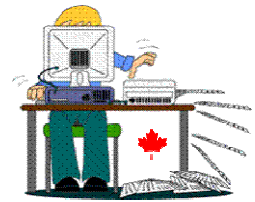


## **Media Watch...**

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.

**20 July 2015 Edition | Issue #419**



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**Compiled & Annotated by Barry R. Ashpole**

**Engaging patients and the wider community with palliative and end-of-life care conversations: Scroll down to [Specialist Publications](#) and 'Why don't end-of-life conversations go viral? A review of videos on YouTube' (p.12), in *BMJ Supportive & Palliative Care*.**

## **Canada**

### **Elder care**

#### **Three steps for better home care**

*THE GLOBE & MAIL* | Online – 16 July 2015 – A solution ... is available but requires political will. First, all provinces and territories should cover all basic home-care core services – not just short-term, post-hospital care, but also longer-term, preventive-care services. The investment required is relatively low and will reduce the need for other expensive investments in health infrastructure – from bigger hospitals to more long-term care facilities. Second, we need to start measuring health-care outcomes that are aligned with the desire of patients to stay at home. The current focus on issues such as wait times for emergency-room visits is too narrow and creates pressure to address the effects, not the causes, of these problems. Third, we need to give family doctors the flexibility to conduct home visits. The number of physicians doing house calls has dropped dramatically in the past few decades. In part, due to a fee structure in many provinces that acts as a disincentive for them to do so... But the biggest barrier expressed by physicians is a lack of time: Typically only one patient can be seen at home for every three or four seen in the office. Innovative approaches, such as dedicated mobile family health teams, need to be explored. <http://www.theglobeandmail.com/globe-debate/three-steps-for-better-home-care/article25537295/>

*The Globe & Mail* series on home care in Ontario:

- 'Home care for Ontario seniors affected by move to non-profit agencies,' 13 July 2015. <http://www.theglobeandmail.com/news/national/ontario-moving-some-seniors-home-care-to-private-agencies/article25487019/>
- 'Ontario shifting home care to private clinics as province seeks savings,' 13 July 2015. <http://www.theglobeandmail.com/news/national/ontario-shifting-home-care-to-private-clinics-as-province-seeks-savings/article25476203/>

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- **'No place like home? Investigating Ontario's home-care shortcomings,'** 10 July 2015. [Noted in Media Watch, 13 July 2015, #418 (p.1)] <http://www.theglobeandmail.com/news/national/no-place-like-home-investigating-ontarios-home-care-shortcomings/article25409974/>

Noted in Media Watch, 16 March 2015, #401 (p.1):

- ONTARIO | *The Toronto Star* – 12 March 2015 – **'Ontario's home care system should be overhauled now: Editorial.'** A study by the Ontario Health Coalition, an advocacy group, is calling for a complete overhaul of the home care system.<sup>1</sup> If their message isn't strong enough to be heard by the Ontario government, many of the group's findings are reinforced by a second report on home care by a group of experts commissioned by the provincial government.<sup>2</sup> <http://www.thestar.com/opinion/editorials/2015/03/12/ontarios-home-care-system-should-be-overhauled-now-editorial.html>

1. The Care We Need: Ontarians Speak Out on the State of Home Care – A Proposal for Reforming Home Care in the Public Interest,' Ontario Health Coalition, March 2015. <http://www.ontariohealthcoalition.ca/wp-content/uploads/home-care-the-care-we-need-report-final.pdf>
2. 'Bringing Care Home,' Report of the Expert Group on Home & Community Care,' March 2015. [http://health.gov.on.ca/en/public/programs/ccac/docs/hcc\\_report.pdf](http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf)

### When health care becomes unnecessary care

*THE GLOBE & MAIL* | Online – 14 July 2015 – Sir Bruce Keogh, head of England's National Health Service (NHS), said on the weekend that a "substantial proportion" of health spending in Western health care systems is wasted on ineffective and unnecessary care. He estimated 10 to 15% of all medical and surgical treatments offer little or no benefit and, in many cases, do more harm than good. The candour is refreshing but, if anything, he is underestimating the scope of the problem. Research in the U.S. shows 30 to 40% of care is unnecessary, driven by the foolish consumerist philosophy that more is necessarily better. In Canada, there is, unfortunately, little research on the topic but, on the profligate waste scale, we probably lie somewhere between Britain's 15% and the U.S.'s 40%. In this country, there is not the same temptation to over treat in the quest for profit as in the U.S., but

there is also little accountability and cost control the way there is in the NHS. In analyzing our health spending, we seem to prefer blissful ignorance to the uncomfortable truth we are probably wasting somewhere between \$32-billion and \$86-billion in health spending annually. Regardless of dollar value, the reality is the challenges of delivering appropriate, effective and cost-efficient care are similar in most Western countries. <http://www.theglobeandmail.com/globe-debate/when-health-care-becomes-unnecessary-care/article25486001/>

#### International

**'One in seven treatments not necessary, warns National Health Service chief'** (p.6), in *The Telegraph* (England).

### McMaster and St. Joes grant dying wishes, and comfort comes cheap

ONTARIO | CBC News – 13 July 2015 – Frieda Rowan's favourite flowers were sunflowers. Their glow captivated the 75-year-old, who was in good shape for her age, her daughter Ingrid Thompson says. She had no health problems – she wasn't even on any prescription drugs. That's why it was so shocking when Frieda suddenly dropped to the floor, convulsing, at a Fortinos last August. She suffered a catastrophic brain aneurysm and ended up in the ICU at St. Joseph's Healthcare. That's where her daughter was introduced to McMaster University and St. Joe's Three Wishes Project – courtesy of a huge vase of sunflowers. The premise is just what it sounds

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like – since January 2013, researchers and clinicians have been granting wishes for patients in palliative or critical care. What they found is that most people’s wishes could be granted for under \$200 – as they or their families requested small personal comforts or momentos, not grand or extravagant acts.<sup>1</sup> <http://www.cbc.ca/news/canada/hamilton/news/mcmaster-and-st-joes-grant-dying-wishes-and-comfort-comes-cheap-1.3149937>

1. ‘Personalizing death in the intensive care unit: The 3 Wishes Project – a mixed-methods study,’ *Annals of Internal Medicine*, 14 July 2015. <http://annals.org/article.aspx?articleid=2395727>

### **Assisted (or facilitated) death**

Representative sample of recent news media coverage:

