

## 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

**Replicating the hospice approach: [Specialist Publications](#) and ‘Palliative care experience in the last 3 months of life: A quantitative comparison of care provided in residential hospices, hospitals, and the home from the perspectives of bereaved caregivers’ (p.7), in *American Journal of Hospice & Palliative Medicine*.**

## Canada

### What makes a life worth living? The debate behind continuing life support

*THE GLOBE & MAIL* | Online – 15 June 2017 – Over the past 20 years, neuroscientist Dr. Adrian Owen has studied many patients who are minimally conscious or in a vegetative state. To assume they’re all unhappy is “extremely naive,” he says. While these patients may not be perfectly content inhabiting seriously damaged brains and bodies, he believes one can’t assume theirs is a fate worse than death. What makes a life worth living? And at what point is it not? According to a 2013 Supreme Court decision on the fate of Toronto patient Hassan Rasouli, these questions should have been determined by the Consent & Capacity Board (CCB), an independent body created by the Ontario government. (Similar boards exist in other provinces.) While doctors said they believed Rasouli had no chance of recovery and that keeping him alive would force them to violate their obligation to do no harm, Rasouli’s wife, Parichehr Salasel, said

his life was worth preserving and that she believed life-and-death decisions should be left to God. By ruling against the doctors, the Supreme Court determined that when there’s a disagreement about whether to continue life support, the case should be heard by the CCB. If Rasouli’s case provided clarity about the legal procedure for making decisions about continuing or discontinuing life support, the ethics involved in making such decisions remain a matter of debate. <https://goo.gl/wknVxz>

### [Specialist Publications](#)

**‘Next up: A proposal for values-based law reform on unilateral withholding and withdrawal of potentially life-sustaining treatment’ (p.6), in *Alberta Law Review*.**

### Related

- *THE GLOBE & MAIL* | Online – 15 June 2017 – **‘Some unresponsive patients see, hear and comprehend more than previously thought.’** Consider what makes you the person you are: your memories, your personality, your ability to think and feel. Now imagine losing your ability to make contact with the outside world. If others could no longer tell whether you were aware of yourself and your surroundings, would you still be you? <https://goo.gl/rRqkz>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALBERTA | *The Edmonton Journal* – 15 June 2017 – **‘One year after medically assisted dying was legalized, the attitude in Alberta is less fraught than some feared.’** As of 4 June, nearly a year after federal Bill C-14 came into effect, 150 Albertans have received medical assistance to end their lives. That number – combined with relatively few complaints about the way the service has been delivered – has surprised observers who wondered how the province might respond to such a monumental shift in society’s conception of medicine. <https://goo.gl/GZ7yWP>
- QUEBEC | CBC News – 15 June 2017 – **‘2 Montrealers with degenerative diseases challenge medically assisted dying law.’** Two Montrealers with degenerative diseases are challenging both Canada’s and Quebec’s doctor-assisted dying laws. They say the laws are too limiting in their criteria of who can obtain medical assistance to die, which goes against their charter rights. This is the first Quebec Superior Court challenge to the federal law, which requires that death be reasonably foreseeable for a patient to receive aid to die. <https://goo.gl/rmTSQw>
- ONTARIO | CBC News – 13 June 2017 – **‘Doctors challenge Ontario policy requiring referral for services that clash with morals.’** The debate over Ontario doctors’ right to refuse to provide medical services that clash with their moral or religious beliefs is headed to court. A group of five doctors and three professional organizations is challenging a policy issued by the College of Physicians and Surgeons of Ontario that requires doctors who have a moral objection to the treatment sought by a patient to refer them to another medical professional who can provide the service. <https://goo.gl/oklHnE>
- CTV NEWS | Online – 12 June 2017 – **‘Hearing set on whether right to medically assisted death violated by government.’** A court hearing will determine how long grievously ill Canadians must wait to find out if their right to a medically assisted death has been violated by the federal government’s restrictive approach to the issue. The Supreme Court of British Columbia is scheduled to hear arguments ... on the government’s contention that the facts on which the Supreme Court of Canada struck down the ban on assisted dying two years ago are not applicable to the new federal law. <https://goo.gl/Aoc2zi>
- CBC | ‘The Sunday Edition’ – 11 June 2017 – **‘Two palliative care doctors talk about helping their patients to die.’** Dr. Anna Towers, a physician in Supportive & Palliative Care Services at the McGill University Health Centre in Montreal, and Dr. James Downar, a Critical Care & Palliative Care Physician at Toronto’s University Health Network and Sinai Health System, discuss about how the new law [Bill C-14] is changing the landscape for patients, their families, and for the health professionals who care for them. <https://goo.gl/BLDi5q>

### Specialist Publications

‘New frontiers in end-of-life ethics (and policy): Scope, advance directives and conscientious objection’ (p.17), in *Bioethics*.

## U.S.A.

### Some seniors just want to be left alone, which can lead to problems

KAISER HEALTH NEWS | Online – 15 June 2017 – As many as 28% of patients offered home health care when they’re being discharged from a hospital – mostly older adults – say “no” to those services, according to a new report.<sup>1</sup> Understanding why this happens and what can be done about it is important – part of getting smarter about getting older. Refusing home health care after a hospitalization puts patients at risk of a difficult, incomplete or slower-than-anticipated recovery. Without these services, older adults’ odds of being readmitted to the hospital within 30 or 60 days double, according to one study.<sup>2</sup> Why, then, do seniors, resist getting this assistance? <https://goo.gl/f6XMdX>

1. “I can take care of myself!”: Patients’ refusals of home health care services,’ United Hospital Fund and the Alliance for Home Health Quality & Innovation, May 2017. <https://goo.gl/Cq1pkm>
2. ‘Higher 30-day and 60-day readmissions among patients who refuse post acute care services,’ *American Journal of Managed Care*, 2015;21(6):424-433. <https://goo.gl/djLJnr>

