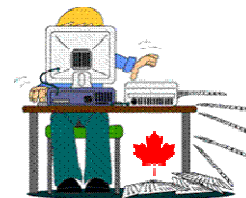


## Media Watch...

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

**The illness experience: Scroll down to [Specialist Publications](#) and 'Reframing, refocusing, referring, reconciling, and reflecting: Exploring conflict resolution strategies in end-of-life situations' (p.12), in *Health Communication*.**

## Canada

### Provincial Select Standing Committee on Health report

#### **Improving End-of-Life Care for British Columbians**

BRITISH COLUMBIA | Legislative Assembly (Select Standing Committee on Health) – Accessed 19 May 2016 – Definitions around palliative care (PC) have changed to include a focus on those living with serious life-threatening illnesses, as opposed to only those who may succumb to their illness in the near future. This new definition is not constrained by a patient's age or where palliative services may be delivered, whether it be in the home, the community or a hospital setting. Research findings indicate that the sooner a patient is able to access PC, the better the outcomes; thus the focus shifts to helping those with serious illnesses live well. The need for PC services applies to communities across the province, including those in rural, remote and isolated areas. The Committee supports moving toward a more integrated palliative model of care and recommends that: timely information regarding available social services and advance care planning be provided to patients with chronic life-limiting illnesses; patients be referred to PC earlier in the course of their illness; the expansion of in-home services for the frail elderly be supported, based on successful models already in place; the provision of services for palliative and end-of-life care (EOLC) in rural, remote and isolated communities is fairly

distributed to meet the needs of those communities; an integrated and interdisciplinary palliative model of care be applied across the health service continuum to reflect a patient-centred approach to cultural practices and sensitivities regarding EOLC; initiatives to implement proactive home visits be supported; and a patient-centered approach be focussed on the optimization of quality of life and include an emphasis on comfort and function. <http://goo.gl/jjBmTS>

#### **Report offers solutions for British Columbia's aging population**

BRITISH COLUMBIA (B.C.) | *The Vancouver Sun* – 16 May 2016 – The province's health system is not prepared for the challenges of its aging population and changes are needed, according to a policy paper<sup>1</sup> ... [which] ... explores ways B.C. can improve services to seniors in the community with the goal of the province becoming "an aging centre of excellence." Nearly one-quarter of B.C.'s population is expected to be 65 years or older in the next 20 years. <http://goo.gl/WLMx2p>

1. 'Sustainability and Innovation: Exploring Options for Improving B.C.'s Continuing Care Sector,' B.C. Care Providers Association, May 2016. <http://goo.gl/77pbdY>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- **THE GLOBE & MAIL** | Online – 20 May 2016 – **‘Dying Canadians deserve better than a “raucous with the caucus.”**’ The government appears to have an agenda to end debate and swiftly push this bill forward because it knows there are many questions that remain unanswered. The legislation is unsatisfactory and is in clear breach of what the Supreme Court said. The proposed legislation requires that the patient’s death be “reasonably foreseeable,” something not required by the Supreme Court in its landmark ruling. What does that mean? Everyone’s death is “reasonably foreseeable.” What isn’t foreseeable is the time line, certainly for healthy patients but also for many people with terminal conditions. Medical complications, effective cures and even a person’s will to live (or lack thereof) will affect the time line. What if death is “reasonably foreseeable” within five years? Ten years? The provision requiring the applicant be in “an advanced state of irreversible decline in capability” does not make sense if “capability” is in reference to a mental condition, because at the time death is “administered,” the patient must be capable. The government did not table the regulations setting out when and how reports of medical assisted death must be made, or to whom. If these are not available when the legislation is passed, what assurances of consistent application of the law, of protection of the vulnerable, of access to assisted death for all Canadians equally, do the people of Canada have? <http://goo.gl/UPOi9T>
  - **ALBERTA** | The Canadian Press – 18 May 2016 – **‘Federal rationale for restricting assisted dying shot down by Alberta appeal court.’** The federal government’s rationale for a restrictive approach to medically assisted dying has been shot down in flames by the Alberta Court of Appeal, even before its controversial legislation is put to a vote in the House of Commons. A panel of three appeal court judges says the government is flouting last year’s landmark ruling by the Supreme Court when it argues that assisted dying should apply only to those who are close to death. It’s also not complying with the top court’s ruling ... when it excludes people suffering solely from psychiatric conditions, the judges say. <http://goo.gl/RS9V53>
  - **THE GLOBE & MAIL** | Online – 17 May 2016 – **‘Assisted-dying bill mired in debate ahead of dead-line.’** A Senate committee has recommended key changes to the government’s doctor-assisted-dying bill, including advance requests for patients diagnosed with conditions such as dementia while at the same time limiting the procedure to those with terminal illness. The message from the Red Chamber comes as MPs continue to debate Bill C-14 in the House of Commons, where further changes can be introduced. Amid procedural bickering on all sides, Liberal House Leader Dominic LeBlanc signalled ... that the government will cut off the discussion in order to pass the legislation by the end of this week. The bill then goes to the Senate where it must also pass the legislative process – and some senators are warning the Commons that stronger safeguards are needed. <http://goo.gl/kj64oU>
  - **CTV NEWS** | Online – 13 May 2016 – **‘Most ALS doctors support assisted death, but not for early-stage patients: Study.’** Most doctors who care for patients with amyotrophic lateral sclerosis (ALS) support the availability of assisted death for those with moderate to severe disease, but few are willing to offer the lethal procedure themselves, a survey of specialists across Canada suggests.<sup>1</sup> As well, the survey found the majority of health providers at 15 ALS clinics who responded feel unprepared for the upcoming legalization of physician-assisted death and believe guidelines and training are needed prior to its implementation. <http://goo.gl/WYhVxN>
1. ‘Physician-assisted death: A Canada-wide survey of ALS health care providers,’ *Neurology*, 13 May 2016. <http://goo.gl/KSluqG>



The screenshot shows the IPCRC.NET website. The header includes the logo and navigation links: Home, About IPCRC, OIA, NGI, Partners, Contact, Acknowledgements. Below the header, there is a section titled 'GLOBAL PALLIATIVE CARE NEWS ARCHIVE' and 'MEDIA WATCH, CREATED AND DISTRIBUTED BY BARRY R. ASHPOLE'. A 'Media Watch Archives' sidebar lists back issues from 2014 to 2015. The main content area features a news item titled 'MW 452: Dying better, even if it means sooner' with a download link for the PDF. Below this, there is a small text block mentioning a study on physician-assisted death in ALS patients.