- CBC | Online – 17 July 2015 – ‘**Doctor-assisted suicide panel includes original Crown witnesses.**’ The three-person panel to advise the federal government on doctor-assisted suicide includes two of the Crown’s witnesses in the original case that led to the landmark Supreme Court ruling. The federal government has named three academics, including an expert on palliative care, to lead consultations on how to respond to the Supreme Court ruling on doctor-assisted dying. Harvey Max Chochinov, the Canada research chair in palliative care at the University of Manitoba, will head the panel. The other two members are Catherine Frazee, a former co-director of the Ryerson-RBC Institute for Disability Studies Research & Education, and Benoît Pelletier, a University of Ottawa law professor and former Quebec Liberal cabinet minister. Chochinov and Frazee were both witnesses used to support the Crown’s case against doctor-assisted dying in the original British Columbia Supreme Court challenge, which eventually led to the Supreme Court of Canada ruling that asserted the right of some patients to ask for a doctor’s help to die. The only direct consultations to be done by the panel, according to the government’s frequently asked questions, will be those who intervened in the Supreme Court case, as well as “relevant medical authorities.” The panel is to provide a final report to the ministers of justice and health by late fall. <http://www.cbc.ca/news/politics/doctor-assisted-suicide-panel-includes-original-crown-witnesses-1.3157361>

## **U.S.A.**

### **Study: Family caregivers provide \$470 billion in unpaid services**

*U.S.A. TODAY* | Online – 16 July 2015 – A study by the American Association of Retired Persons (AARP) says family caregivers in the U.S. provided an estimated \$470 billion in unpaid services and care to their loved ones in 2013 – more than total Medicare spending in the same year. The study ... found in 2013 there were 40 million family caregivers in the U.S. providing an average of 18 hours of care per week. Forty-six percent of those workers provide complex care activities, such as wound care, managing medications, giving injections and operating medical equipment. <http://www.usatoday.com/story/money/2015/07/16/study-caregivers-provide-470-billion-unpaid/30196423/>

### **What happens when EMTs encounter dying patients – and their families**

*NEW YORK MAGAZINE* | Online – 15 July 2015 – When someone works as an emergency first responder for long enough, they’re going to encounter a person who is dying. While these sorts of calls aren’t necessarily common (though it varies from place to place, of course), they can naturally be jarring for emergency medical technicians and paramedics when they occur. They can be even worse when the dying person is surrounded by family members who are grieving, panicking, or both. Suddenly the EMT [medical emergency technician] or paramedic is thrust into one of the most intimate, emotionally charged family situations imaginable – an interloper powerless to stop

Cont.

what's coming. In a recent paper<sup>1</sup> ... a team led by Dr. Deborah Waldrop, a social-work researcher at the University of Buffalo, sheds some fascinating light on these situations. <http://nymag.com/scienceofus/2015/07/what-happens-when-emts-encounter-dying-patients.html>

1. "We are strangers walking into their life-changing event": How pre-hospital providers manage Emergency Calls at the End of Life,' *Journal of Pain & Symptom Management*, 27 March 2015. (Noted in Media Watch, 6 April 2015, #404 (p.9)] [http://www.jpmsjournal.com/article/S0885-3924\(15\)00149-9/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00149-9/abstract)

Noted in Media Watch, 1 June 2015, #412 (p.10):

- *EMERGENCY MEDICINE JOURNAL*, 2015;32(6):e13. '**Does current pre-hospital care for patients at the end of their life reflect best practice guidance.**' The end-of-life care good practice guide encourages organisations to enable terminally ill patients to be cared for and die outside of hospital. Ambulance services play a critical role in achieving this goal, however little guidance exists for ambulance crews. <http://emj.bmj.com/content/32/6/e13.2.abstract>

### The error in "there's nothing more we can do"

*THE NEW YORK TIMES* | Online – 15 July 2015 – These words are often spoken by a physician just before transitioning a patient to hospice and palliative care and are regrettably uttered only days, if not hours, before the person dies. These words leave no room for hope; they make a transition to comfort care a much-feared and often avoided final destination. Yet here's the reality: More can always be done. More important, patients know exactly the "more" that they want. The real question is: Why don't we ask? "If I had a magic wand, what is it you would wish for today?" This is a question I ask of my patients receiving hospice and palliative care. No one has ever asked that I rid them of their disease. Rather, I have been met with immediate replies of "make my anxiety go away" or "let me travel to see my family" and "let me go home and sit in my garden." These are the things people say, over and over again, when they are given the opportunity to answer. The real test for physicians, then, is being willing to meet the challenge

of discovering our patient's true wishes, the fulfillment of which may push us well outside our own professional comfort zone. <http://opinionator.blogs.nytimes.com/2015/07/15/the-error-in-theres-nothing-more-we-can-do/?action=click&pgtype=Homepage&version=Most-Visible&module=inside-nyt-region&region=inside-nyt-region&WT.nav=inside-nyt-region&r=0>

#### Specialist Publications

'Hospice eligibility and election: Does policy prepare us to meet the need?' (p.14), in *Journal of Aging & Social Policy*.

'Geographic variation of hospice use patterns at the end of life' (p.14), in *Journal of Palliative Medicine*.

'The developmental transition from living with to dying from cancer: Hospice decision-making' (p.14), in *Journal of Psychosocial Oncology*.

Of related:

- OKLAHOMA | *Tulsa World* – 18 July 2015 – '**Silver tsunami' creating need for social hospices.**' America is facing a "silver tsunami" as aging baby boomers move into their latter years. And that, combined with a breakdown of the traditional family, is giving birth to new ministry — the social hospice... [http://www.tulsaworld.com/news/local/silver-tsunami-creating-need-for-social-hospices/article\\_92b31381-854c-54b7-96f9-a6c0dd6600ce.html](http://www.tulsaworld.com/news/local/silver-tsunami-creating-need-for-social-hospices/article_92b31381-854c-54b7-96f9-a6c0dd6600ce.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.17.

## Two graphs show just how little progress the U.S. has made on end-of-life care

*NEW YORK MAGAZINE* | Online – 13 July 2015 – Americans do not do end-of-life care well. Far too many terminally ill Americans spend their final days in the hospital undergoing painful and largely futile medical procedures, rather than in a potentially more comfortable home or hospice setting. This has a negative effect not only on the person who is dying him- or herself, but also on their friends and family – for one thing, as a team led by Dr. Amol Narang of the John Hopkins School of Medicine explains ... “hospital deaths are associated with worse mental health outcomes in bereaved caregivers.”<sup>1</sup> The culprit here is a lack of planning, particularly when it comes to (usually) slowly developing diseases like cancer. End-of-life care is a difficult thing to talk about, and the transition from active medical treatment to palliative care entails the rather formidable psychological barrier of acknowledging that you’re “giving up” on saving the life of a loved one. <http://nymag.com/scienceofus/2015/07/two-graphs-on-end-of-life-care-in-the-us.html>

Figure 1. Adjusted Yearly Percentages of Advance Care Planning (ACP) and Subtypes Over Time