## The troubling American Association for Retired Persons' long-term score card

*FORBES* | Online – 14 June 2017 – Roughly 52% of people turning 65 today will require long-term care at some point, according to the U.S. Department of Health & Human Services. The new American Association for Retired Persons (AARP) ... scorecard finds most states aren't doing a great job helping people needing such care. Overall, AARP says states have made "incremental improvements" since its 2014 Scorecard, but calls the pace of change "slow and uneven." <https://goo.gl/svHSb5>

1. 'American Association for Retired Persons Long-Term Services & Supports State Scorecard, June 2017. <https://goo.gl/nUUxJo>

## Assistance to employee caregivers good for everyone's bottom line

GOLOCAL24 | Online – 12 June 2017 – The American Association of Retired Persons (AARP) and the Respect a Caregiver's Time Coalition released a report detailing innovative practices and policies of 14 organizations to support their employees with caregiver responsibilities.<sup>1</sup> With the graying of America, supporting caregiver employees should be considered "a potentially new weapon" to attract or retain talented employees, say the researchers, by flexible work arrangements and paid leave policies. It is estimated that of the 40 million unpaid family caregivers in the U.S., 60% are employed. According to the National Alliance for Caregiving and the AARP Public Policy Institute, nearly 25% of all family caregivers are millennials, and 50% are under the age of 50. <https://goo.gl/sTLnhA>

1. 'Supporting working caregivers: Case studies of promising practices,' American Association of Retired Persons & Respect a Caregiver's Time Coalition, June 2017. <https://goo.gl/lxUOqV>

**N.B.** Selected articles on family caregivers and the workplace are noted in the 23 May 2016 issue of Media Watch (#463, p.5).

## "How long have I got, Doc?": Why many cancer patients don't have answers

*KAISER HEALTH NEWS* | Online – 12 June 2017 – Surprisingly, huge numbers of cancer patients lack basic information, such as how long they can expect to live, whether their condition is curable or why they're being prescribed chemotherapy or radiation, said Dr. Rab Razzak, director of outpatient palliative medicine at Johns Hopkins Medicine in Baltimore. The result: People with advanced cancer don't know enough about their disease to make informed decisions about treatment or how they want to spend their remaining time. "Avoiding these issues is really irresponsible," said Dr. Ira Byock, executive director at the Institute for Human Caring of Providence Health & Services... Even the oncologists who prescribe cancer treatment might not realize that so many of their patients are clueless about what's going on. Some patients approaching the end of life are in denial, assuming that they'll live much longer than is realistic. Yet doctors often have a far more pessimistic estimate of their life expectancy, said Dr. Robert Gramling, the Holly & Bob Miller chair in palliative medicine at the University of Vermont College of Medicine. In a study published last year ... only 5% of cancer

patients with less than six months to live had an accurate understanding of their illness.<sup>1</sup> Thirty-eight percent couldn't remember ever talking to their doctor about their life expectancy. And, in a 2012 study ... 69% of patients with metastatic lung cancer and 81% of people with advanced colorectal cancer thought they could still be cured, although both conditions are generally considered fatal...<sup>2</sup> Such misunderstandings can have profound consequences for patients and their caregivers. Patients who don't understand how long they have to live often choose overly aggressive therapy that can cause pointless pain and suffering. <https://goo.gl/836Aa7>

### [Specialist Publications](#)

'Early palliative care for adults with advanced cancer' (p.14), in *Cochrane Reviews*.

'Specialized palliative care in advanced cancer: What is the efficacy? A systematic review' (p.14), in *Palliative & Supportive Care*.

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1. 'Discussions of life expectancy and changes in illness understanding in patients with advanced cancer,' *Journal of Oncology*, published online 23 May 2016. [Noted in Media Watch 20 May 2016, #464 (p.3)] <http://goo.gl/K2szxn>
2. 'Patients' expectations about effects of chemotherapy for advanced cancer,' *New England Journal of Medicine*, 2012;367(17):1616-1625. [Noted in Media Watch 29 October 2012, #277 (p.2)]. <https://goo.gl/CZqfsb>

Noted in Media Watch 11 January 2016, #444 (p.9):

- *CLINICAL ONCOLOGY* | Online – 14 December 2015 – '**Prognosis, treatment benefit and goals of care: What do oncologists discuss with patients who have incurable cancer?**' In this study, there was substantial variation in the frequency of medical oncology providers discussing with patients prognosis, treatment intent and goals of care. Medical oncology documentation of prognosis, treatment benefit and goals of care was poor. <http://goo.gl/W7iooz>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- GALLUP | Online – 12 June 2017 – '**Majority of Americans remain supportive of euthanasia.**' As right-to-die legislation is under debate in many states, 73% of U.S. adults say a doctor should be allowed to end a terminally ill patient's life by painless means if the patient requests it. This is in line with the 69% to 70% Gallup has recorded since 2013, but much higher than support for euthanasia before 1990. <https://goo.gl/LejMC3>

## International

### Bereaved families criticise lack of privacy in hospitals

IRELAND | *The Irish Times* (Dublin) – 15 June 2017 – Lack of privacy, absence of palliative care at weekends, unclear communication and car parking fees were among concerns raised by people whose loved ones had died in an acute hospital. The findings are contained in a study, the largest of its kind undertaken in Ireland, of bereaved families' experience of losing someone in a hospital. The next-of-kin of 792 people who died in the Mater hospital or St James's Hospital between 1 August 2014 and 31 January 2015 were surveyed, of which 356 responded in full. The report, Voices MaJam (a combination of the names of the hospitals), finds 90% of respondents said their loved one was treated with dignity and respect, as were relatives, though some reported negative experiences. "Many highlighted good communication practices . . . However many were dissatisfied with the type and level of communication received." <https://goo.gl/V8JTRd>

**N.B.** Selected articles on hospital bereavement programs are noted in the 12 June 2017 issue of Media Watch (#516, p.6).



