICS*, 2014;25(3):245-257. Death determined by neurological criteria (DDNC) or "brain death" has been legally established for decades in the U.S. But recent conflicts between families and hospitals have created some uncertainty. Clinicians are increasingly unsure about the scope of their legal and ethical treatment duties when families object to the withdrawal of physiological support after DDNC. This experience is not unique. Hospitals across the country are seeing more DDNC disputes. The author categorizes recent legal developments into nine categories: 1) history of determining death by neurological criteria; 2) legal status of determining death by neurological criteria; 3) legal duties to accommodate family objections; 4) protocols for determining death by neurological criteria; 5) court cases seeking physiological support after DDNC; 6) court cases seeking damages for intentionally premature DDNC; 7) court cases seeking damages for negligently premature DDNC; 8) court cases seeking damages for emotional distress; and, 9) pregnancy Limitations on DDNC. <http://www.clinicalethics.com/>

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#### **[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>

Of related interest:

- *JOURNAL OF MEDICAL LAW & ETHICS*, 2014;2(2-3):23-35. **'Losing faith in the dead donor rule.'** According to the dead donor rule (DDR), vital organs can only be removed from donors who are already dead. Organ procurement, in other words, must not be the cause of their deaths. The rule purports to protect dying and vulnerable individuals from being sacrificed for the benefit of other people who are in need of those organs. This notion that innocent human beings should not be used as means to an end is undoubtedly a concern that is unequivocally shared by Abrahamic faith communities. In this regard, the philosophy and rationale of the DDR fully cohere with their religious teachings. However, the method by which death is officially diagnosed to determine when an individual qualifies as a dead donor is not one that they necessarily share. Whilst English law recognises death as having occurred when the brainstem is dead, these faith communities ordinarily associate death with the departure of the soul. <http://www.ingentaconnect.com/content/plp/jmle/2014/00000002/F0020002/art00002>

### **Factors associated with fulfilling the preference for dying at home among cancer patients: The role of general practitioners**

*JOURNAL OF PALLIATIVE CARE*, 2014;30(3):141-150. In spite of differences in the cultures and the healthcare systems of the four countries in this study [i.e., Belgium, The Netherlands, Italy and Spain], 66-92% of the cancer patients that the authors looked at died at home, their preferred place to die. They discovered that GPs' provision of palliative care is related to the fulfillment of cancer patients' preferences for home death across all four countries. This is an important finding as GPs are expected to play an increasing role in ensuring access to palliative care for all patients. <http://nvl002.nivel.nl/postprint/PPpp5557.pdf>

Of related interest:

- *CANADIAN FAMILY PHYSICIAN*, 2014;60(9):860. **'Accompanying our patients at the end of their journey.'** By 2030, more than 20% of the Canadian population will be older than 65 years of age. Canadians will live longer, and many will need to cope with 2 or more chronic illnesses, contributing to frailty and vulnerability in old age. For a variety of reasons (e.g., barriers of time and money, and involvement of multiple providers, often in hospital settings), family physicians have become less involved in end-of-life care. Yet new legislative requirements, such as those in Quebec, combined with changing demographic trends and societal attitudes about death and dying beg renewed and enhanced involvement of family doctors in end-of-life care. <http://www.cfp.ca/content/60/9/860.full>
- *JOURNAL OF CHRISTIAN NURSING*, 2014;31(4):240-245. **'Palliative care doula: An innovative model.'** This article introduces a model for experienced and advanced practice palliative care nurses to support patients and families during the ... period of end-of-life care. [http://journals.lww.com/journalofchristiannursing/Abstract/2014/12000/Palliative\\_Care\\_Doula\\_An\\_Innovative\\_Model.12.aspx](http://journals.lww.com/journalofchristiannursing/Abstract/2014/12000/Palliative_Care_Doula_An_Innovative_Model.12.aspx)

### **Reported availability and gaps of pediatric palliative care in low- and middle-income countries: A systematic review of published data**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 September 2013 – The majority of young people in need of palliative care live in low- and middle-income countries, where curative treatment is less available. The most pervasive gaps were in national health system support (unavailable in 7 of 17 countries with programs reporting), specialized education (unavailable in 7 of 19 countries with programs reporting), and comprehensive opioid access (unavailable in 14 of 21 countries with programs reporting). Comprehensive pediatric palliative care provision is possible even in markedly impoverished settings. Improved national health system support, specialized training and opioid access are key targets for research and advocacy. Application of a checklist methodology can promote awareness of gaps to guide program evaluation, reporting, and strengthening. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0095>

Cont.