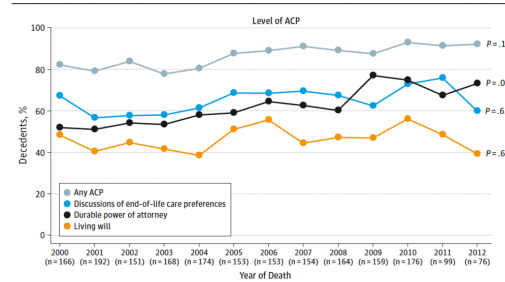
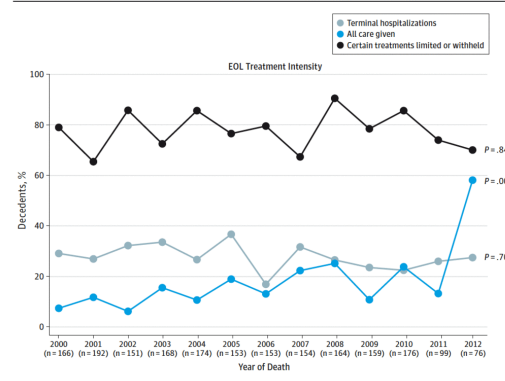


Figure 2. Adjusted Yearly Percentages of End-of-Life (EOL) Treatment Intensity Over Time



1. ‘Trends in advance care planning in patients with cancer: Results from a national longitudinal survey,’ *JAMA Oncology*, 9 July 2015. [Noted in Media Watch, 13 July 2015, #418 (p.11)] <http://oncology.jamanetwork.com/article.aspx?articleid=2383145>

Of related interest:

- *FORBES* | Online – 13 July 2015 – ‘**A new vision for long-term care.**’ Supports and services for frail elders or younger people with disabilities are delivered in a fragmented, disorganized way that puts recipients of care at risk for serious harm or even death and likely wastes billions of dollars. Indeed, if the goal of supports and services is to provide the best possible quality of life for those who need personal assistance, we are doing almost everything wrong. <http://www.forbes.com/sites/howardgleckman/2015/07/13/a-new-vision-for-long-term-care/>
- *FORBES* | Online – 13 July 2015 – ‘**White House tackles aging amid booming market for long-term care.**’ A quick look at recent statistics shows just how big a challenge long-term care is becoming. About 15% of Americans who are over age 65 and who seek out long-term care are living below the poverty level, according to statistics collected by the Family Caregiver Alliance. The “oldest old” ... are among the fastest growing segments of the population, and they are the ones that will need the most support going forward, both financially and emotionally. <http://www.forbes.com/sites/arnenweintraub/2015/07/13/white-house-tackles-aging-amid-booming-market-for-long-term-care/>

### [Media Watch: Palliative Care Network-e Website](#)

The website promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

## International

### End-of-life care in England

#### Hospice funding levels “patchy”

U.K. (England) | *The Belfast Telegraph* (Northern Ireland) – 15 July 2015 – Hospice UK and Together for Short Lives ... warned if hospices are forced to reduce the level of care they provide it will also have a knock-on effect on already overstretched National Health Service (NHS) services.<sup>1</sup> They found nearly three in five (58%) children’s hospices have seen their funding either frozen or cut this year, while almost three quarters (74%) of the hospices [surveyed] in England ... said they expected to see this happen soon. Demand for hospices is likely to rise due to the country’s increasingly ageing population, meaning freezing or cutting funding is “both short-sighted and potentially damaging.” It said investment in hospices is actually cost-effective in terms of reducing spend on hospital care in the last year of life, supporting more deaths at home and in care homes. and at the same time improving patient experience and choice. On average adult hospices receive 32% of their funding from the government, but this varies widely across the country and is “patchy and inconsistent.” The rest must come from fundraising, with hospices collectively needing to raise £1.9 million a day – amounting to more than £9,000 per hospice each day. <http://www.belfasttelegraph.co.uk/news/uk/hospice-funding-levels-patchy-31374764.html>

1. ‘Commissioning and statutory funding arrangements for hospices in England: Survey results 2015,’ Hospice UK and Together for Short Lives, July 2015. Since 2013 Hospice UK has carried out an annual survey of hospices to understand their experiences of the commissioning and statutory funding environment. Together for Short Lives has undertaken a similar survey of children’s hospices since 2008. The two organizations worked together to undertake this survey. [http://www.togetherforshortlives.org.uk/assets/0001/1502/Hospice\\_commissioning\\_and\\_funding\\_survey\\_results\\_2015.pdf](http://www.togetherforshortlives.org.uk/assets/0001/1502/Hospice_commissioning_and_funding_survey_results_2015.pdf)

Of related interest:

- U.K. (England) | *The Telegraph* – 12 July 2015 – **‘One in seven treatments not necessary, warns National Health Service chief.’** The country’s most senior doctor described the level of waste in the NHS as “profligate,” saying that there was no shame in admitting the problem and tackling it. Sir Bruce Keogh ... said that “a substantial proportion” of spending in the NHS was wasted on ineffective care, and he estimated that ten to 15% of medical and surgical treatments should not have been carried out on patients. [And, the authors of] a new report details a series of treatments in the NHS, believed unnecessary or ineffective...<sup>1</sup> £36 million a year could be saved if the NHS stopped over treating patients dying of terminal illnesses such as cancer in hospitals. It would be better, and cheaper, for dying patients to receive expert palliative care outside of the hospital environment. <http://www.telegraph.co.uk/news/health/news/11733871/One-in-seven-treatments-not-necessary-warns-NHS-chief.html>

#### Extract from The King’s Fund report

Although the U.K. was ranked first among 40 countries for the quality of its end-of-life care in 2010 (The Economist Intelligence Unit 2010), it is widely acknowledged that there are significant quality problems in end-of-life care services and a wide variation in the experience of death across the country.<sup>2</sup> Recent attention has focused on patients whose wishes about where they die are not honoured, and problems with implementation of The Liverpool Care Pathway...

**N.B.** See pp.92-101 *vis-à-vis* end-of-live care.

1. ‘Better Value in the National Health Service: The Role of Changes in Clinical Practice,’ The King’s Fund (London, England), July 2015. [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/better-value-nhs-Kings-Fund-July%202015.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/better-value-nhs-Kings-Fund-July%202015.pdf)
2. *The Quality of Death: Ranking End-of-life-Care Across the World*, commissioned by the Lien Foundation (Singapore), and published by The Economist Intelligence Unit, July 2010. [http://graphics.eiu.com/upload/QOD\\_main\\_finaledition\\_Jul12\\_toprint.pdf](http://graphics.eiu.com/upload/QOD_main_finaledition_Jul12_toprint.pdf)

## End-of-life care in Northern Ireland

### **End-of-life care pilot scheme launched in Derry**

U.K. (Northern Ireland) | *Derry Now* – 15 July 2015 – A pilot scheme asking local people to undertake small acts of compassion for people receiving end of life care has been launched in Derry. Led by the Foyle Hospice and supported by Macmillan GPs from the Western Trust, Compassionate Communities ... has begun in the Waterside area. The overall aim of the initiative is to create capacity in the community to support people and their families in living well to the end of their lives. <http://www.derrynow.com/news/end-of-life-care-pilot-scheme-launched-in-derry/35203>