Media Watch: Back Issues: <http://goo.gl/frPgZ5>

## U.S.A.

### Hospice care in the LGBT community

CALIFORNIA | *Bay Times* (San Francisco) – 20 May 2016 – Historically, the lesbian, gay, bisexual and transgender (LGBT) community has been reluctant to seek health care from straight providers. Lack of health insurance, stigma, and lack of safety in a mainstream healthcare environment. The situation has greatly improved, but facing a terminal illness is hard enough without wondering if a team of healthcare workers will treat you with respect and dignity. The challenges of a life-threatening illness can be compounded by other issues: questions of reconciliation with families of origin when there has been harm done in the past; trauma and compassion fatigue from the multitude of deaths from HIV in the 1980s and 1990s; and, financial stress as a result of employment and housing discrimination. Members of the transgender

community can suffer the most from this isolation and discrimination; their desire to die in their preferred gender is often disrespected. Having an understanding of all of these dynamics helps us be better prepared to offer services to the LGBT community. <http://goo.gl/IzIM3a>

#### Specialist Publications

**'How U.S. doctors die: A cohort study of health-care use at the end of life'** (p.12), in *Journal of the American Geriatrics Society*.

**'Determination of death and the dead donor rule: A U.S. survey of the current law on brain death'** (p.14), in *Journal of Medicine & Philosophy*.

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.'** 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 they need. <http://goo.gl/bqLJv>

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

- *ADVOCATE* (U.S.) | Online – 27 December 2013 – **'End-of-life care for an aging LGBT population.'** With the number of self-identified LGBT adults age 65 or older in the U.S. expected to double by 2030 – from 1.5 million to 3 million – 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://goo.gl/gP7t33>

1. 'The Aging and Health Report: Disparities and Resilience Among Lesbian, Gay, Bisexual, and Transgender Older Adults,' National Resource Center on LGBT Aging, New York, NY, November 2011. <http://goo.gl/eicjFG>

### Much of world suffers not from abuse of painkillers, but absence of them

*THE NEW YORK TIMES* | Online – 17 May 2016 – While Americans are confronting an epidemic of prescription drug abuse, particularly for addictive painkillers, the reverse problem prevails in much of the world. Many ill people with a legitimate need for drugs like oxycodone and other narcotics known as opioid analgesics cannot get them and are suffering and dying in pain, according to health officials, doctors and patients' rights advocates. In Russia, India and Mexico, many doctors are reluctant to prescribe these painkillers, fearful of possible prosecution or other legal problems, even if they believe the prescriptions are justified. In Kenya, health officials only recently authorized the production of morphine, one of the most effective drugs for pain relief, after criticism that it was available in only seven of the country's 250 public hospitals. In Morocco ... only a small fraction of physicians are permitted to prescribe opioid analgesics, which the country's law on controlled substances identifies as poisons. And in most poor and

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middle-income countries, these drugs are restricted and often unavailable, even for patients with terminal cancer, AIDS or grievous war wounds. The reasons include an absence of medical training, onerous regulations, costs, a focus on eliminating illicit drug use and, in some cultures, a stoic acceptance of pain without complaint. The problem has been amplified, public health experts say, by the stigmatization of the drugs, partly from fear of what has happened in the U.S., where opioid misuse is a growing cause of death. <http://goo.gl/yJxfW9>

Noted in Media Watch, 21 March 2016, #454 (p.2):

- **THE WALL STREET JOURNAL** | Online – 15 March 2016 – ‘**Centers for Disease Control & Prevention issues guidelines to limit opioid painkiller prescriptions.**’ The guidelines apply to primary care clinicians treating patients for certain types of chronic pain, but not for patients in cancer treatment, palliative or end-of-life care.<sup>1</sup> <http://goo.gl/1qgCGT>

1. ‘CDC Guideline for Prescribing Opioids for Chronic Pain – U.S., 2016,’ *Morbidity & Mortality Weekly Report*, 15 March 2016, Centers for Disease Control & Prevention. <http://goo.gl/Nq6PZ5>

**N.B.** Selected articles on the availability and accessibility of opioids are noted in the issue of Media Watch of 23 November 2015, #437 (p.3). See also ‘Availability of Opioid Painkillers,’ in ‘2015 Quality of Death Index’ (Figure 5.2, p.42), Economist Intelligence Unit, October 2015. [Noted in Media Watch, 26 October 2015, #433 (p.12)] <http://goo.gl/smDyHy>

### Study examines how optimism shapes medical decisions

PENNSYLVANIA | *The Pittsburgh Tribune-Review* – 17 May 2016 – Doctors know that friends and family members tend to be more optimistic about a sick patient’s chances of survival than doctors. A [new] study ... offers a deeper look at what’s behind the optimism.<sup>1</sup> Among study participants who were more optimistic than doctors about a loved one’s chances, many said they thought a positive attitude could improve the patient’s chance of survival... Others told researchers they felt that the patient had strength the doctor didn’t know about, and a third group reported their optimism was rooted in religious belief. “It changes how physicians should respond to this in clinical practice,” Dr. Douglas White, the study’s lead author and a University of Pittsburgh School of Medicine pro-

fessor, said of the study. Differences in expectation between doctors and those who make medical decisions for incapacitated patients are often attributed to decision-makers not understanding medical information, White said. Understanding that more factors are at play could help doctors communicate better with people making difficult medical decisions, he said. <http://goo.gl/iv1LWR>

#### Specialist Publications

‘**Reframing, refocusing, referring, reconciling, and reflecting: Exploring conflict resolution strategies in end-of-life situations**’ (p.12), in *Health Communication*.

1. ‘Prevalence of and factors related to discordance about prognosis between physicians and surrogate decision makers of critically ill patients,’ *Journal of the American Medical Association*, 2016;315(19): 2086-2094. <http://goo.gl/VG6Xf3>

Noted in Media Watch, 9 August 2010, #161 (p.6):

- **AMERICAN MEDICAL NEWS** | Online – 2 August 2010 – ‘**Families’ optimism often at odds with physicians’ prognoses.**’ Family members of intensive care patients are likely to be more optimistic about their loved ones’ chances of survival, regardless of how a physician presents a grim prognosis.<sup>1</sup> <http://goo.gl/DQMECP>

1. ‘A randomized trial of two methods to disclose prognosis to surrogate decision makers in ICUs,’ *American Journal of Respiratory & Critical Care Medicine*, 2010;182(7):905-909. <http://goo.gl/yynu0fp>

## Caregiver discrimination lawsuits increased 269% in the last decade

*TIME MAGAZINE* | Online – 17 May 2016 – Workplace discrimination against employees based on caregiving responsibilities – called “family responsibilities discrimination” – is often blatant. A new report ... found a 269% increase in this type of lawsuit in the past decade.<sup>1</sup> Employees won two-thirds of cases that went to trial – a far higher success rate than other employment discrimination cases – and employers paid about half a billion dollars in verdicts and settlements in the decade ending in 2015, more than double the amount paid out in the decade before. <http://goo.gl/nJE0OS>

### Rise in discrimination claims by employees caring for elders

As the need for employees to care for sick or aging parents increases, so does the number of claims for discrimination based on eldercare. Claims based on eldercare responsibilities have grown to 465, or 10.5% of the cases in the dataset, and now are the second most common type of claim.