Noted in Media Watch, 15 September 2014, #375 (p.11):

- **HEALTH AFFAIRS**, 2014;33(9):1612-1619. **'Innovation can improve and expand aspects of end-of-life care in low- and middle-income countries.'** Provision for end-of-life care around the world is widely variable and often poor, which leads to millions of deaths each year among people without access to essential aspects of care. However, some low- and middle-income countries have improved specific aspects of end-of-life care using innovative strategies and approaches such as international partnerships, community-based programs, and philanthropic initiatives. <http://content.healthaffairs.org/content/33/9/1612.short>

#### Preventing hospital and nursing home admissions

#### **Home health agency work environments and hospitalizations**

*MEDICAL CARE*, 2014;52(10):877-883. An important goal of home health care is to assist patients to remain in community living arrangements. Yet home care often fails to prevent hospitalizations and to facilitate discharges to community living, thus putting patients at risk of additional health challenges and increasing care costs. Home health agencies with good work environments had lower rates of acute hospitalizations and higher rates of patient discharges to community living arrangements compared with home health agencies with poor work environments. Improved work environments in home health agencies hold promise for optimizing patient outcomes and reducing use of expensive hospital and institutional care. [http://journals.lww.com/ww-medicalcare/Fulltext/2014/10000/Home\\_Health\\_Agency\\_Work\\_Environments\\_and.4.aspx](http://journals.lww.com/ww-medicalcare/Fulltext/2014/10000/Home_Health_Agency_Work_Environments_and.4.aspx)

#### 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.

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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.

## **The pendulum time of life: The experience of time, when living with severe incurable disease – a phenomenological and philosophical study**

*MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 10 September 2014 – In our modern health care system there is an on-going focus on utilizing and recording the use of time, but less focus on the patient's experience of time, which highlights the need to explore the patients' experiences, particularly when life is vulnerable and time is limited. The diversity of the experience of time is oscillating between going fast or slow, being busy or calm, being unpredictable but predictable, safe or unsafe and between being good or bad, depending on the embodied situation of the individual. <http://link.springer.com/article/10.1007/s11019-014-9590-9#>

## **Situation, possibilities and difficulties of the hospice and palliative care in Hungary**

*ORVOSI HETILAP*, 2014;155(38):1504-1509. Hospice-palliative care has existed in Hungary for more than 20 years, but physicians know very little about it. At present there are 90 active hospice providers in Hungary, which provide service for more than 8,000 terminally ill cancer patients. There are also problems concerning the attitude and, therefore, patients are admitted into hospice care too late. Hospice care is often confused with chronic or nursing care due to lack of information. The situation may be improved with proper forms of education such as palliative licence and compulsory, 40-hour palliative training for residents. The authors conclude that a broad dissemination of data may help to overcome misbeliefs concerning hospice and raise awareness concerning death and dying. <http://europepmc.org/abstract/med/25217766>

**N.B.** Hungarian language article.

## **Patients' perception of implantable cardioverter defibrillator deactivation at the end of life**

*PALLIATIVE MEDICINE* | Online – 19 September 2014 – Individualised care at the end of life requires professional understanding of the patient's perception of implantable cardioverter defibrillator deactivation. Patients regard the implantable cardioverter defibrillator as a complex and solely beneficial device, with little insight regarding its potential impact on a peaceful death. This review confirms the need for professionals to discuss with patients and families implantable cardioverter defibrillator functionality and deactivation at appropriate opportunities. The authors collected from six databases, citations from relevant articles and expert recommendations. <http://pmj.sagepub.com/content/early/2014/09/17/0269216314550374.abstract>