### [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>

## End-of-life care in England

### **Doctors let dying patients waste their last days in A&E**

U.K. (England) | *The Times* – 14 June 2017 – Tens of thousands of dying cancer patients spend their final year in and out of A&E (i.e., Accident & Emergency) because doctors are reluctant to tell them the end may be near. Some are taken to hospital every other week in pain or struggling to breathe because of a lack of proper palliative care (PC), analysis of National Health Service data shows. Patients and their families wasted precious time in a “revolving door” of emergency treatment that was unlikely to extend their lives, said campaigners. They urged the health service to stop poor coordination between hospitals and local services. One in ten hospital inpatients will die during their stay, but a review of services by the Royal College of Physicians last year found big variations, with only one in ten hospitals offering round-the-clock PC.<sup>1</sup> Researchers at Macmillan Cancer Support have looked at data on 316,000 patients with eight of the most common cancers, finding that 90% had at least one emergency visit in the last year of their life. More than 33% had to be taken to hospital five times or more, equivalent to 22,000 patients a year, the charity found. <https://goo.gl/MTMLyU>

#### [Specialist Publications](#)

“Coordinate My Care’: Enabling patient choice when it matters most’ (p.9), in *Hospital Healthcare Europe*.

1. ‘End-of-life care audit: Dying in hospital national report for England 2016,’ Royal College of Physicians, May 2016. [Noted in Media Watch 9 May 2016, #461 (p.6)] <https://goo.gl/x2qSih>

### **Palliative care services in regional New South Wales to get a \$100 million boost after outcry over system**

AUSTRALIA (New South Wales) | ABC News (Sydney) – 12 June 2017 – The New South Wales Government has announced a record \$100 million spend on palliative care services, with the focus on improving access for country families. The money will fund extra services and training for hundreds of staff over the next four years [see sidebar right]. The announcement follows protests and consultations about a lack of services in country New South Wales. The state’s Health Minister Brad Hazzard said at the moment 70% of people who want to die at home do not get their wish. <https://goo.gl/DeC5y6>

Noted in Media Watch 13 March 2017, #503 (p.5):

- AUSTRALIA (New South Wales) | ABC News (Sydney) – 6 March 2017 – ‘**Palliative care in regional New South Wales at 1960s standards, expert says.**’ One of Australia’s first specialist palliative care doctors has accused New South Wales health authorities of dropping the ball when it comes to end-of-life care. Yvonne McMaster said regional areas are faring the worst, with standards of care she has not seen since the 1960s. <https://goo.gl/OT82Ry>

### **It’s time for action to stop the inappropriate and damaging use of CPR**

IRELAND | *The Irish Times* (Dublin) – 12 June 2017 – Why has CPR become a reflex response in hospitals rather than allowing nature to take its course, even when advance directives are in place? Fear of regulators seems to be part of the problem. Consultant physician at Worthing Hospital in Sussex (England), Gordon Cauldwell, in an open letter to the General Medical Council, has called on the U.K. regulator to stop the inappropriate use of CPR. “We need to reinvigorate trust in professionalism across the health system,” Cauldwell told *The Irish Times*. He acknowledges, however, that ensuring the do not attempt cardiopulmonary resuscitation decision is readily available to hospital teams called to a patient who

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becomes unresponsive can be a challenge. Guidance at his hospital trust states: “Clear and full documentation of decisions about CPR, the reasons for them, and the discussions that informed those decisions is an essential part of high-quality care... Recorded decisions about CPR should accompany a patient when they move from one setting to another.” *British Medical Journal* columnist Iona Heath makes the point that the default position for most medical interventions is that patients have to opt in by giving informed consent for the procedure. “Why should this not be the position for CPR?” Dr. Heath asks. “Those in previously good health and who therefore have the best chance of survival after CPR would be likely to opt in without hesitation, but those already in poor health would have to be offered a realistic assessment of their prospects if they needed resuscitation.” <https://goo.gl/pwluPs>

Noted in Media Watch 6 March 2017, #502 (p.9):

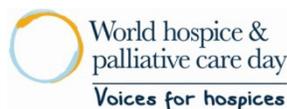
- *BRITISH MEDICAL JOURNAL* | Online – 28 February 2017 – ‘**Resuscitation policy should focus on the patient, not the decision.**’ The authors discuss the problems with current practice and outline newer approaches that place the patient, and their family, at the centre of the discussions. They focus on overall treatment plans and supporting clinicians and patients to make shared decisions about emergency treatments. <https://goo.gl/e88gY1>

**N.B.** Additional articles on resuscitation policies and practices are noted in this issue of Media Watch.

## Specialist Publications

### **Next up: A proposal for values-based law reform on unilateral withholding and withdrawal of potentially life-sustaining treatment**

*ALBERTA LAW REVIEW*, 2017;54(3):803-830. The authors attempt to take a step back from the drama and vitriol surrounding conflict that can arise when the health care team believes that treatment should not be provided and the patient’s loved ones believe that it should. They suggest and model an approach to law and policy reform in this area. To that end, the authors begin with a review of what is known about what is going on in relation to unilateral withholding and withdrawal of treatment (without the consent or knowledge of the patient or patients substitute decision-maker) demonstrating that: it is happening; it is controversial; it is being challenged in courts; and it is not being approached by the law in the same way in every country (or indeed, even in the same way within a country). They then present a process for pursuing law reform, exploring Canada as a case study, to provide a model strategy for approaching law reform in other countries and to advance the project of law reform in Canada. To that end, the authors reflect on the fundamental values that should underpin a legal framework for decision-making on whether potentially life-sustaining treatment should be withheld or withdrawn. These values and the ways to balance these values against each other are drawn from the constitution, legislation, the common law, conventions and treaties that have been ratified by Canada, and “fundamental values of Canadian society” within which the ethical debate about the unilateral withholding and withdrawal of potentially life-sustaining treatment is situated. They then develop a proposal for how the law could be reformed such that it will more closely align with the fundamental values it is supposed to serve. <https://goo.gl/9TTahg>



14 October 2017

*Universal health coverage and palliative care – Don’t leave those suffering behind*