1. ‘Caregivers in the Workplace: Family Responsibilities Discrimination Litigation Update 2016,’ Center for WorkLife Law, Hastings College of the Law, University of California, May 2016. <http://goo.gl/Nmq6qN>

### Selected articles on family caregivers and the workplace

- *HUMAN RESOURCE EXECUTIVE* | Online – 10 February 2014 – ‘**Focus on family-caregiver discrimination growing.**’ With aging baby boomers still lingering in the workplace, a growing number of them caring for elderly and ailing parents, and with the federal government – namely the U.S. Equal Opportunity Commission – continuing to step up policing efforts against family and caregiver responsibility discrimination, attention to this segment of employment law is intensifying. [Noted in Media Watch, 17 February 2014, #345 (p.4)] <http://goo.gl/qzdVrm>
- *FORBES* | Online – 10 February 2014 – ‘**The family leave law is failing family caregivers.**’ The Family & Medical Leave Act [1993] is failing for many working Americans in their 50s and 60s who need time off to care for their parents, spouses or partners. The law has an admirable goal: guaranteeing up to 12 weeks of unpaid leave to workers recovering from a serious medical condition and those caring for seriously ill spouses, parents or children or for new children. [Noted in Media Watch, 17 February 2014, #345 (p.4)] <http://goo.gl/5rV75v>
- AMERICAN ASSOCIATION FOR RETIRED PERSONS | Online – 17 June 2013 – ‘**Demographics, family caregiving demands call for modernizing workplace leave for caregivers.**’ A new report argues for improving family leave for working caregivers, citing the growing population of older Americans, increasing numbers of family caregivers on the job, and escalating demands and stress on caregivers.<sup>1</sup> [Noted in Media Watch, 24 June 2013, #311 (p.3)] <http://goo.gl/Ab5q0c>

1. *Keeping Up with the Times: Supporting Family Caregivers with Workplace Leave Policies*, American Association for Retired Persons, Public Policy Institute, Washington, June 2013. <http://goo.gl/sevJ5z>

### Long-term care in an aging population

#### Health issues presidential candidates aren’t talking about – but should be

*KAISER HEALTH NEWS* | Online – 16 May 2016 – The nation in the next few years faces many important decisions about health care – most of which have little to do with the controversial federal health law [among them long-term care (LTC)]. Every day, another 10,000 baby boomers turn 65 and qualify for Medicare. An estimated 70% of people who reach that threshold will need some sort of LTC. It’s not cheap. The annual cost of these services can range from approximately \$46,000 for a home health aide to \$80,000 or more for a bed in a nursing home. Yet Medicare, the health program for the elderly and some disabled, does not pay for most LTC services. Medicare has both nursing home and home care benefits, but they are temporary and limited to those with specific medical needs. Most people who need

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LTC don't need special medical interventions, just help with "activities of daily living." By contrast, Medicaid, the joint state-federal health program for people with low incomes, paid just over half of the nation's estimated \$310 billion tab for LTC in 2013, the most recent year for which this information is available. But you either have to be very poor, or spend nearly all of your savings, in order to qualify. Private insurance for LTC exists, but it is expensive, and remains uncommon – paying for just 8% of the 2013 bill. And private insurance for LTC has been getting more difficult to purchase as insurers pull back from the products because of rising costs as people, especially women, live longer. <http://goo.gl/s7TB6C>

#### **Selected articles on long-term care in the U.S.**

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 29 March 2016 – '**Culturally competent palliative and hospice care training for ethnically diverse staff in long-term care facilities.**' Between 2013 and 2030, older adults 65 years and older of racial/ethnic populations in the U.S. is projected to increase by 123% in comparison to the Whites (Non-Hispanics). To meet this demand, training of ethnically diverse health staff in long-term care facilities in palliative and hospice care is imperative. [Noted in Media Watch, 4 April 2016, #456 (p.9)] <http://goo.gl/Ef1IV7>
- *HEALTH AFFAIRS*, 2015;34(6):936-945. '**Future demand for long-term care workers will be influenced by demographic and utilization changes.**' The occupations anticipated to grow the most over the period are counselors and social workers (94%), community and social services workers (93%), and home health and personal care aides (88%). If 20% of nursing home care were shifted to home health services, total employment growth would be about 12% lower. [Noted in Media Watch, 15 June 2015, #414 (p.12)] <http://goo.gl/xyLNyn>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 3 December 2014 – '**Knowledge, skills, and attitudes in caring for older adults with advanced illness among staff members of long-term care and assisted living facilities.**' An needs assessment was conducted to determine the learning needs and preferences of staff members related to providing care for patients with life-limiting illnesses. They placed importance on understanding the principles of palliative care, pain assessment, pain management, and non-pain symptom management. [Noted in Media Watch, 8 December 2014, #387 (p.9)] <http://goo.gl/1uDvt6>

#### **Dying traditions, and new life, in the funeral industry**

MASSACHUSETTS | *The Boston Globe* – 16 May 2016 – Death is inevitable, but, increasingly, traditional burials are not. From diamonds made from cremated remains to eco-friendly interments, the \$20 billion funeral industry is being reshaped, creating opportunities for the entrepreneurially minded – and financial hardship for those with business models more set in stone. Death rates are rising as America's population ages, but with some estimating that cremations surpassed burials for the first time last year, and other cheaper alternatives becoming more popular, profits are being tamped down. Interest in cremations has risen swiftly in recent years, particularly among the growing ranks of the non-religious. In the 1960s, less than 5% of deaths resulted in cremations, according to the Cremation Association of North America. But after the Catholic Church lifted the ban on cremations in 1963 and started allowing cremated remains at funeral Masses in 1997, the practice has become more common. In Maine, which has one of the country's highest cremation rates, 73% of deaths resulted in cremations last year. In Massachusetts, it was 45%. By 2030, the national cremation rate is expected to be 71%. <https://goo.gl/r3jRTE>

#### **Related**

- STATE OF NEW YORK | *The New York Times* – 15 May 2016 – '**Over a million people are buried in the city's potter's field on Hart Island.**' New York is unique among American cities in the way it disposes of the dead it considers unclaimed: interment on a lonely island, off-limits to the public, by a crew of inmates. Buried by the score in wide, deep pits, the Hart Island dead seem to vanish – and so does any explanation for how they came to be there. To reclaim their stories from erasure is to confront the unnoticed heartbreak inherent in a great metropolis, in the striving and missed chances of so many lives gone by. Bad childhoods, bad choices or just bad luck – the chronic calamities of the human condition figure in many of these narratives. Here are the harshest consequences of mental illness, addiction or families scattered or distracted by their own misfortunes. <http://goo.gl/7KWjWM>