Selected articles on defibrillator deactivation in end-of-life care noted in recent issues of Media Watch:

- *JOURNAL OF CARDIAC FAILURE*, 2014;20(8):S11. **'Shared decision-making about end-of-life care for heart failure patients with an implantable cardioverter defibrillator: A national cohort study.'** Implantable cardioverter defibrillator recipients with heart failure hold many perceptions that could interfere with effective decision-making. [Noted in Media Watch, 11 August 2014, #370 (p.12)] [http://www.onlinejcf.com/article/S1071-9164\(14\)00269-3/fulltext](http://www.onlinejcf.com/article/S1071-9164(14)00269-3/fulltext)
- *THE PATIENT – PATIENT-CENTERED OUTCOMES RESEARCH* | Online – 26 March 2014 – **'Making decisions about implantable cardioverter-defibrillators from implantation to end of life: An integrative review of patients' perspectives.'** Patients faced with decisions often misunderstood the functionality of their ICD, or overestimated its benefit. They expressed mixed preferences for the desire to be involved in decisions. [Noted in Media Watch, 21 April 2014, #354 (p.13)] <http://link.springer.com/article/10.1007/s40271-014-0055-2#>
- *CURRENT HEART FAILURE REPORTS* | Online – Accessed 18 March 2014 – **'Ethical challenges of deactivation of cardiac devices in advanced heart failure.'** While patients with ICDs are routinely counseled with regard to the benefits of ICDs, they have a poor understanding of the options for device deactivation and related ethical and legal implications. [Noted in Media Watch, 24 March 2014, #350 (pp.9-10)] <http://link.springer.com/article/10.1007/s11897-014-0194-8>

## Moving from research generation to knowledge translation in end-of-life care in long term care

*PALLIATIVE MEDICINE*, 2014;28(9):1979-1080. The recognition and importance of the need for palliative or end-of-life care in long term care has, over the last two decades, led to increased research, education and practice development initiatives in most developed countries. The breadth and depth of some of these initiatives has been catalogued by the European Association of Palliative Care Taskforce on Palliative Care in Long Term Care Settings for Older People.<sup>1</sup> In total over 60 initiatives across 13 European countries were identified. These initiatives were mapped by level of change – that is at the national, regional, organisational, team or individual level, with many targeting more than one level. Unfortunately not possible as part of this mapping activity, was an evaluation to examine if any of these initiatives successfully translated into sustained knowledge or practice change. <http://pmj.sagepub.com/content/28/9/1079.full>

1. 'European Association of Palliative Care Taskforce on Palliative Care in Long Term Care Settings for Older People,' *European Journal of Palliative Care*, 2013;20(5):251-253. [Noted in Media Watch, 16 September, 2013, #323 (p.11)]  
<http://www.eapcnet.eu/LinkClick.aspx?fileticket=XObWJ15LoCk%3D&tabid=1938>

Of related interest:

- *JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION*, 2014;14(10):741-748. 'Site of death among nursing home residents in the U.S.: Changing patterns, 2003-2007.' The proportion of U.S. deaths occurring in nursing homes (NHs) has been increasing ... and is expected to reach 40% by 2020. Despite being recognized as an important setting in the provision of end-of-life (EOL) care, little is known about the quality of care provided to dying NH residents. There has been some, but largely anecdotal evidence suggesting that many U.S. NHs transfer dying residents to hospitals, in part to avoid incurring the cost of providing intensive on-site care, and in part because they lack resources to appropriately serve the dying residents. <http://www.sciencedirect.com/science/article/pii/S1525861013001400>