<https://goo.gl/diYn7i>

## End-of-life care in Canada

### **Palliative care experience in the last 3 months of life: A quantitative comparison of care provided in residential hospices, hospitals, and the home from the perspectives of bereaved caregivers**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 14 June 2017 – This is one of few quantitative examinations of the care experience of patients who accessed multiple care settings in the last months of life and died in a specialized setting such as residential hospice. The findings emphasize the importance of replicating the hospice approach in institutional and home settings, including greater attention to emotional and spiritual dimensions of care. 1,153 caregivers responded to the survey (44% response rate). In addition to hospice care, caregivers reported that 74% of patients received home care, 61% had a hospitalization, 42% received care at a cancer center, and 10% lived in a nursing home. Most caregivers (84%-89%) rated the addressing of each support domain (relief of physical pain, relief of other symptoms, spiritual support, and emotional support) by hospice as either “excellent” or “very good.” These proportions were less favorable for home care (40%-47%), cancer center (46%-54%), and hospital (37%-48%). Significantly, better experiences were reported for the last week of life where hospice was considered the main setting of care, opposed to other settings. Overall, across settings pain management tended to be the highest-rated domain and spiritual support the lowest. <https://goo.gl/kp6tGb>

**N.B.** Click on pdf icon to access full text.

### **What I learned from predatory publishers**

*BIOCHEMIA MEDICA*, 2017;27(2):273-279. This article is a first-hand account of the author’s work identifying and listing predatory publishers from 2012 to 2017. Predatory publishers use the gold (author pays) open access model and aim to generate as much revenue as possible, often foregoing a proper peer review. The paper details how predatory publishers came to exist and shows how they were largely enabled and condoned by the open-access social movement, the scholarly publishing industry, and academic librarians. The author describes tactics predatory publishers used to attempt to be removed from his lists, details the damage predatory journals cause to science, and comments on the future of scholarly publishing. <https://goo.gl/wjNV3K>

#### **BIOCHEMIA MEDICA**

The latest issue of *Biochemia Medica* includes several articles on predatory journals. Contents page: <https://goo.gl/GZLYvu>

**N.B.** Additional articles on predatory journals are noted in the 15 May 2017 issue of Media Watch (#512, p.8). See also the 23 January 2017 issue of the weekly report (#496, p.1) for links to postings on ‘The Conversation’ and ‘Retraction Watch’ websites, and ‘Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals,’ International Committee of Medical Journal Editors, December 2016. <https://goo.gl/uDQePz> **BRA**

### **Related**

- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 14 June 2017 – ‘**Is this conference for real? Navigating presumed predatory conference invitations.**’ Academic conferences provide researchers with the opportunity to share their findings with other like-minded individuals. Indeed, conference attendance and, in particular, presenting at an international conference are used by some institutions as part of their decision making regarding promotions. Therefore, apart from the publish-or-perish pressure researchers face, they are also conscious of the importance of conference attendance. Unfortunately, there is a trend for some conference organizers to aggressively solicit conference abstract submissions or to widely send invited speaker requests via e-mail. These types of conference invitations have been termed as predatory because it is thought that many of these conferences fail to conduct themselves with transparency and integrity. <https://goo.gl/G8AuJi>

## The bereavement exclusion debate in the *DSM-5*: A history

*CLINICAL PSYCHOLOGICAL SCIENCE* | Online – 13 June 2017 – Beginning with the *Diagnostic & Statistical Manual of Mental Disorders* (3rd edition), depressive episodes following the loss of a loved one were considered to represent normal grief if they did not include certain severe symptoms or if they lasted less than two months. This was called the bereavement exclusion rule. A debate about whether to eliminate the bereavement exclusion became a hotly contested issue during the *DSM-5* revision process. The debate involved disagreements about which research studies were most relevant to assessing the validity of the bereavement exclusion rule, different value commitments regarding the distinction between normal and abnormal, and contrasting philosophical assumptions about the nature of psychiatric disorder. Based on a review of the arguments offered in academic journals, the blogosphere, and in the mass media, and on interviews with active participants in the debate, this article narrates a consensus history that reflects the diversity of viewpoints promoted during the debate and the diversity of views on the outcome. <https://goo.gl/fgrqoP>

Noted in Media Watch 6 February 2017, #498 (p.4):

- *AMA JOURNAL OF ETHICS*, 2017;19(2):192-198. ‘**Seeking legitimacy for *DSM-5*: The bereavement exception as an example of failed process.**’ The authors argue that while the American Psychiatric Association can claim legitimate authority for deciding scientific questions, it does not have legitimacy for resolving what is ultimately a question of ethics and public policy. They show how the “accountability for reasonableness” framework for seeking legitimacy in health policy could have been used to achieve a better resolution of the conflict than actually occurred. <https://goo.gl/NQRonp>

**N.B.** Additional articles on the *DSM-5* are noted in the 30 May 2016 issue of Media Watch (#464, p.9).

## Clinical ethics support for healthcare personnel: An integrative literature review

*HEC FORUM* | Online – 9 June 2017 – This study describes which clinical ethics approaches are available to support healthcare personnel in clinical practice in terms of their construction, functions and goals. Healthcare personnel frequently face ethically difficult situations in the course of their work and these issues cover a wide range of areas from prenatal care to end-of-life care. Although various forms of clinical ethics support have been developed, to the authors’ knowledge there is a lack of review studies describing which ethics support approaches are available, how they are constructed and their goals in supporting healthcare personnel in clinical practice. In total, 54 articles worldwide described clinical ethics support approaches that include clinical ethics consultation, clinical ethics committees, moral case deliberation, ethics rounds, ethics discussion groups, and ethics reflection groups. Clinical ethics consultation and clinical ethics committees have various roles and functions in different countries. They can provide healthcare personnel with advice and recommendations regarding the best course of action. Moral case deliberation, ethics rounds, ethics discussion groups and ethics reflection groups support the idea that group reflection increases insight into ethical issues. Clinical ethics support in the form of a “bottom-up” perspective might give healthcare personnel opportunities to think and reflect more than a “top-down” perspective. A “bottom-up” approach leaves the healthcare personnel with the moral responsibility for their choice of action in clinical practice, while a “top-down” approach risks removing such moral responsibility. <https://goo.gl/NNN2mx>

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### 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 beginning on p.18.