## Expedited compassionate use for investigational drugs coming soon, FDA Says

*REGULATORY FOCUS* (Regulatory Affairs Professionals Society) | Online – 16 May 2016 – The fight over patients gaining access to investigational drugs via the compassionate use process is expected to get a lot easier in the near future, just as the U.S. Food & Drug Administration (FDA) ... is working to build an online navigator to help patients and physicians understand that process better. Compassionate use, also known as expanded access, is a process by which physicians can request that FDA allow the use of an investigational drug outside of a clinical trial for a patient with a terminal illness or no other treatment options. But the process can only be initiated if the company developing the drug and the physician treating the patient agree to move forward and make the FDA request. The need for such a navigator comes as 28 states since 2014 have passed “right-to-try” laws that aim to skirt FDA’s compassionate use process to help terminally ill patients or those with no treatment options gain access to potential drugs still undergoing clinical trials. But what’s unclear about these new laws is whether they are actually helping patients gain access to investigational therapies. <http://goo.gl/MqxXvR>

Noted in Media Watch, 22 February 2016, #450 (p.12):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 11 February 2016 – ‘**The ethical challenges of compassionate use.**’ Granting access to drugs, vaccines, biologics, and devices not yet approved by governmental regulatory authorities is a growing challenge for physicians, public officials, patient advocacy groups, institutional review boards, and patients. Although the issue of rapid access to investigational agents is not new, the pace of requests has increased. <http://goo.gl/Llu1iO>

Noted in Media Watch, 5 October 2015, #430 (p.7):

- *ANNALS OF INTERNAL MEDICINE* | Online – 29 September 2015 – ‘**Right-to-try laws: Hope, hype, and unintended consequences.**’ Most “right-to-try” laws do not set qualifications for either the health care provider making attestation of terminal illness or the physician recommending experimental treatment. Worse, the door is left open for the unscrupulous or inept to prey on desperately ill patients and their families. Further, the laws absolve companies and physicians from legal liability should be the experimental product cause harm. <http://goo.gl/JWifuy>

## International

### End-of-life care in Scotland

#### **Longer hospital stays for terminally-ill rural Scots patients**

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 21 May 2016 – Terminally-ill patients in rural communities are facing longer hospital stays due to challenges in finding end-of-life care in their area, a study has found.<sup>1</sup> Glasgow University experts found that remote areas such as Orkney and Shetland incurred much higher healthcare costs for dying patients than cities, through analysis of 15 years of patient records from across Scotland. Rural patients tended to stay for longer periods of time in hospital, which could have a negative impact on their health and wellbeing, due to a lack of social care or hospice care available so the patients can be discharged. The team suggested providing more care at home would reduce costs and prove better for patients, in line with the Scottish Government’s plans to shift care away from hospitals. Travelling longer distances to hospital is linked to higher mortality rates from heart attacks and stroke... <http://goo.gl/KtLkni>

1. ‘Geographic variation of inpatient care costs at the end of life.’ Age & Ageing, 28 March 2016. [Noted in Media Watch, 4 April 2016, #456 (p.12)] <http://goo.gl/6Xbo84>

### **Media Watch: Online**

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.16.

## End-of-life care in England

### **Councils and GP groups “overlooking local end-of-life care needs”**

U.K. (England) | *The Northern Echo* (Buckinghamshire) – 19 May 2016 – The charity Hospice UK used the Freedom of Information Act to find out how well councils and National Health Service (NHS) groups assessed the needs of dying people in their communities. The results showed more than a third (34%) of health and wellbeing boards, which are run by councils, do not consider the needs of dying people in their assessments of local needs. Some 57% do not include the needs of dying adults and children in their key strategies that inform local service planning. More than a quarter (27%) of clinical commissioning groups (CCGs), which control a big chunk of the NHS budget, do not have a strategy for addressing end-of-life care for adults. Most (71%) of CCGs do not have a strategy for sup-

porting children and young people living with life-limiting illnesses. <http://goo.gl/1K8sDk>

#### **New service launched in Herefordshire for local people living with a terminal illness and their families in Herefordshire**

U.K. (England) | *The Ross Gazette* – 20 May 2016 – The Herefordshire Hospice at Home service, funded by Herefordshire Clinical Commissioning Group, will see St Michael's Hospice and Marie Curie working together to support more local people with a terminal illness to be cared for in their own home, care home or the local hospice. <http://goo.gl/l3nduz>

Noted in Media Watch, 15 September 2014, #375 (p.5):

- U.K. (England) | Press Association – 12 September 2014 – **‘Many boards “ignore needs of dying.”’** The needs of dying people and their families are being “ignored” by many local health bodies, charities warned.<sup>1</sup> Just over four in 10 Health & Wellbeing Boards in England consider the needs of people nearing the end of their lives, according to Help the Hospices and the National Council for Palliative Care. <http://goo.gl/Efj4X>

1. ‘Mapping England’s Health & Wellbeing Boards’ vision of dying people,’ Help the Hospices and the National Council for Palliative Care, September 2014. <http://goo.gl/x8NGJs>

### **Boy who no longer giggles should be allowed to die, judge rules**

U.K. (England) | *The Daily Telegraph* – 18 May 2016 – The parents of a “profoundly neurologically disabled” two-year-old boy said their child had been treated like a dog, following a High Court judge’s decision to allow medics to provide only palliative care. They said Mrs. Justice Parker’s ruling “effectively condemns their son to death” and expressed their belief that their son’s life “is worth saving.” The care received by the boy, who no longer giggles when he is tickled because of his condition, will now be limited after the judge agreed with National Health Service hospital bosses. Specialists said the little boy, who cannot be named, suffered from an incurable, but unidentified, neurological disorder – and that his condition was deteriorating. <http://goo.gl/RYNQdP>

Noted in Media Watch, 2 May 2016, #460 (p.3):

- U.K. (England) | *The Independent* – 27 April 2016 – **‘Judge to decide treatment of two-year-old disabled boy who “no longer giggles.”’** Specialists have told a High Court judge that their treatment of a “profoundly neurologically disabled” two-year-old boy who they say no longer giggles when tickled and is “largely unresponsive” should be limited to palliative care (PC). Doctors want a ruling that limiting treatment to PC would be lawful and in the boy’s best interests. <http://goo.gl/rAOEK9>

#### **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://goo.gl/8JyLmE>



## Elder care in the U.K.

### **“Hidden army” of carers in their 80s, says Age UK**

U.K. (England, Northern Ireland, Scotland & Wales) | BBC News – 18 May 2016 – The number of people in their 80s or older who are relied on as carers has rocketed in the last seven years... Age UK says one in seven of the “oldest old” – an estimated 417,000 people in all – now provides some sort of unpaid care to family or friends. Over half of these clock up more than 35 hours a week. Many are exhausted and say they worry about how long they might be able to carry on, says the charity. The findings come from a yearly representative household survey of 15,000 people aged 60 and older. <http://goo.gl/v3xy0v>