## Grief reactions and impact of patient death on pediatric oncologists

*PEDIATRIC BLOOD & CANCER* | Online – 11 September 2014 – Pediatric oncologists [i.e., study participants] reported a range of reactions to patient death including sadness, crying, sleep loss, exhaustion, feeling physically ill, and a sense of personal loss. They also reported self-questioning, guilt, feelings of failure and helplessness. The impact of these deaths had personal consequences that ranged from irritability at home, feeling disconnected from family members and friends, and becoming more desensitized towards death, to gaining a greater and more appreciative perspective on life. Professional impacts included concern about turnover or burnout at work and improving holistic care as a result of patient deaths. Grief over patient death and the emotional labour involved in these losses are a robust part of the pediatric oncology workplace and have major impacts on pediatric oncologist's personal and professional lives. <http://onlinelibrary.wiley.com/doi/10.1002/pbc.25228/abstract;jsessionid=E4FDC9C1FD99DA61A515B0A59A28CBF9.f01t02?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Of related interest:

- *HR MAGAZINE* (U.K.) | Online – 17 September 2014 – '**Acas releases guide to managing bereavement in the workplace.**' Advisory, Conciliation & Arbitration Service has released guidance for employers to support members of staff affected by bereavement.<sup>1</sup>  
<http://www.hrmagazine.co.uk/hro/news/1146635/acas-releases-guide-managing-bereavement-workplace>

1. 'Managing bereavement in the workplace: a good practice guide, Advisory, Conciliation and Arbitration Service, September 2014. <http://www.acas.org.uk/media/pdf/0/m/Managing-bereavement-in-the-workplace-a-good-practice-guide.pdf>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE GERONTOLOGIST*, 2014;54(5):808-817. '**Discussing physician-assisted dying: Physicians' experiences in the U.S. and The Netherlands.**' Physicians [i.e., study participants] found discussions to be emotionally intense, but often rewarding. Where PAD [physician-assisted dying] was legal, physicians utilized existing criteria to guide communication, and discussions were open and honest with patients and colleagues. Where PAD was illegal, conversations were less explicit, and physicians dealt with requests in relative isolation. <http://gerontologist.oxfordjournals.org/content/54/5/808.abstract>
- *JOURNAL OF AMERICAN ACADEMY OF PSYCHIATRY & LAW*, 2014;42(3):350-361. '**End-of-life mental health assessments for older aged, medically ill persons with expressed desire to die.**' The ethics-related and legal questions raised by end-of-life suicide and decisional capacity to refuse treatment assessments are complex. In treating patients with end-stage medical conditions or disorders that severely affect the future quality of their lives, clinicians tend to engage in suicide prevention at all costs. Overriding the patient's expressed desire to die conflicts with another value, however, that of the individual's right to autonomy. The authors provide a framework for understanding these difficult decisions, by providing a review of the epidemiology of suicide in later life; reviewing findings from a unique dataset of suicides among the elderly obtained from the Los Angeles County Coroner's Office, as well as data from states with legalized assisted suicide; presenting a discussion of the two frameworks of suicidal ideation as a pathological versus an existential reaction; and giving a case example that highlights the dilemmas faced by clinicians addressing decisional capacity to refuse treatment in an elderly, medically ill patient who has expressed the wish to die. <http://www.jaapl.org/content/42/3/350.abstract>
- *JOURNAL OF ETHICS* | In-press – Accessed 18 September 2014 – '**No last resort: Pitting the right to die against the right to medical self-determination.**' Many participants in debates about the morality of assisted dying maintain that individuals may only turn to assisted dying as a "last resort," i.e., that a patient ought to be eligible for assisted suicide or voluntary euthanasia only after she has exhausted certain treatment or care options. Here the author argues that this last resort condition is unjustified, that it is in fact wrong to require patients to exhaust a prescribed slate of treatment or care options before being eligible for assisted dying. The last resort condition effectively pits one right of patients, their right to refuse medical treatment or interventions, against another patient right acknowledged by advocates of assisted dying, the right to die. Drawing on an analogy with the legal notion of an unconstitutional condition, the author argues that the last resort condition unjustly demands that an arguably more fundamental right – the right to refuse medical treatment or intervention – be foregone in order to acquire a less fundamental right – the right to die. He then addresses three rationales for the last resort condition and find that they subject individuals to arbitrarily stringent standards for exercising the right to die, standards to which those who seek to end their lives by voluntarily ending life-sustaining treatments are not subject. Subjecting those who seek assisted dying to the last resort condition therefore wrongfully infringes on their right to refuse medical treatment or interventions. <http://philpapers.org/rec/CHONLR>
- *OMEGA – JOURNAL OF DEATH & DYING*, 2014;69(2):191-216. '**Experiences and motivations underlying wishes to die in older people who are tired of living: A research area in its infancy.**' Until now insight into the experiences and thoughts of people who are tired of life but not suffering from a severe depression or a life-threatening disease is lacking. Studies focussing specifically on this topic are rare. The existential impact of age-related loss experiences play an important role in developing a wish to die. Other influencing factors are: personal characteristics, biographical factors, social context, perceptions and values. Further research to experiences and motivations underlying these specific age-related wishes to die and the existential impact of the loss-experiences seems necessary to deepen the understanding of this group of older people and for the development of policy and good care. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,6,7;journal,1,272;linkingpublicationresults,1:300329,1>