Noted in Media Watch 13 March 2017, #503 (p.11):

- *JOURNAL OF BIOETHICAL INQUIRY* | Online – 6 March 2017 – ‘**The role of a hospital ethics consultation service in decision-making for unrepresented patients.**’ Despite increased calls for hospital ethics committees to serve as default decision-makers about life-sustaining treatment for unrepresented patients who lack decision-making capacity or a surrogate decision-maker and whose wishes regarding medical care are not known, little is known about how committees currently function in these cases. <https://goo.gl/jRHu1y>

Noted in Media Watch 9 May 2016, #461 (p.7):

- *AMERICAN MEDICAL ASSOCIATION JOURNAL OF ETHICS*, 2016;18(5):475-478. ‘**Health care ethics committees and palliative care services.**’ Whereas palliative care (PC) cases almost always involve patients with a limited life expectancy, cases referred for health care ethics consultations involve, in addition to terminal illness, ethical issues pertaining to the entire spectrum of clinical medicine. On the other hand, PC has a clinical focus that is much broader than that of ethics committees because it is concerned with so many aspects of a patient’s care. <http://goo.gl/t5dD5d>

### End-of-life care in England

#### ‘Coordinate My Care’: Enabling patient choice when it matters most

*HOSPITAL HEALTHCARE EUROPE* | Online – 15 June 2017 – Over 500,000 people die in England & Wales every year, and almost half of those die in hospital – despite the fact that under 3% of people say that is where they want to spend their final days. Statistics such as these highlight why the Coordinate My Care service is so important, beginning in London’s Royal Marsden hospital as a way of recording an individual’s end-of-life care wishes. Now, the service not only captures patient wishes, it is sharing this information between the capital’s multiple health and care providers especially when urgent care is required, for all patients not only those who are terminally ill. Working with London’s 32 clinical commissioning groups, GPs, out of hours, 111 service providers, the London Ambulance Service, and based on InterSystems’ health information sharing platform HealthShare®, Coordinate My Care has developed into an intuitive, personalised urgent care plan that is putting patient choice at the heart of healthcare. By sharing patient wishes at times of most need, the programme is helping people receive care in the place they would like, most usually the home. And at a time of financial pressures, the programme is also saving tens of millions of pounds across the capital, and could save England’s National Health Service over £500 million if it was implemented across the country. <https://goo.gl/P4lBn7>

#### Related

- *PLOS ONE* | Online – 16 June 2017 – ‘**Factors influencing practitioner adoption of carer-led assessment in palliative homecare: A qualitative study of the use of the Carer Support Needs Assessment Tool (CSNAT).**’ This study explored practitioners’ experiences of implementing the CSNAT in palliative homecare. Not all practitioners [interviewed] appreciated that using the CSNAT required a shift towards a more person-centred approach to assessment; consequently they tagged the tool onto their existing practitioner-led practice. Practitioners who did use the CSNAT as intended were able to act as role models and support their colleagues in making this transition. <https://goo.gl/oYrpFV>

## Palliative Care Network Community

### Prison Hospice: Backgrounder

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

## End-of-life care in Hong Kong

### **Care toward the end of life in older populations and its implementation facilitators and barriers: A scoping review**

*JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION* | Online – 13 June 2017 – Thematic synthesis using 35 reports identified key features in end-of-life care (EoLC): 1) Enabling policies and environments; 2) Care pathways and models; 3) Assessment and prognostication; 4) Advance care planning and advance directives; 5) Palliative and hospice care; 6) Integrated and multidisciplinary care; (7) effective communication; (8) staff training and experience; (9) emotional and spiritual support; (10) Personalized care; and, (11) Resources. Barriers in implementing EoLC include fragmented services, poor communication, difficult prognostication, difficulty in accepting prognosis, and the curative focus in medical care. Quality EoLC for older populations requires many core components, but the local context and implementation issues may ultimately determine if these elements can be incorporated into the system to improve care. Changes at the macro-level (system/national), meso-level (organizational), and micro-level (individual) will be required to successfully implement service changes to provide holistic and person-centered EoLC for elderly populations. <https://goo.gl/dSfpLv>

Noted in Media Watch 20 February 2017, #500 (p.14):

- *JOURNAL OF POST ACUTE & LONG TERM CARE MEDICINE* | Online – 14 February 2017 – ‘**Knowledge, attitudes, and preferences of advance decisions, end-of-life care, and place of care and death in Hong Kong: A population-based telephone survey of 1,067 adults.**’ This is the first population-representative survey of the Hong Kong adult population on the knowledge, attitude, and preferences of advance directives, end-of-life care, and place of care/death. <https://goo.gl/UHHBqm>

## New York Family Health Care Decisions Act

### **A patient (not) alone**

*JOURNAL OF CLINICAL ETHICS*, 2017;28(2):117-121. This case analysis examines questions that arise when an ethically appropriate recommendation initially appears to be in conflict with the legally appropriate recommendation. The case involves a dying, incapacitated octogenarian who had friends who were willing to share her values, but not to make decisions on her behalf. These circumstances put the patient in the unique position of being legally considered a “patient alone,” but who was ethically like a patient with surrogates – distinctions that are crucial when making end-of-life decisions under the New York Family Health Care Decisions Act. A strict interpretation of the law initially seemed to be in conflict with an ethically appropriate outcome. By gaining a deeper understanding of the patient from those who cared about her, however, and by considering a broader interpretation of the law, an outcome was reached that worked within the framework of the law and honored the patient’s reported values. <https://goo.gl/7NdEr1>

## End-of-life care in Israel

### **Treatment and communication – that is what matters: An analysis of complaints regarding end-of-life care**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 15 June 2017 – Investigating complaints concerning end-of-life care (EoLC) is a necessary step for improving the quality of life at its final stage. 82.9% of survey participants [i.e., primary family caregivers of deceased patients] had complaints about the care received. Within this, 62.9% related to provision of services, 51.4% to communication, 27.1% to system issues, 15.7% to institutional issues, and 10.0% to staffing issues. Qualitative analysis revealed potential causal relationships between these end-of-life issues. The authors propose a theoretical model involving the distal factors of system, institution, and staff that impact the proximal factors of provision of services and communication. The new model has the potential to clarify directions in research, quality assessment, and intervention regarding EoLC. <https://goo.gl/7ght2d>

Cont.