## End-of-life care in the Channel Islands

### **Charter outlines what people can expect at the end of their life**

U.K. (Channel Islands) | *The St. Helens Star* – 17 May 2016 – The End-of-Life Care Citizen’s Charter for St. Helens & Knowsley<sup>1</sup> ... “is designed to help professionals achieve best practice ... [and] ... it articulates what people and carers should expect and ask for. It’s about what somebody facing the end of their life needs to live as well as they possibly can during that time.” The document consists of 12 statements which outline what patients should expect, with four key principles at its heart: 1) Keeping the patient and family informed and supported; 2) Sharing information with other organisations; 3) Promoting choice and control; and, 4) Insuring the care is personal to the person. <http://goo.gl/ijShNO>

1. ‘The End-of-Life Care Citizen’s Charter for St. Helens & Knowsley.’ <http://goo.gl/1rhkPd>

## End-of-life care in Scotland

### **Terminally ill patients “denied consistent standards of care”**

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 14 May 2016 – Terminally ill patients are being denied consistent standards of care despite attempts to improve treatment, new research has found.<sup>1</sup> People who die of frailty or organ failure are less likely to be given care planning before death than those dying of cancer, and there are major variations between GP practices, according to a study led by Edinburgh University. Around 60% of patients are getting some form of care planning before death, but poor communication, fear and lack of training for healthcare professionals continue to be a problem. Using GP records from more than 600 deceased Lothian patients, researchers measured how many patients had a vital electronic record, known as a Key Information Summary, where GPs can record people’s preferences and share them with hospital staff or ambulance workers. While three-quarters of patients who died with cancer and 66% of those with dementia and frailty had this record, only 40% of patients who died with organ failure had their preferences recorded. Patients with this record were more likely to die outside of hospital, which is seen as a marker of good end-of-life care. The figures varied widely between practices, with 92% of patients in one to just 36% in another, said the study. <http://goo.gl/ivznSl>

1. ‘Many people in Scotland now benefit from anticipatory care before they die: An after death analysis and interviews with GPs,’ *BMJ Supportive & Palliative Care*, 13 April 2016. [Noted in Media Watch, 18 April 2016, #458 (p.8)] <http://goo.gl/83tc2N>

## **Selected articles on end-of-life care in Scotland**

- U.K. (Scotland) | STV News (Glasgow) – 18 December 2015 – **‘Everyone to have palliative care access, pledges Scottish Government.’** Palliative care will be made available to every Scot, regardless of diagnosis, in a new government strategy backed by a £3.5 million investment...<sup>1</sup> [Noted in Media Watch, 21 December 2015, #441 (p.8)] <http://goo.gl/nqudyp>

1. ‘Strategic Framework for Action on Palliative and End-of-Life Care,’ Scottish Government, December 2015. <http://goo.gl/CKePjU>

Cont.

- *BMC FAMILY PRACTICE* | Online – 10 December 2015 – ‘**Improving primary palliative care in Scotland: Lessons from a mixed methods study.**’ The authors identified several key issues needed to improve palliative care (PC) in the community: 1) The need for training to identify patients with PC needs (particularly non-cancer); 2) Communication skills training; 3) Improvements in sharing information across the National Health Service; 4) Under resource of – and lack of – coordination with district nurses; 5) Improvements in information technology; and, 6) Tools for working with enlarged PC registers. [Noted in Media Watch, 21 December 2015, #441 (p.9)] <http://goo.gl/lm8V5W>
- U.K. (Scotland) | *The Courier* (Dundee) – 15 September 2015 – ‘**Report says 10,000 people miss out on palliative care before dying.**’ More than 10,000 Scots who could benefit from palliative care towards the end of their life die without receiving it, a new report has suggested.<sup>1</sup> Professor David Clark, of the End-of-Life Studies Group at Glasgow University, said an estimated 40,000 people in Scotland could benefit from the specialist form of care. [Noted in Media Watch, 21 September 2015, #428 (p.6)] <http://goo.gl/4JWxaz>
  1. ‘International comparisons in palliative care provision: What can the indicators tell us?’ Health & Sport Committee, September 2015. <http://goo.gl/KhqtqU>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- INDIA | *The Hindustan Times* (New Delhi) – 17 May 2016 – ‘**Government’s draft bill again stirs debate on passive euthanasia.**’ A draft bill by the Union health ministry on passive euthanasia, withholding medical treatment or life support system required to keep a patient alive, has ... stoked a debate over “right to life” and “right to die with dignity.” The Government of India has decided to solicit public opinion/comments before formulation of a law on passive euthanasia...<sup>1</sup> <http://goo.gl/ZILXlp>
  1. Terminally Ill Patients (Protection of Patients and Medical Practitioners) Bill: <http://goo.gl/rZBolr>

### 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, research and teaching tool.

### Distribution

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

### Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. 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.

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

### **End-of-life decisions and palliative care in advanced heart failure**

*CANADIAN JOURNAL OF CARDIOLOGY* | Online – 13 May 2016 – Future care planning (FCP) for heart failure (HF) patients should incorporate the basic tenets of shared decision-making. These include understanding the patient's perspective and care preferences, articulating what is medically feasible, and integrating these considerations into the overall care plan. Use of defined triggers for FCP can stimulate important patient-caregiver conversations. Guidelines advocate an annual review of HF status and future care preferences. Advance directives are important for any individual with a chronic, life-limiting illness and should be integrated into FCP. Nevertheless, use of advance directives by HF patients is extremely low. Consideration of illness trajectories and risk-scoring tools may facilitate prognostication and delivery of appropriate HF care. Decisions about heart transplantation or left ventricular assist device implantation should include planning for potential complications associated with these therapies. <http://goo.gl/rtboJB>

### **Palliative care for non-communicable diseases: A global snapshot in 2015**



The WHO fact sheet summarises key results of the Non-Communicable Diseases Country Capacity Survey sent to all ministries of health in 2015 and captures information relating to palliative care (PC) funding, national policies, availability of oral morphine in primary care and the provision of palliative care services through primary care and home-care. The results demonstrate a mixed global picture for access to PC. <http://goo.gl/aD4b2X>

Noted in Media Watch, 28 March 2016, #455 (p.7):

- *AMERICAN JOURNAL OF CARDIOLOGY* | Online – 17 March 2016 – ‘**Choosing words wisely in communication with heart failure patients and families.**’ The complex and often unpredictable course of heart failure provides many opportunities for communication between clinicians and patients about important subjects as advance care planning, disease-state education, therapeutic options and limitations, and end-of-life care. Studies of heart failure patients demonstrate that, when engaging in such complex communication, specific language matters in patient experience and in shared decision-making with providers. <http://goo.gl/BFrgnA>

### **Paramedics’ experiences of end-of-life care decision making with regard to nursing home residents: An exploration of influential issues and factors**

*EMERGENCY MEDICINE JOURNAL* | Online – 17 May 2016 – For a patient nearing the end of his or her life, transfer from a nursing home to the emergency department (ED) can be inappropriate, with potentially negative consequences, but transfer in these circumstances is, regrettably, all too common. There is a lack of published literature exploring how paramedics make decisions in end-of-life care (EOLC) situations. Three themes emerged in relation to the decision to transport patients from nursing homes to EDs in EOLC situations. Paramedics identified difficulties in understanding nursing home residents’ wishes. When a patient no longer had the capacity for decision making, paramedics’ reasoning processes were aligned to best interest decision making, weighing the risks and benefits of hospitalisation. Paramedics found it challenging to balance patients’ best interests with pressure from others: nursing staff, patients’ relatives and colleagues. This paper considers how paramedics might be better trained and supported in dealing with these situations, with the aim of providing dignified and appropriate care to patients as they reach the end of their lives. <http://goo.gl/LIXSNC>

Cont.