### **How can homeless people die with dignity?**

IRELAND | *The Irish Times* (Dublin) – 14 July 2015 – Given the choice, most of us would like to die at home in the safety and comfort of our own bed surrounded by family and friends. But what if you don't have a home and your bed is in a homeless hostel? This is the reality for a number of homeless people in Ireland who suffer with a life-limiting illness, many of whom are estranged from their family and friends. Despite their highly complex medical and social needs, there is a dearth of information and research in the area of palliative care for homeless people in Ireland. A highly marginalised and vulnerable group, homeless people die on average much earlier than the general population. While there is no consistent Irish data, a 2011 U.K. study found that the average age of death of homeless men was 47, while for women it was 43. The study by the University of Sheffield found that drug and alcohol abuse accounted for just over one-third of all deaths, and that homeless people were more than nine times more likely to take their own lives than the general population. <http://www.irishtimes.com/life-and-style/health-family/how-can-homeless-people-die-with-dignity-1.2277607>

Noted in Media Watch, 6 July 2015, #417 (pp.11-12):

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 24 June 2015 – ‘**When dying at home is not an option: Exploration of hostel staff views on palliative care for homeless people.**’ The Department of Health in the U.K. suggest that hostel staff are the most appropriate key workers for their dying homeless residents and that hostel-based palliative care may be the best way forward. However, little is known about the views of hostel staff with regard to this. <http://www.magonlinelibrary.com/doi/abs/10.12968/ijpn.2015.21.5.236>

Noted in Media Watch, 16 February 2015, #397 (p.10):

- *DEATH STUDIES* | Online – 12 February 2015 – ‘**What constitutes a good and bad death? Perspectives of homeless older adults.**’ The themes for a good death were: 1) dying peacefully; 2) not suffering; 3) experiencing spiritual connection; and, 4) making amends with significant others. Themes for a bad death were: 1) experiencing death by accident or violence; 2) prolonging life with life supports; 3) becoming dependent while entering a dying trajectory; and, 4) dying alone. <http://www.tandfonline.com/doi/abs/10.1080/07481187.2014.958629>

**N.B.** The Summer 2014 issue of *European Network of Homeless Health Worker*, which includes an article on homelessness, ageing and dying (p.7) is available at: [http://www.sophie-project.eu/pdf/ENHW\\_2014.pdf](http://www.sophie-project.eu/pdf/ENHW_2014.pdf). Selected articles on end-of-life care for the homeless noted in past issues of Media Watch are listed in the issue of the weekly report of 3 February 2014, #343 (p.4).

### **Media Watch: Back Issues**

Back issues of Media Watch are available on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

## End-of-life care in Scotland

### **We have a duty of care to patients with life threatening illnesses and their families**

U.K. (Scotland) | *The Herald* (Glasgow) – 14 July 2015 – Marie Curie research suggests that nearly 11,000 people are not accessing palliative care (either general or specialist). The Palliative Care Register last year listed only 12,000 people receiving it. Of these people we know that those with terminal conditions other than terminal cancer – such as dementia, heart failure and Chronic obstructive pulmonary disease (COPD) – are far less likely to receive palliative care, yet they would be just as likely to benefit. There are a number of reasons why this is the case. First, some health and social care professionals are not clear about whom it could benefit and when it should be introduced. For many with terminal cancer, the trajectory of the disease is predictable, which makes it easier for professionals to begin introducing palliative care. For other terminal conditions such as heart failure, it is far less predictable. A person may live for weeks, months or even years with the disease, experiencing periods of decline and recovery, but with the possibility of dying at any point. This can make it much harder for professionals to think about palliative care, yet the patient would likely benefit. Some clinicians also struggle to identify diseases as terminal, for example dementia, which means that their patients are not referred to palliative care. [http://www.heraldscotland.com/opinion/13420753.Agenda\\_We\\_have\\_a\\_duty\\_of\\_care\\_to\\_patients\\_with\\_life\\_threatening\\_illnesses\\_and\\_their\\_families/](http://www.heraldscotland.com/opinion/13420753.Agenda_We_have_a_duty_of_care_to_patients_with_life_threatening_illnesses_and_their_families/)

### **Armenia: Needless pain at end of life**

ARMENIA | Human Rights Watch – 13 July 2015 – Thousands of patients with advanced cancer in Armenia suffer from avoidable, severe pain every year because they cannot get adequate pain medications, said in a report<sup>1</sup>... While effective, safe, and inexpensive pain medications are available in Armenia, most patients and their families face insurmountable bureaucratic barriers to getting them, in violation of the right to health. The report ... describes the devastating impact of the lack of palliative care on people with advanced cancer and their families. It documents the overall lack of palliative care services in Armenia and the government's overly restrictive regulations for getting strong pain medication. It also describes ingrained practices among healthcare professionals that impede adequate pain relief, and the lack of training and education of healthcare professionals in palliative care. <https://www.hrw.org/news/2015/07/13/armenia-needless-pain-end-life>

1. 'Cancer and the Struggle for Palliative Care in Armenia,' Human Rights Watch, July 2015. [http://www.hrw.org/node/278990?\\_ga=1.155511483.1400386076.1436899195](http://www.hrw.org/node/278990?_ga=1.155511483.1400386076.1436899195)

Noted in Media Watch, 28 April 2014, #355 (p.4):

- ARMENIA | Eurasianet – 23 April 2014 – '**Armenians struggle for the right to die without pain.**' Although eligible patients are entitled to free, state-subsidized opioid painkillers, the process for acquiring them can prove so complicated and time-consuming that patients often die before they receive the medication. <http://www.eurasianet.org/node/68300>

Noted in Media Watch, 14 October 2013, #327 (p.4):

- ARMENIA | ARKA News Agency – 11 October 2013 – '**About 3,600 people in Armenia need daily palliative care.**' Armenia has four pilot palliative care centers, which can treat up to 15 people a month. In addition, the National Cancer Centre has a palliative care center able to treat only 57 people in one year. These centers opened as part of palliative care concept developed in 2012. To date, a day's palliative care is worth 20 thousand drams (about \$50). [http://arka.am/en/news/society/about\\_3\\_600\\_people\\_in\\_armenia\\_need\\_daily\\_palliative\\_care/](http://arka.am/en/news/society/about_3_600_people_in_armenia_need_daily_palliative_care/)



## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (England) | BBC News – 16 July 2015 – ‘**Right-to-die campaigners’ case rejected in Europe.**’ A bid by U.K. campaigners to overturn the law on assisted dying has been rejected by the European Court of Human Rights. Applications by Jane Nicklinson, whose husband Tony had locked-in syndrome, and Paul Lamb, who was paralysed in a crash, were ruled inadmissible. The court said the U.K. Parliament was “best placed” to rule on such a sensitive issue. <http://www.bbc.com/news/uk-england-33547155>
- NEW ZEALAND | TV3 News (Auckland) – 13 July 2015 – ‘**Doctors admit helping patients die.**’ More than one in 10 doctors say they’ve helped a terminally ill patient die, a new survey has found. The latest New Zealand Doctor/IMS FaxHealth poll found 11.8% of doctors surveyed said they had assisted a patient’s death; another 1.8% declined to answer the question. But the survey ... found only 44.5% of doctors thought they should have have some role assisting terminally ill patients die and 45.5% believed a law change was needed to allow the practice, with a similar amount opposing it. However, 73.6% of those surveyed also said they had concerns a law about the right to die could be misused or manipulated. The report’s authors said many doctors expressed very outspoken views opposing assisted suicide and it would be a divisive issue among doctors even if a law was passed. <http://www.3news.co.nz/nznews/doctors-admit-helping-patients-die-2015071319#axzz3fnbJVXZN>

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

### Literature review

#### Looking through the lens of receptivity and its role in bereavement support

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 15 July 2015 – There is a dearth of research that specifically focuses on individuals’ receptivity in relation to bereavement support. This is particularly the case within the context of rural, regional, and remote locations. There is also an absence in the literature on support to aboriginal families. Understanding receptivity in relation to bereavement in rural areas is important, particularly as bereavement support is an important area of service to the community by palliative care services. Receptivity to bereavement services has been identified as a critical factor in participation in bereavement support programs. <http://ajh.sagepub.com/content/early/2015/07/15/1049909115595608.abstract>

#### An initial investigation of do not resuscitate acceptance in Egypt

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 12 July 2015 – This survey was conducted in Cairo, Egypt, using a structured questionnaire including 23 questions. A total of 461 persons participated. These (and additional) results provide objective evidence that do not resuscitate (DNR) will not be rejected outright in Egypt. More formal surveys are justified and will provide needed guidance for implementing DNR and related end-of-life medical care in Egypt. <http://ajh.sagepub.com/content/early/2015/07/08/1049909115594613.abstract>



## Physician communication in pediatric end-of-life care: A simulation study

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 12 July 2015 – Fifteen percent of the participants [i.e., pediatric emergency medicine and pediatric critical care fellows] decided not to initiate life-sustaining technology (intubation), and 23% offered alternatives to life-sustaining care, such as comfort measures. Although 92% of the participants initiated an end-of-life conversation, the quality of that discussion varied widely. Findings, particularly that physician-parent end-of-life communication is often unclear and alternatives to life-sustaining technology are often not offered, suggest physicians need more training in communication and end-of-life care. <http://ajh.sagepub.com/content/early/2015/07/08/1049909115595022.abstract>

### Research shows power of dream fulfilment for children with life-limiting illness

*MEDICALXPRESS* | Online – 13 July 2015 – Fulfilling the dreams of children with life-limiting illnesses can empower them and their families and could have an enduring positive impact, according to University of Stirling research. Fulfilling a dream can create a sense of empowerment and hope for the future, a validation of their illness and a sense of normalisation and engagement in a world outside of illness. It also creates an opportunity for the child and their family to create memories that strengthen family bonds. <http://medicalxpress.com/news/2015-07-power-fulfilment-children-life-limiting-illness.html>

Noted in Media Watch, 15 June 2015, #414 (p.9):

- *INTERNATIONAL ARCHIVES OF MEDICINE*, 2015;8(126):1-5. ‘Obstacles to the promotion of dialogue between parents, children and health professionals about death and dying in pediatric oncology.’ The family is essential to overcome the communication barriers, acting as liaison between the multidisciplinary team and the patient. Children should be invited to participate in the decision making process and their wishes should be honored at the end of life. Professionals should be able to meet the physical, psychosocial, spiritual, social and cultural rights of patients and families. <http://imed.pub/ojs/index.php/iam/article/view/1188/844>

**N.B.** Selected articles on communication in the pediatric palliative care setting noted in past issues of Media Watch are listed in the issue of the weekly report of 6 April 2015, #404 (pp.6-7)

Of related interest:

- *NURSING CHILDREN & YOUNG PEOPLE* | Online – 9 July 2015 – ‘Nurses cite time and training issues for inability to offer terminally ill children choice to die at home.’ Many terminally ill children are not being given the choice to die at home because of a lack of staff training and resources to provide 24/7 care in the community, according to a U.K.-wide survey conducted by the Royal College of Nursing.<sup>1</sup> <http://journals.rcni.com/doi/10.7748/ncyp.27.6.7.s6>

1. ‘Terminally ill children let down by poor end-of-life care,’ Royal College of Nurses, June 2015. Almost all children’s nurses (97%) work with infants, children and young people with limited life expectancy each year. Fewer than half (48%) said they have the time, skills and resources to deliver the right levels of palliative care for children. [Noted in Media Watch, 29 June 2015, #416 (p.5)] [http://www.rcn.org.uk/\\_data/assets/pdf\\_file/0007/626227/RCN-Children-and-Young-Peoples-palliative-care-survey-report-2015.pdf](http://www.rcn.org.uk/_data/assets/pdf_file/0007/626227/RCN-Children-and-Young-Peoples-palliative-care-survey-report-2015.pdf)

### Thematic literature review

#### **The importance of providing spiritual care for end-of-life patients who have experienced transcendence phenomena**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 12 July 2015 – The objectives [of this study] were firstly to acknowledge the importance of such experiences and secondly to provide supportive spiritual care to dying patients. Information surrounding the afore-

Cont.

mentioned concepts is underreported in the literature. The following 4 key themes emerged: 1) Spiritual comfort; 2) Peaceful, calm death; 3) Spiritual transformation; and, 4) Unfinished business. The review established the importance of transcendence phenomena being accepted as spiritual experiences by health care professionals. Nevertheless, health care professionals were found to struggle with providing spiritual care to patients who have experienced them. Such phenomena are not uncommon and frequently result in peaceful death. Additionally, transcendence experiences of dying patients often provide comfort to the bereaved, assisting them in the grieving process. <http://ajh.sagepub.com/content/early/2015/07/08/1049909115595217.abstract>

Noted in Media Watch, 3 June 2013, #308 (p.8):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 26 May 2013 – ‘**Harnessing complex emergent metaphors for effective communication in palliative care: A multimodal perceptual analysis of hospice patients’ reports of transcendence experiences.**’ Terminally ill patients can have unexpected, enigmatic, and profound cognitive shifts that significantly alter their perception of themselves, thereby eliminating their fear of death and dying. However, there are no systematic studies into these remarkable yet ineffable transcendence experiences. They therefore remain easily overlooked or viewed as isolated anomalies... <http://ajh.sagepub.com/content/early/2013/05/23/1049909113490821.abstract>

**N.B.** Selected articles on spirituality in the context of end-of-life care noted in past issues of Media Watch are listed in the issue of the weekly report of 8 June 2015, #413 (pp.10-11).