Noted in Media Watch 17 March 2014, #349 (p.15)

- *SUPPORTIVE CARE IN CANCER* | Online – 4 March 2014 – ‘**Quality of dying and death with cancer in Israel.**’ This retrospective study demonstrated that the overall quality of dying and death was regarded as poor by almost half of caregivers [i.e., study participants]. These findings may reflect the relative lack of specialized palliative care and advance care planning in Israel at the time of this study, which took place between 2006 and 2009. <https://goo.gl/PPyFMq>

### **A multifactorial approach to predicting death anxiety: Assessing the role of religiosity, susceptibility to mortality cues, and individual differences**

*JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 14 June 2017 – Death anxiety is not only experienced by individuals receiving end-of-life care (EoLC), but also by family members, social workers, and other service providers who support these individuals. Thus, identifying predictors of individual differences in experienced death anxiety levels may have both theoretical and clinical ramifications. This study assessed the relative influence of religiosity, susceptibility to mortality cues, state and trait anxiety, and demographic factors in the experience of death anxiety through an online survey distributed to members of two online communities related to EoLC. Cognitive and emotional susceptibility to mortality cues, as well as gender, predicted differences in death anxiety. Conversely, religiosity and age did not increase the predictive power of the model. <https://goo.gl/59abiy>

### **France’s Claeys-Leonetti law**

#### **End of life and unreasonable obstinacy of the lawmaker**

*MÉDECINE PALLIATIVE* | Online – 12 June 2017 – This article sheds light on the founding principles of the so-called ‘Leonetti Law,’ looks briefly at the positioning of the media and the polls, and summarises the recent debates about changing this legal frame. The author comments the report of the French committee for reflection over the end of life, the opinions of the French national ethic committee ... and of a conference of citizens, as well as a recent law proposition that lead to a new law voted on 2 February 2016. The reflection focuses on the following controversial themes: early directives, sedation, assisted suicide, euthanasia. These opinions illustrate the mentality of our time that puts forward individualism rather than universal considerations, simplifying complex questions, even claiming to bring a response to all problems. Modifications of the Leonetti Law are however necessary and the author recommends an evolution which would strengthen the quality of the proposed answers by using more collegial cooperation with a wider scope of interventions and more ethical requirements. <https://goo.gl/Ms2zmc>

**N.B.** French language article.

Noted in Media Watch 23 January 2017, #496 (p.6):

- *BMC PALLIATIVE CARE* | Online – 21 January 2017 – ‘**Opinions about the new law on end-of-life issues in a sample of French patients receiving palliative care.**’ In February 2016, the French government enacted the Claeys-Leonetti law that forbade euthanasia and established the right to deep and continuous sedation for end-of-life patients. Moreover, the law also obliges clinicians to abide by any advance directives (ADs) regarding treatment and investigation, except in cases where they are “obviously inappropriate” in a given medical situation, or in cases of emergency, in order to allow medical staff to take time to assess the patient’s situation. Artificial feeding and hydration are considered as treatment. The aim of this report is to investigate individuals receiving palliative care about their opinion about euthanasia, about ADs, about the right to deep and continuous sedation, and the right to stopping artificial feeding and hydration. <https://goo.gl/u8J853>

## **End-of-life care in France**

### **Gap in end-of-life medical care at home**

*MÉDECINE PALLIATIVE*, 2017;16(3):112-119. The causes of medical abandonment in at home end-of-life situations are numerous: patients are not informed of the end of curative possibilities, preventing the anticipation of the palliative care needs at home; default of communication between hospital and city-based professionals; absence or weak involvement of the general practitioner; withdrawal of the hospital physician when there is no longer a curative possibility; and, lack of financial resources of the local actors. This article suggests a few recommendations to improve the situation. <https://goo.gl/gMndsi>

**N.B.** French language article.

#### **Related**

- *PALLIATIVE MEDICINE* | Online – 12 June 2017 – ‘**Barriers and facilitators influencing death at home: A meta-ethnography.**’ Significant variation exists in the proportion of home deaths achieved internationally, with many countries unable to meet the wishes of a large number of patients. This review builds on previous literature investigating factors influencing home death, synthesising qualitative research to supplement evidence that quantitative research in this field may have been unable to reach. <https://goo.gl/jtyzjm>

### **Is palliative care sometimes required in severe eating disorders treatment?**

*MÉDECINE PALLIATIVE*, 2017;16(3):143-151. As doctors working in a twelve-bed unit, tending to patients suffering from anorexia and bulimia in complete, long-term hospitalization, the authors were solicited by colleagues from palliative care (PC) units to tackle the question of the possible status of PC during the course of severe eating disorders treatment, on a meeting organized by the regional coordination. This text is inspired from the richness of the ensuing debates, and presents the thoughts of doctors, psychologists and nurses on the matter. They draw the common conclusion, that the nursing staff must not regard a patient refusing to feed as a will to death, and as such, as a refusal of one’s care. One must thus rethink the latter to offer a more individual and comforting approach that will allow the patient to escape this ambivalence, without risking of dragging the nursing staff into it. <https://goo.gl/0DpIC3>