Noted in Media Watch, 27 January 2014, #342 (p.11):

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2014;20(1):37-44. ‘**Challenges U.K. paramedics currently face in providing fully effective end-of-life care.**’ This article highlights barriers to effective paramedic end-of-life care provision and introduces examples of collaborative work in the U.K. that aim to overcome these. Given the similarities in the international evolution of paramedic education, readers from other countries will be able to relate to these findings. <http://goo.gl/3ZkeVM>

### **Reframing, refocusing, referring, reconciling, and reflecting: Exploring conflict resolution strategies in end-of-life situations**

*HEALTH COMMUNICATION* | Online – 13 May 2016 – Many problems can occur between family members at the end of a patient’s life, resulting in conflict that others – the nurses, patient advocates, clergy, and social workers involved in the case – must resolve. This article explores the strategies used by those individuals to resolve conflict. Using grounded practical theory as a theoretical and method-ological framework, qualitative interviews revealed how they manage family conflict at the end of life. The management styles include reframing, refocusing, referring, reconciling, and reflecting (the “5 Rs”). <http://goo.gl/svw3Cj>

#### **Related**

- *JOURNAL OF MEDICAL ETHICS* | Online – 13 May 2016 – ‘**Can I trust them to do everything? The role of distrust in ethics committee consultations for conflict over life-sustaining treatment among Afro-Caribbean patients.**’ Distrust played a role in several of the cases [included in this study], with surrogates of three patients, in particular, illustrating the way that perceived health disparities, past labelling, and concerns about continued maltreatment generated distrust leading to conflict over life-sustaining treatment. <http://goo.gl/Sqs0an>

### **How U.S. doctors die: A cohort study of healthcare use at the end of life**

*JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 16 May 2016 – New research suggests that U.S. physicians are more likely to use hospice and intensive or critical care units in the last months of life than non-physicians. Hospitalization rates were similar. The retrospective study analyzed fee-for-service Medicare beneficiaries across the U.S. using Medicare Part A claims data from 2008 to 2010 for 9947 decedent physicians and a random sample of 192,006 Medicare decedents. “Our findings seem to run exactly counter to the prevailing message that doctors die different and better – it turns out doctors are human too,” said Dr. Daniel Matlock, lead author. “Also, we think this raises concerns that the high utilization seen at the end-of-life is a larger, systems issue.” <http://goo.gl/dKCZ2a>

#### **Good concordance between patients and their non-professional carers about factors associated with a “good death” and other important end-of-life decisions**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 17 May 2016 – Only 69% of patients [i.e., study participants] stated they had discussed their preferences for end-of-life care with their respective carer. The rankings were similar for the patient and the carer’s views of what was important for the patient, although the patients ranked “to be involved in decisions about my care” as less important than the carers, while the carers ranked “to have sorted out my personal affairs” as less important than the patients. When discussions around end-of-life choices do occur, carers generally appear to agree with the patients’ preferences around end-of-life treatment, and preferred place of death. <http://goo.gl/qu9bCy>

Noted in Media Watch, 25 January 2016, #446 (p.4):

- U.S. | ABC News – 19 January 2016 – ‘**Many doctors choose end-of-life care differently than the general population, two studies show.**’ Researchers [in one study] found physicians were slightly less likely to die in a hospital, get surgery shortly before their death or be admitted to the intensive care unit compared with the general population.<sup>1</sup> A second study also found physicians were less likely to die in a medical facility than the general population.<sup>2</sup> <http://goo.gl/Bn4ZkB>

Cont.

1. 'End-of-life care intensity for physicians, lawyers, and the general population,' *Journal of the American Medical Association*, 2016;315(3):303-305. <http://goo.gl/TdqUx8>
2. 'Association of occupation as a physician with likelihood of dying in a hospital,' *Journal of the American Medical Association*, 2016;315(3):301-303. <http://goo.gl/nCpJ8>

**N.B.** Additional articles on physician's choices in their personal end-of-life care are listed in the 25 May 2015 issue of Media Watch, #411 (p.3).

### Reasons doctors provide futile treatment at the end of life: A qualitative study

*JOURNAL OF MEDICAL ETHICS* | Online – 17 May 2016 – Doctors [i.e., study participants] attributed the provision of futile treatment to a wide range of inter-related factors. One was the characteristics of treating doctors, including their orientation towards curative treatment, discomfort or inexperience with death and dying, concerns about legal risk and poor communication skills. Second, the attributes of the patient and family, including their requests or demands for further treatment, prognostic uncertainty, and lack of information about patient wishes. Third, there were hospital factors including a high degree of specialisation, the availability of routine tests and interventions, and organisational barriers to diverting a patient from a curative to a palliative pathway. Doctors nominated family or patient request and doctors being locked into a curative role as the main reasons for futile care. A combination of strategies is necessary to reduce futile treatment, including better training for doctors who treat patients at the end of life, educating the community about the limits of medicine and the need to plan for death and dying, and structural reform at the hospital level. <http://goo.gl/K3y4Fn>

#### Selected articles on medical futility

- *MEDICAL JOURNAL OF AUSTRALIA*, 2016;204(8):318. 'What does "futility" mean? An empirical study of doctors' perceptions.' Despite a broad conceptual consensus about what futility means, doctors [i.e., study participants] noted variability in how the concept was applied in clinical decision making. More than half the doctors also identified treatment that is futile but nevertheless justified, such as short term treatment that supports the family of a dying person. [Noted in Media Watch, 9 May 2016, #461 (p.13)] <https://goo.gl/qU7Q0v>
- *JOURNAL OF MEDICINE & PHILOSOPHY* | Online – 17 December 2015 – 'Medically inappropriate or futile treatment: Deliberation and justification.' This paper reframes the futility debate, moving away from the question "Who decides when to end what is considered to be a medically inappropriate or futile treatment?" and toward the question "How can society make policy that will best account for the multitude of values and conflicts involved in such decision-making?" [Noted in Media Watch, 21 December 2015, #441 (p.14)] <http://goo.gl/0Ucl2W>
- *JOURNAL OF MEDICINE & PHILOSOPHY* | Online – 1 August 2015 – 'Laying futility to rest.' The author examines the formal structure of the concept of futility, enabling identification of the appropriate roles played by patient, professional, and society. He argues that the concept of futility does not justify unilateral decisions to forego life-sustaining medical treatment over patient or legitimate surrogate objection, even when futility is determined by a process or is subject to ethics committee review. <http://goo.gl/q2aqGd>