Of related interest:

- *JOURNAL OF HEALTH CARE CHAPLAINCY* | Online – 13 July 2015 – ‘**Recognizing success in the chaplain profession: Connecting perceptions with practice.**’ The current investigation examines the communicative hallmarks of successful chaplaincy work as articulated by professional chaplains providing spiritual care at the end-of-life. Chaplains reported *nonverbal hallmarks* of success consist of 1) Intrapersonal sense of accomplishment; 2) Progress in fulfilling patient needs; and, 3) meaningful connection with patients. *Verbal hallmarks* of success include 1) Patient affirmation; 2) family affirmation; and, 3) The chaplain being asked to participate in religious rites. In practice, the authors conjecture, chaplains assess professional competency in the self, patient, and family domains. Implications ... are discussed. <http://www.tandfonline.com/doi/abs/10.1080/08854726.2015.1071543#.VaqPrHIRGos>

### **The ethics of continued life-sustaining treatment for those diagnosed as brain-dead**

*BIOETHICS* | Online – 16 July 2015 – Given the long-standing controversy about whether the brain-dead should be considered alive in an irreversible coma or dead despite displaying apparent signs of life, the ethical and policy issues posed when family members insist on continued treatment are not as simple as commentators have claimed. In this article, the authors consider the kind of policy that should be adopted to manage a family’s insistence that their brain-dead loved one continues to receive supportive care. They argue that while it would be ethically inappropriate to continue to devote scarce acute care resources to such patients in a hospital setting, it may not be ethically inappropriate for patients to receive these resources in certain other settings. Thus, if a family insists on continuing to care for their brain-dead loved at their home, we should not, from a policy perspective, interfere with the family’s wishes. The author’s also argue that healthcare professionals should make some effort to facilitate the transfer of brain-dead patients to these other settings when families insist on continued treatment despite being informed about the lack of any potential for recovery of consciousness. Their arguments are strengthened by the fact that patients in a persistent vegetative state, who, when correctly diagnosed, also have no potential for recovery of consciousness, are routinely transferred from hospitals to nursing homes or long-term care facilities where they continue to be ventilated, tube fed and to receive other supportive care. <http://onlinelibrary.wiley.com/doi/10.1111/bioe.12178/abstract>

## Why don't end-of-life conversations go viral? A review of videos on YouTube

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 16 July 2015 – The YouTube search identified 23,100 videos with 213 retrieved for assessment and 42 meeting eligibility criteria. The majority of videos had been posted to YouTube since 2010 and produced by organisations in the U.S. (71%). Viewership ranged from 171 to 10,642. Most videos used a documentary style and featured healthcare providers (60%) rather than patients (19%) or families (45%). A minority of videos (29%) used upbeat or hopeful music. The videos frequently focused on completing legal medical documents (86%). None of the advance care planning (ACP) videos on YouTube went viral and a relatively small number of them contained elements endorsed by stakeholders. In emphasising the completion of legal medical documents, videos may have failed to support more meaningful ACP. Further research is needed to understand the features of videos that will engage patients and the wider community with ACP and palliative and end-of-life care conversations. <http://spcare.bmj.com/content/early/2015/07/16/bmjspcare-2014-000805.abstract>

Of related interest:

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 14 July 2015 – ‘**Older adults’ recognition of trade-offs in healthcare decision-making.**’ [Study] participants were asked to describe a decision they had made in the past involving a trade-off. If they could not, they were asked to describe a decision they might face in the future and were then given an example of a decision. They were also asked about communication with their primary care provider about their priorities when faced with a trade-off. The majority were able to recognize the trade-offs ... and wanted their providers to know their priorities regarding the trade-offs. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.13534/abstract?userIsAuthenticated=false&deniedAccessCustomisedMessage=>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 17 July 2015 – ‘**The language of end-of-life decision making: A simulation study.**’ Among 114 physician subjects, 106 discussed life-sustaining treatment (LST), 86 palliation, and 84 discussed both. The authors identified five frames: 1) Will (decided); 2) Must (necessary); 3) Should (convention); 4) Could (option); and, 5) Ask (elicitation of preferences). Physicians broached LST differently than palliation, most commonly framing LST as necessary (53%), while framing palliation as optional (49%). Among physicians who framed LST as imperative (will or must), 16 (30%) felt intubation would be inappropriate in this clinical situation. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0089>

## Living actively in the face of impending death: Constantly adjusting to bodily decline at the end-of-life

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 16 July 2015 – [Study participants with advance cancer] described living with rapidly disintegrating bodies and how this affected their ability to participate in everyday activities. People experienced a shifting sense of self. They had to continuously reinterpret changing bodies. Previously automatic movements became disjointed and effortful. Simple actions like standing or getting out of bed required increasing concentration. Relentless bodily breakdown disrupted peoples’ relationship with time, hindering their ability, but not their desire, to participate in everyday activities. Contending with this deterioration is the work of adaptation to functional decline at the end-of-life. <http://spcare.bmj.com/content/early/2015/07/16/bmjspcare-2014-000744.abstract>

### Extract from *BMJ Supportive & Palliative Care* article

This study highlights the role active participation in everyday activities plays in mediating adjustment to functional decline. These findings challenge us to look beyond palliation of physical symptoms and psycho-spiritual care as ends in themselves. Symptom control and palliation should be viewed as mechanisms to optimise active participation in essential and valued activities.

## The importance of communication in sustaining hope at the end of life

*BRITISH JOURNAL OF NURSING* | Online – 8 July 2015 – How can health professionals, especially those working in busy environments, foster hope and communicate effectively and therapeutically with patients at the end of their lives? Many authors agree failure to comprehend the essence of what patients are communicating, either verbally or non-verbally, can adversely affect the level of support that health professionals can offer, and risks increasing patients' suffering and isolation, leaving them feeling hopeless. Anxiety and fear frequently invoke hopelessness and often cause patients to reject advice and important information given by clinicians. This article focuses on the importance of therapeutic communication in sustaining hope for patients at the end of life. <http://www.magonlinelibrary.com/doi/abs/10.12968/bjon.2015.24.13.702>

### **“Talk to me”: A mixed methods study on preferred physician behaviours during end-of-life communication from the patient perspective**

*HEALTH EXPECTATIONS* | Online – 14 July 2015 – Patients desire candid information from their physician and a sense of familiarity. The quantitative results suggest a paucity of certain end-of-life (EOL) communication behaviours in this seriously ill population with a limited prognosis. The qualitative findings suggest that at times, physicians did not engage in EOL communication despite patient readiness, while sometimes this may represent an appropriate deferral after assessment of a patient's lack of readiness. <http://onlinelibrary.wiley.com/doi/10.1111/hex.12384/abstract>