**N.B.** French language article.

### **Pain management in home hospice patients: A retrospective descriptive study**

*NURSING & HEALTH SCIENCES* | Online – 13 June 2017 – The development and evaluation of evidence-based, safe, and effective home-based pain management models for caregivers implementation is receiving greater attention in the literature because of international initiatives intended to increase the number of people who receive end-of-life care in home-based settings. The purpose of this “retrospective descriptive design” study was to describe pharmacological pain management and outcomes for 40 cancer and non-cancer patients receiving hospice care at home. While the median pain score was higher at admission in the cancer group than in the hospice care at home group, the difference was not significant at or within 48 hour of admission. Overall, there was a significant decrease in pain from the first measurement to the second. Within the last seven days of life, the majority of participants were not able to provide a pain severity score when asked to evaluate the effectiveness of pain management, thus their caregiver provided a proxy evaluation. Pain management was effective in the home setting. More research is needed on the best methods to teach lay caregivers to assess pain and evaluate the effectiveness of pharmacological modalities to manage pain. <https://goo.gl/pNnKw3>

Cont.

### **Selected articles on managing end-of-life medications**

- U.K. (England) | National Institute for Health & Care Excellence (NICE) – 17 October 2016 – **‘Home care services should give people more responsibility to manage their medicines, says National Institute for Health & Care Excellence.’** In a new draft guideline being published for public consultation NICE has set out how staff can help adults who are receiving social care support at home to manage their medicines safely and correctly. [Noted in Media Watch 24 October 2016, #484 (p.5)] <https://goo.gl/sLzAyK>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 14 March 2016 – **‘Family caregivers’ pain management in end-of-life care: A systematic review.’** This review identified themes similar to previous reviews on family caregivers of patients with cancer or in palliative care: inadequate knowledge and assessment skills in pain management, misunderstanding of pain medications, and poor communication with the care team. [Noted in Media Watch 21 March 2016, #454 (p.7)] <http://goo.gl/iE15nG>
- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 25 September 2014 – **‘Managing end-of-life medications at home: Accounts of bereaved family carers.’** Although some support with medications is provided by GPs and nurses in the community, family carers take primary responsibility for drug administration and storage. They report anxiety about giving correct and timely dosages and concerns about keeping the patient comfortable without overdosing them or risking shortening their lives. [Noted in Media Watch 29 September 2014, #377 (p.9)] <http://goo.gl/bHWZCx>

### **European Certificate in Essential Palliative Care**

#### **A multi-professional educational intervention to improve and sustain respondents’ confidence to deliver palliative care: A mixed-methods study**

*PALLIATIVE MEDICINE* | Online – 12 June 2017 – Education has been highlighted as fundamental in equipping healthcare professionals with essential knowledge and skills to provide good end-of-life care. Multi-professional educational programmes have a positive influence on knowledge, attitude and confidence, but few have sought to understand the longer term impact on care delivery. The European Certificate in Essential Palliative Care is an 8-week home-study-based programme for healthcare professionals and is currently run in nine centres. Successful candidates have undertaken the course from their own countries around the world. This article describes the evaluation of the European Certificate in Essential Palliative Care, which has been evolving over 15 years. At three months, candidates had almost 20 times higher odds of being above any given level of confidence than at baseline which was sustained at six months. Qualitative analysis identified examples of increased competence and confidence improving palliative care delivery. <https://goo.gl/oTNCt1>

#### **Product or process: Cultural competence or cultural humility?**

*PALLIATIVE MEDICINE & HOSPICE CARE* | Online – 17 April 2017 – The Institute of Healthcare’s Triple Aim Initiative (TAI) identifies the improvement of patients’ experience as one of three key components necessary for optimizing the American health care and cost-delivery systems. Widely adopted today, the TAI’s focus on patient-centered care also implicitly embeds the idea of care that is culturally sensitive (CS). Perhaps nowhere in the health-care delivery system is this emphasis on patient-centered, CS care more important than for those addressing life-limiting illness or for frail elders who are coping with the advanced stages of multiple chronic conditions. These two patient populations have been the target of numerous studies in cross-cultural research, much of which has shown that dialogue surrounding palliative care and hospice is eased when caregivers, both clinical and laypersons, are CS. Cultural sensitivity supports the development of trust and rapport with patients. The crucial question is how cultural sensitivity can best be achieved when working with a diverse patient population. This editorial provides insight into the meaning of culture and to examine two leading methods for acquiring some degree of cultural sensitivity: cultural competence and cultural humility. <https://goo.gl/jaF3xJ>

## Specialized palliative care in advanced cancer: What is the efficacy? A systematic review

*PALLIATIVE & SUPPORTIVE CARE* | Online – 13 June 2017 – The authors' primary objective was to review the existing literature about specialized palliative care (SPC) and its effect on quality of life (QoL), on physical and psychological symptoms, and on survival in adult patients with advanced cancer. Six randomized controlled trials (RCTs) were selected for analysis (out of a total of 1,115 studies). Two other studies were found by hand search, one of which was only published in conference abstract form. The RCTs differed in terms of aims, interventions, control groups, and outcomes; however, the primary aim of all of them was to investigate the effect of SPC on patient QoL. Five studies found improved QoL in the intervention group. Physical symptom intensity decreased in two studies, and three studies found improved mood in the intervention group. However, physical and psychological symptoms were secondary outcomes in these studies. Survival was improved in two studies. All the studies offered generalizability, but the level of evidence validity varied among them. Due to several methodological limitations, the evidence offered in these studies ranged from low to high. The evidence in this field of study in general is still nascent, but there is growing support for the utilization of SPC to improve the quality of life of adult patients with advanced cancer. The evidence that SPC reduces physical and psychological symptoms is moderate, while the evidence that it prolongs survival is low. <https://goo.gl/AZN1fB>

### Related

- *JOURNAL OF PEDIATRIC ONCOLOGY NURSING* | Online – 10 June 2017 – '**Improving the quality of end-of-life care in pediatric oncology patients through the early implementation of palliative care.**' There are barriers to implementing palliative care (PC) for children with cancer, including the need to clarify the PC philosophy, parental acknowledgement and acceptance of a child's disease and uncertain future, nursing awareness of services, perception of availability, and a shortage of research guidance. <https://goo.gl/PuJE7p>