#### 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://goo.gl/5CHoAG>



## Determination of death and the dead donor rule: A U.S. survey of the current law on brain death

*JOURNAL OF MEDICINE & PHILOSOPHY*, 2016;41(3):237-256. Despite seeming uniformity in the law, end-of-life controversies have highlighted variations among state brain death laws and their interpretation by courts. This article provides a survey of the current legal landscape regarding brain death in the U.S., for the purpose of assisting professionals who seek to formulate or assess proposals for changes in current law and hospital policy. The public is increasingly wary of the role of organ transplantation in determinations of death, and of the variability of brain death diagnosing criteria. The authors urge any attempt to alter current state statutes or to adopt a national standard must balance the need for medical accuracy with sound ethical principles, which reject the utilitarian use of human beings and are consistent with the dignity of the human person. Only in this way can public trust be rebuilt. <http://goo.gl/L7FZ8f>

**N.B.** This issue of *Journal of Medicine & Philosophy* includes several articles on determination of death. Journal contents page: <http://goo.gl/xXQHLD>

## The Patient Care Connect Program: Transforming health care through lay navigation

*JOURNAL OF ONCOLOGY PRACTICE* (American Society of Clinical Oncology) | Online – 10 May 2016 – The Patient Care Connect Program (PCCP) is a lay patient navigation program, implemented by the University of Alabama at Birmingham Health System Cancer Community Network. The PCCP's goal is to provide better health and health care, as well as to lower overall expenditures. The program focuses on enhancing the health of patients, with emphasis on patient empowerment and promoting proactive participation in health care. Lay navigators are integrated into the health care team, with the support of a nurse supervisor, physician medical director, and administrative champion. The intervention focuses on patients with high needs to reach those with the greatest potential for benefit from supportive services. Navigator activities are guided by frequent distress assessments, which help to identify patient concerns across multiple domains, triage patients to appropriate resources, and ultimately overcome barriers to health care. <http://goo.gl/lx8Km8>

### Extract from *Journal of Oncology Practice* article

Navigator training emphasizes palliative care principles and includes development of skills to facilitate advance care planning conversations.

Noted in Media Watch, 18 January 2016, #445 (p.15, under 'Worth Repeating'):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2007;10(5):1023-1028. '**Patient navigation: A culturally competent strategy to address disparities in palliative care.**' There is growing acceptance and increasing application of patient navigation in the care of underserved populations. The roles of navigator vary across programs but usually include some degree of case management, patient education, social work, and advocacy. However, to the best of the authors' knowledge, patient navigators have not been utilized in palliative care. <http://goo.gl/yilH7h>

## Analyzing the impact of palliative care interventions on cost of hospitalization: Practical guidance for choice of dependent variable

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 18 May 2016 – The purpose of this paper is to compare three different established approaches to estimating treatment effect on hospital costs, to highlight that different approaches yield different results, and to provide some practical guidelines for investigators performing hospital cost analysis in future. Both the magnitude of an intervention's cost-saving effect and the relative impact of different interventions vary according to which dependent variable is used. Cost of hospitalization provides the most useful results of the three options for evaluating an intervention's impact on resource use. Alternative approaches visible in the literature can be misleading with respect to cost-effects. Where the intervention is first administered to different patients at different points in a hospital admission, incorporating intervention timing is essential to maximize accuracy of cost-effect estimates. <http://goo.gl/Y6RyNo>

## **Death pronouncements: Recommendations based on a survey of bereaved family members**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 May 2016 – Most of the family members who had experienced a patient's death at home were satisfied with the death pronouncement. All pronouncements were performed by physicians. Behaviors of physicians significantly positively correlated with the family-perceived necessity of improvement were that physicians acted calmly, and were not rushed. Those negatively associated were that physicians did not verify the time of death clearly, left the patient's clothes disheveled, and touched the family members' backs or shoulders as an expression of empathy. More than 90% of family members recommended that physicians act calmly, have a suitable appearance for the situation, introduce themselves to family members, explain the cause of death explicitly, and conduct a check using a light and stethoscope for death pronouncement. <http://goo.gl/ORkapt>

## **The World Report on Ageing & Health: A policy framework for healthy ageing**

*THE LANCET*, 2016;387(10033):2145-2154. Although populations around the world are rapidly ageing, evidence that increasing longevity is being accompanied by an extended period of good health is scarce. A coherent and focused public health response that spans multiple sectors and stakeholders is urgently needed. To guide this global response, WHO has released the first world report on ageing and health, reviewing current knowledge and gaps and providing a public health framework for action.<sup>1</sup> The report is built around a redefinition of healthy ageing that centres on the notion of functional ability: the combination of the intrinsic capacity of the individual, relevant environmental characteristics, and the interactions between the individual and these characteristics. This Health Policy highlights key findings and recommendations from the report. <http://goo.gl/AIYBSm>

1. *World Report on Ageing & Health*, World Health Organization, September 2015. <http://goo.gl/rxEtZV>

## **The near-failure of advance directives: Why they should not be abandoned altogether, but their role radically reconsidered**

*MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 5 May 2016 – Advance directives (ADs) have been hailed for two decades as the best way to safeguard patients' autonomy when they are totally or partially incompetent. In many national contexts they are written into law and they are mostly associated with end-of-life decisions. Although advocates and critics of ADs exchange relevant empirical and theoretical arguments, the debate is inconclusive. The authors argue that this is so for good reasons: the ADs' project is fraught with tensions, and this is the reason why they are both important and deeply problematic. They outline six such tensions, and conclude with some positive suggestions about how to better promote patients' autonomy in end-of-life decision. The authors argue that ADs should continue to be an option, but they cannot be the panacea that they are expected to be. <http://goo.gl/RxuyVt>

### **Related**

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 17 May 2016 – **'Utilization of patient electronic messaging to promote advance care planning in the primary care setting.'** Among primary care patients aged 65 years and older, use of advance directive (AD) specific electronic messaging statistically significantly increased the rate of AD completion, but the absolute number of completed AD remained relatively low. <http://goo.gl/xSKDPJ>

Noted in Media Watch, 2 May 2016, #460 (p.10):

- *PALLIATIVE MEDICINE*, 2016;30(5):421-422. **'Advance care planning: Not a panacea.'** The authors distinguish a number of steps in moving advance care planning (ACP) forward. There is a need for a broader base of evidence from methodologically sound studies such as randomized controlled trials, demonstrating the extent of effectiveness of different models of ACP. Whereas previous studies have shown beneficial effects, ACP is a complex intervention and we lack insight into which elements exactly bring these beneficial effects about and what their potential drawbacks are. <http://goo.gl/lq1LtU>

Cont.