Noted in Media Watch, 11 May 2015, #409 (p.12):

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 6 May 2015 – **‘Solicitude: Balancing compassion and empowerment in a relational ethics of hope – an empirical-ethical study in palliative care.’** The ethics of hope has often been understood as a conflict between duties: do not lie versus do not destroy hope. However, such a way of framing the ethics of hope may easily place healthcare professionals at the side of realism and patients at the side of (false) hope. <http://link.springer.com/article/10.1007/s11019-015-9642-9>
- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 4 May 2015 – **‘Reflections on hope and its implications for end-of-life care.’** Physicians caring for individuals with life-altering, incurable illnesses often have a desire to convey a sense of hope while also helping their patients prepare for the end of life to minimize unnecessary suffering and grief. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.13392/abstract>

## A cultural analysis of New Zealand palliative care brochures

*HEALTH PROMOTION INTERNATIONAL* | Online – 9 July 2015 – Low utilization of palliative care services by Māori remains despite increases in services designed to meet Māori needs. The purpose of this study is to explore palliative care information brochures in the context of Māori principles of well-being and communication protocols, and health literacy. The authors examined ninety-nine brochures from palliative care services in New Zealand and held two focus groups with twelve Māori elders (kaumātua) and extended family (whanau) members. Taking a cultural-discursive approach incorporating Māori worldviews, they analysed textual and conceptual features of the brochures. The findings centred on cultural connection and disconnection within the brochures and serve as a critique of the prominent messages currently presented in these brochures. The findings raise questions about the capacity of agencies to convey culturally resonant messages to kaumātua and their whānau. The authors identify implications of palliative care brochures for health literacy of provider organizations as well as kaumātua and whanau. <http://heapro.oxfordjournals.org/content/early/2015/07/09/heapro.dav067.abstract>

**N.B.** Additional articles on Māori beliefs and practices in the context of end-of-life care are noted in issues of Media Watch dated 15 June 2015, #414 (p.5), 16 June 2014, #362 (p.8), and 17 March 2014, #349 (p.9).

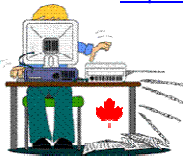
## End-of-life care in the U.S.

### **Hospice eligibility and election: Does policy prepare us to meet the need?**

*JOURNAL OF AGING & SOCIAL POLICY* | Online – 10 July 2015 – A seven-point policy model is used to examine policy on hospice eligibility and election in the U.S. Despite the growth of hospice, many eligible patients continue to lack access due to difficulties experienced by providers in discerning six-month prognoses among chronically ill patients, the inability of patients to elect hospice alongside curative care, and to limited reimbursement for hospice providers. Though the landscape of dying has evolved with more deaths occurring later in life from chronic illness, Medicare hospice eligibility requirements have historically remained the same. Utilization would increase if hospice agencies were able to provide fewer restrictions by including ongoing treatments such as transfusions, intravenous nutrition, or palliative radiation. Hospices would be more likely to enrol critically ill patients who require some ongoing curative measures if Medicare reimbursement rates were higher, and patients would be more likely to seek hospice earlier if Medicare election policies were altered to allow concurrent care. Participation would also be increased by extending hospice eligibility past the traditional prognosis of 6 months. Though expansion in public spending of hospice care has been met with some opposition, current research suggests that potential savings due to decreased costs in acute care is promising. <http://www.tandfonline.com/doi/abs/10.1080/08959420.2015.1054234#.VaeKHmdRGos>

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 14 July 2015 – ‘**Geographic variation of hospice use patterns at the end of life.**’ In 2011, the percentage of decedents who used hospice in the last 6 months of life nationally was 47.1%, and varied across states from 20.3% in Alaska to 60.8% in Utah. Hospice utilization patterns also varied by state, with the percentage of hospice users with very short hospice enrollment ranging from 23.0% in the District of Columbia to 39.9% in Connecticut. The percentage of very long hospice use varied from 5.7% in Connecticut to 15.9% in Delaware. The percentage of hospice disenrollment ranged from 6.2% in Hawaii to 19.0% in the District of Columbia. Nationally, state-level hospice use among decedents was positively correlated with the percentage of potentially concerning patterns (including very short hospice enrollment, very long hospice enrollment, and hospice disenrollment) among hospice users... Oregon was the only state in the highest quartile of hospice use and the lowest quartiles of both very short and very long hospice enrollment. The percentage of decedents who use hospice may mask important state-level variation in these patterns, including the timing of hospice enrollment, a potentially important component of the quality of end-of-life care. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0425>
- *JOURNAL OF PSYCHOSOCIAL ONCOLOGY* | Online – 15 July 2015 – ‘**The developmental transition from living with to dying from cancer: Hospice decision-making.**’ Despite increasing utilization of hospice care, older adults with cancer enrol in hospice for shorter periods of time than those with other life-limiting illnesses. How older adults with cancer and their family members consider hospice is unknown. The purpose of this study was to compare decision-making in late-stage cancer in people who enrolled in hospice with those who declined. <http://www.tandfonline.com/doi/abs/10.1080/07347332.2015.1067282#.Vae5DWdRGos>



### 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>

## **Posttraumatic stress symptoms in palliative care professionals seeking mindfulness training: Prevalence and vulnerability**

*PALLIATIVE MEDICINE* | Online – 17 July 2015 – Vicarious exposure to trauma is ubiquitous in palliative medicine. Repeated exposure to trauma may contribute to compassion fatigue and posttraumatic stress disorder (PTSD) symptoms in medical and supportive care professionals such as physicians, nurses, and social workers. These symptoms may be intensified among medical and supportive care professionals who use avoidant or rigid coping strategies. A total of twenty-one professionals working with palliative care patients completed assessments prior to beginning mindfulness-based communication training. PTSD symptoms were prevalent in this sample of professionals; 42% indicated positive screens for significant PTSD symptoms, and 33% indicated probable posttraumatic stress disorder diagnosis. PTSD symptoms may be common among professionals working in palliative medicine. Professionals prone to avoidant coping and those with more rigid negative thought processes may be at higher risk for PTSD symptoms. <http://pmj.sagepub.com/content/early/2015/07/15/0269216315596459.abstract>

### **Literature review**

## **Hospice and palliative care for older lesbian, gay, bisexual and transgender adults: The effect of history, discrimination, health disparities and legal issues on addressing service needs**