Cont.



- *OMEGA – JOURNAL OF DEATH & DYING*, 2014;69(2):137-149. **'Does the experience of interpersonal predictors of suicidal desire predict positive attitudes toward physician assisted suicide?'** Results [of this study] suggest that attitudes toward physician assisted suicide may be influenced by the experience of thwarted belongingness and perceived burdensomeness and provide a clear rationale for the study of these variables in populations more apt to consider hastened death. Future work regarding the application of the interpersonal-psychological theory of suicidal behavior in hastened death research is discussed. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,3,7;journal,1,272;linkingpublicationresults,1:300329,1>
- *PAKISTAN JOURNAL OF MEDICAL SCIENCES*, 2014;30(5):1159-1160. **'The right to live or die? A perspective on voluntary euthanasia.'** The debate on euthanasia in [the] medical community stays unresolved. The authors present arguments for and against euthanasia, review arguments from both sides, and they conclude with their opinion. <http://www.pjms.com.pk/index.php/pjms/article/view/5777>

## Worth Repeating

### **Why are newly qualified doctors unprepared to care for patients at the end of life?**

*MEDICAL EDUCATION*, 2011;45(4):389-399. Little is known about what doctors learn about end-of-life care while at medical school and how they learn to care for dying patients in their first year as doctors. Undergraduate medical education is currently failing to prepare junior doctors for their role in caring for dying patients by omitting to provide meaningful contact with these patients during medical school. This lack of exposure prevents trainee doctors from realising their own learning needs, which only become evident when they step onto the wards as doctors and are expected to care for these patients. Newly qualified doctors [i.e., study participants] perceive that they receive little formal teaching about palliative or end-of-life care in their new role and that the culture within the hospital setting does not encourage learning about this subject. They report that they learn from "trial and error" while "doing the job," but that their skills and

knowledge are limited and that they therefore seek advice from those outside their usual medical team, mainly from nursing staff and members of palliative care teams. <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2923.2010.03873.x/full>

#### **Extract from *Medical Education* article**

Two main groups of themes emerged. The first pertained to medical school experiences of end-of-life care, including: lack of exposure; a culture of "clerking and signs"; being kept and keeping away from dying patients; lack of examinations; variable experiences, and theoretical awareness. The second group of themes pertained to the experiences of recently qualified doctors and included: realising that patients really do die; learning by doing; the role of seniors; death and dying within the hospital culture; the role of nursing staff, and the role of the palliative care team.

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## Media Watch Online

### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/9/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](http://www.ipcrc.net/archive-global-palliative-care-news.php) to access the weekly report]

### **Canada**

ALBERTA HOSPICE PALLIATIVE CARE ASSOCIATION: <http://ahpca.ca/> (Scroll down to 'Media Watch')

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](http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1)

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://hpcconnection.ca/general-resources/in-the-news/>

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://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes>

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>