Noted in Media Watch, 24 August 2015, #424 (p.13):

- *PALLIATIVE MEDICINE* | Online – 20 August 2015 – ‘**Does facilitated advance care planning reduce the costs of care near the end of life? Systematic review and ethical considerations.**’ Looking at the impact of advance care planning (ACP) on costs raises delicate ethical issues. Given the increasing pressure to reduce expenditures, there may be concerns that cost considerations could unduly influence the sensitive communication process, thus jeopardising patient autonomy. Safeguards are proposed to reduce these risks. The limited data indicate net cost savings may be realised with ACP. <http://goo.gl/VAFLBx>

## **The collision of care and punishment: Ageing prisoners’ view on compassionate release**

*PUNISHMENT & SOCIETY* | Online – Accessed 19 May 2016 – Most prisoners wish to spend their last days outside prison. Early release of seriously ill and ageing prisoners, commonly termed compassionate release, can be granted based on legal regulations, but is rarely successful. The aim of this paper is to present the views of ageing prisoners on compassionate release using qualitative interviews. Participants argued for compassionate release on the grounds of illness and old age, citing respect for human dignity. Their hopes of an early release, however, often contradicted their actual experiences. <http://goo.gl/yq9o0t>

### **[Prison Hospice: Backgrounder](#)**

End-of-life care in the prison system has been highlighted on a fairly regular basis in Media Watch. A compilation of articles, reports, etc., on the subject noted in past issues of the weekly report can be downloaded at the Palliative Care Community Network website: <http://goo.gl/qgd4hp>

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

### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://goo.gl/0Q1Mh4>

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://goo.gl/frPgZ5>

PALLIATIVE CARE NETWORK COMMUNITY: <http://goo.gl/8JyLmE>

PALLIMED: <http://goo.gl/7mrgMQ> [Scroll down to ‘Aggregators’ and Barry Ashpole and Media Watch]

### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: [HTTP://GOO.GL/JNHVMB](http://goo.gl/JNHVMB)

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://goo.gl/XrhYCH>

### **Canada**

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <http://goo.gl/AhlqvD>

### **Europe**

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1I9K>

U.K. | Omega, the National Association for End-of-Life Care: <http://goo.gl/UfSZtu>

## **The role of social workers in spiritual care to facilitate coping with chronic illness and self-determination in advance care planning**

*SOCIAL WORK IN PUBLIC HEALTH* | Online – 17 May 2016 – Spiritual values and beliefs of patients and families influence resilience during chronic illness and shape patient choices during advance care planning (ACP). The spiritual needs of Baby Boomers will be more diverse than previous generations, in connection with the questioning, experimental mind-set of this group, and the fact that it includes a higher proportion of immigrant populations outside the Judeo-Christian tradition. Social workers are trained explicitly to intervene with diverse populations and are well positioned to offer spiritual support in ways that do not necessarily conform to traditional religions. To the extent of their individual expertise and competence, social workers should assess and provide spiritual care to clients, including those who either are underserved or prefer not to seek assistance from clergy or chaplains because they feel alienated from religious institutions and representatives. They should also be aware of ethical dilemmas in consulting with spiritual care professionals in developing spiritual interventions. <http://goo.gl/MR3Qf3>

### **Related**

- *BMC GERIATRICS* | Online – 18 May 2016 – ‘**A knowledge synthesis of culturally- and spiritually-sensitive end-of-life care: findings from a scoping review.**’ This review highlights that most research has focused on decision-making. There were fewer studies exploring different cultural and spiritual experiences at the end of life and interventions to improve end-of-life care. Interventions evaluated were largely educational in nature rather than service oriented. <http://goo.gl/K9zKU3>

## **The changing nature of guilt in family caregivers: Living through care transitions of parents at the end of life**

*QUALITY HEALTH RESEARCH* | Online – 19 May 2016 – Older adults cared for at home by family members at the end of life are at risk for care transitions to residential and institutional care settings. These transitions are emotionally distressing and fraught with suffering for both families and the older adult. A theoretical model titled ... was developed using the method of grounded theory. When a dying parent cannot remain at home to die, family members experience guilt throughout the transition process. Findings indicated that guilt surrounding transfers escalated during the initial stages of the transfer but was mitigated by achieving what family members deemed as a “good” death when relatives were receiving hospice care. The findings of this interpretative approach provide new insights into family-focused perspectives in care transfers of the dying. <http://goo.gl/Czm91u>

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

Representative sample of recent news media coverage:

- *JOURNAL OF MEDICAL ETHICS* | Online – 13 May 2016 – ‘**Physician-assisted dying and two senses of an incurable condition.**’ It is commonly accepted that voluntary active euthanasia and physician-assisted suicide can be allowed, if at all, only in the cases of patients whose conditions are incurable. Yet, there are different understandings of when a patient’s condition is incurable. In this article, the author considers two understandings of the notion of an incurable condition that can be found in the recent debate on physician-assisted dying. According to one of them, a condition is incurable when it is known that there is no cure for it. According to the other, a condition is incurable when no cure is known to exist for it. The author proposes two criteria for assessing the conceptions and maintain that, in light of the criteria, the latter is more plausible than the former. <http://goo.gl/IMjThU>
- *PAEDIATRIC & CHILD HEALTH*, 2016;2016;21(4):181-182. ‘**Physician-hastened death in young children: Getting to underlying assumptions.**’ The authors present common issues regarding physician-hastened death (PHD), including suffering, parental autonomy and future quality of life, and examine the basic assumption in which these arguments are made. They conclude that the assumptions required are incorrect and that PHD should not be allowed in the case of children. Instead policies should continue to strive for the protection and promotion of health in all children. <http://goo.gl/PgxMLP>

N.B. Click on  Full-Text PDF

## Worth Repeating

### **Medical errors and patient safety in palliative care: A review of current literature**

*JOURNAL OF PALLIATIVE MEDICINE*, 2010;13(12):1469-1474. Recently, the discussion about medical errors and patient safety has gained scientific as well as public attention. Errors in medicine have been proven to be frequent and to carry enormous financial costs and moral consequences. The authors aimed to review the research on medical errors in palliative care (PC) and to screen relevant literature to appreciate the relevance of safety studies to the field. They found 44 articles concerning medical errors in PC, most of which were case studies. Of these, sixteen deal with PC errors as a key issue, referring mostly to symptom control. Other examples are errors in communication, prognostication, and advance care planning (ACP). Although patients in PC are more vulnerable to errors and their consequences, there is little theoretical or empirical research on the subject. The authors propose a specific definition for errors in PC and analyze the challenges of delineating, identifying and preventing errors in such key areas as prognostication, ACP and end-of-life decision-making. [Noted in Media Watch, 20 December 2010, #180 (p.8)] <http://goo.gl/xdH2gn>

#### **Related**

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 November 2012 – ‘**Errors in palliative care: Kinds, causes, and consequences: A pilot survey of experiences and attitudes of palliative care professionals.**’ Professionals acknowledge errors – in particular errors in communication – to be a common and relevant problem in palliative care, one that has, however, been neglected in training and research. [Noted in Media Watch, 12 November 2012, #279 (p.8)] <http://goo.gl/2Pc8dA>

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