*PALLIATIVE MEDICINE & HOSPICE CARE* | Online – 29 May 2015 – Despite the fact that sound enquiry is needed to improve health-related outcomes, what little research has been done with older lesbian, gay, bisexual and transgender (LGBT) adults in general and, specifically, with older LGBT adults, has focused mainly on HIV/AIDS and other sexually transmitted diseases. LGBT persons are more likely to experience economic insecurity, lack health insurance, experience invisibility, and be victimized and mistreated. This is especially true of older LGBT adults who grew up in a less tolerant era when sexual minorities were criminalized and stigmatized as pathological, sinful, and immoral. Their minority status has led to health issues and health care disparities, and requires health professionals to consider systems in a way that redefines family, addresses legal concerns, and responds with options of care unlike those of their heterosexual counterparts. With recent changes in societal attitudes and some progress in addressing legal concerns, hospice and palliative care organizations have an opportunity to lead the health care community by pioneering culturally sensitive and appropriate methods to serve this population. [http://openventio.org/Volume1\\_Issue2/Hospice\\_and\\_Palliative\\_Care\\_for\\_Older\\_Lesbian\\_Gay\\_Bisexual\\_and\\_Transgender\\_Adults\\_The\\_Effect\\_of\\_History\\_Discrimination\\_Health\\_Disparities\\_and\\_Legal\\_Issues\\_on\\_Addressing\\_Service\\_Needs\\_PMHCOJ\\_1\\_107.pdf](http://openventio.org/Volume1_Issue2/Hospice_and_Palliative_Care_for_Older_Lesbian_Gay_Bisexual_and_Transgender_Adults_The_Effect_of_History_Discrimination_Health_Disparities_and_Legal_Issues_on_Addressing_Service_Needs_PMHCOJ_1_107.pdf)

Noted in Media Watch, 2 March 2015, #399 (p.6):

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 26 February 2015 – ‘**American Geriatrics Society Care of Lesbian, Gay, Bisexual & Transgender Older Adults position statement.**’ Providing high-quality health care for older LGBT adults will require active steps by organizations, institutions, advocacy groups, and health professionals that create an environment that is free from discrimination. This position statement addresses the vision of the Society for the care of LGBT older adults and specific steps that can be taken to ensure they receive the care that they need. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.13297/abstract>

Cont.

Noted in Media Watch, 30 December 2013, #338 (p.2):

- U.S. (New York State) | *Advocate* – 27 December 2013 – ‘**End-of-life care for an aging LGBT population.**’ With the number of self-identified LGBT adults age 65 or older expected to double by 2030 – from 1.5 million to 3 million, according to the National Resource Center on LGBT Aging – the time has never been more urgent to discuss this silent challenge: How do we meet the unique end-of-life care needs for an aging LGBT population? LGBT seniors are at a greater risk of disability and mental distress than their heterosexual counterparts, and face many barriers to accessing care...<sup>1</sup> <http://www.advocate.com/health/2013/12/27/end-life-care-aging-lgbt-population>

1. *The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults*, National Resource Center on LGBT Aging, November 2011. <http://www.lgbtagingcenter.org/resources/resource.cfm?r=419>

**N.B.** Selected articles on the provision and delivery of end-of-life care for LGBT adults noted in past issues of Media Watch are listed in the issue of the weekly report of 21 May 2012, #254 (p.9).

### **Shared decision making: Concepts, evidence, and practice**

*PATIENT EDUCATION & COUNSELING* | Online – 15 July 2015 – Shared decision-making (SDM) is advocated as the model for decision-making in preference-sensitive decisions. In this paper the authors sketch the history of the concept of SDM, evidence on the occurrence of the steps in daily practice, and provide a clinical audience with communication strategies to support the steps involved. Finally, we discuss ways to improve the implementation of SDM. The plea for SDM originated almost simultaneously in medical ethics and health services research. Four steps can be distinguished: 1) The professional informs the patient that a decision is to be made and that the patient’s opinion is important; 2) The professional explains the options and their pros and cons; 3) The professional and the patient discuss the patient’s preferences and the professional supports the patient in deliberation; and, 4) The professional and patient discuss the patient’s wish to make the decision, they make or defer the decision, and discuss follow-up. In practice these steps are seen to occur to a limited extent. Knowledge and awareness among both professionals and patients as well as tools and skills training are needed for SDM to become widely implemented. [http://www.pec-journal.com/article/S0738-3991\(15\)30009-4/abstract](http://www.pec-journal.com/article/S0738-3991(15)30009-4/abstract)

**N.B.** Selected articles on shared decision making noted in past issues of Media Watch are listed in the issue of the weekly report of 25 August 2014 issue of the weekly report (#372, pp.14-15).

### **Assisted (or facilitated) death**

Representative sample of recent news media coverage:

- *THE GERONTOLOGIST* | Online – 16 July 2015 – ‘**Till death do us part: The lived experience of an elderly couple who chose to end their lives by spousal self-euthanasia.**’ This article provides the first qualitative account of spousal self-euthanasia in older people, a previously unexplored phenomenon. It investigates the lived experience of a Dutch elderly couple who strongly wished – and chose – to die together at a self-directed moment, despite not suffering from a life-threatening disease or severe depression. It describes their subjective experiences and considerations prior to their self-chosen death. This article concludes by outlining the practical implications for professionals working in gerontology and recommends further research on the relation between self-euthanasia and depression in elderly people. <http://gerontologist.oxfordjournals.org/content/early/2015/07/15/geront.gnv060.abstract>

Cont.



- *SOUTH AFRICAN MEDICAL JOURNAL*, 2015;105(7):526-727. ‘**Doctor-assisted suicide: What is the present legal position in South Africa?**’ In the case of *Stransham-Ford v. the Minister of Justice & Correctional Services*, the North Gauteng High Court held a terminally ill patient who was experiencing intractable suffering was entitled to commit suicide with the assistance of his doctor and the doctor’s conduct would not be unlawful. The court was careful to state it was not making a general rule about doctor-assisted suicide. The latter should be left to Parliament, the Constitutional Court and “future courts.” The judge dealt specifically with the facts of the case at hand. In order to understand the basis of the decision it is necessary to consider the... 1) Facts of the case; 2) Question of causation; 3) Paradox of “passive” and “active” euthanasia; 4) Test for unlawfulness in euthanasia cases; and, 5) Meaning of doctor-assisted suicide. [http://reference.sabinet.co.za/sa\\_epublication\\_article/m\\_samj\\_v105\\_n7\\_a13](http://reference.sabinet.co.za/sa_epublication_article/m_samj_v105_n7_a13)

Noted in Media Watch, 4 May 2015, #408 (p.8):

- SOUTH AFRICA | BBC News – 30 April 2015 – ‘**South African court grants man “right to die.”**’ [In a landmark ruling] the Pretoria High Court ruled that Robin Stransham-Ford, 65, who was diagnosed with terminal prostate cancer in 2013, could allow a doctor to help him end his life. Judge Hans Fabricius said that the doctor treating him could not now be prosecuted or face disciplinary action. <http://m.bbc.com/news/world-africa-32530580>

### [Media Watch: Online](#)

#### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2015/07/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**

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

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>

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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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### Links to Sources

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

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