### Early palliative care for adults with advanced cancer

*COCHRANE REVIEWS* | Online – 12 June 2017 – This systematic review of a small number of trials indicates that early palliative care (PC) interventions may have more beneficial effects on quality of life and symptom intensity among patients with advanced cancer than among those given usual/standard cancer care alone. Although the authors found only small effect sizes, these may be clinically relevant at an advanced disease stage with limited prognosis, at which time further decline in quality of life is very common. At this point, effects on mortality and depression are uncertain. We have to interpret current results with caution owing to very low to low certainty of current evidence and between-study differences regarding participant populations, interventions, and methods. Additional research now under way will present a clearer picture of the effect and specific indication of early PC. Upcoming results from several ongoing studies and studies awaiting assessment may increase the certainty of study results and may lead to improved decision making. In perspective, early PC is a newly emerging field, and well-conducted studies are needed to explicitly describe the components of early PC and control treatments, after blinding of participants and outcome assessors, and to report on possible adverse events. <https://goo.gl/Nxer8u>

## Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

## End-of-life care for people with dementia: The views of health professionals, social care service managers and frontline staff on key requirements for good practice

*PLOS ONE* | Online – 16 June 2017 – The authors identify seven key themes which staff consider are crucial to the provision of good quality end-of-life care (EoLC) in dementia [see sidebar right]. A major implication is the need to recognise, value and better support the expertise of nursing and care home staff in this area; this should come from both within the “organisation” (by developing an ethos which values both the physical “hands on” and emotional work needed in providing such cares) and from better collaborative working with healthcare services including GPs and palliative care (PC) teams. Better quality care can be achieved by ensuring continuity of care (for example named lead care home nurse and lead GP; planned out-of-hours care), earlier more timely discussions with both people with dementia and their families to understand their personal wishes and appropriate documentation and dissemination of relevant advance care planning forms and closer, more collaborative working with specialist PC services, who provide both essential clinical advice, but also support and mentor less qualified staff. A key component of good quality EoLC in dementia is

also successful engagement with, and support of, family members both before and after the person with dementia’s death. Future research should explore how best this can be achieved within current service configuration and organisation and if new service initiatives, such as EoLC networks or community dementia PC nurses, are required above and beyond usual care to support professionals to deliver good quality care towards, and at, end of life in dementia. <https://goo.gl/YQKKsv>

### Key themes in end-of-life care for people living with dementia

- Recognising end-of-life (EoL) and tools to support end-of-life care
- Communicating with families about EoL
- Collaborative working
- Continuity of care
- Ensuring comfort at EoL
- Supporting families
- Developing and supporting staff

Noted in Media Watch 1 May 2017, #510 (p.10):

- *BMC PALLIATIVE CARE* | Online – 28 April 2017 – ‘**Palliative care for people with dementia in the terminal phase: A mixed-methods qualitative study to inform service development.**’ The European Association for Palliative Care domain of “avoiding overly aggressive, burdensome, or futile treatment” was regarded of particular relevance in the terminal phase, along with a number of recommendations that refer to providing of comfort.<sup>1</sup> <https://goo.gl/l5C3bz>

1. ‘White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care,’ *Palliative Medicine*, 2014;28(3):197-209. [Noted in Media Watch 8 July 2013, #313 (p.10)] <https://goo.gl/LoFDWE>

**N.B.** Additional articles on end-of-life care for people living with Alzheimer’s and other forms of dementia are noted in the 9 January 2017 issue of Media Watch (#494, p.8). Articles focused specifically on communications and advance care planning for this patient population are noted in the 8 May 2017 issue of Media Watch (#511, p.7).

## U.S. perspective on home-centred care

### **Integrating social services and home-based primary care for high-risk patients**

*POPULATION HEALTH MANAGEMENT* | Online – 13 June 2017 – There is a consensus that our current hospital-intensive approach to care is deeply flawed. This review article describes the research evidence for developing a better system of care for high-cost, high-risk patients. It reviews the evidence that home-centered care and integration of health care with social services are the cornerstones of a more humane and efficient system. The article describes the strengths and weaknesses of research evaluating the effects of social services in addressing social determinants of health, and how social support is critical to successful acute care transition programs. It reviews the history of incorporating social services into care management, and the prospects that recent payment reforms and regulatory initiatives can succeed in stimulating the financial integration of social services into new care coordination initiatives. The article reviews the literature on home-based primary care for the chronically ill and disabled, and suggests that it is the emergence of this care modality that holds the greatest promise for delivery system reform. In the hope of stimulat-

ing further discussion and debate, the authors summarize existing viewpoints on how a home-centered system, which integrates social and medical services, might emerge in the next few years. <https://goo.gl/4ym4MQ>

#### **Experts suggest multiple ways to reform hospice organizations**

*NEWS-MEDICAL* | Online – 15 June 2017 – The market for hospice care is growing for both eligible enrollees and providers, yet the quality of care is prone to vary, and many institutions deliver sub-optimal service, says Texas A&M University Distinguished Professor of Marketing Leonard Berry. Low-quality hospice care is often blamed on the growing market share of for-profit hospices, but Berry's research suggests that poor service quality is related to ineffective organizational leadership rather than governmental status.<sup>1</sup> <https://goo.gl/S1HPqs>

1. 'Practical ideas for improving the quality of hospice care,' *Journal of Palliative Medicine*, published online 10 February 2017. <https://goo.gl/tmfkQU>

### **The (palliative) care of Huntington's disease**

*PROGRESS IN PALLIATIVE CARE* | Online – 13 June 2017 – Palliative care (PC) services are increasingly becoming involved in the care of neurodegenerative disorders. Huntington's disease is a rare, familial disorder. Care from diagnosis is palliative. Though other specialist disciplines need to be involved, palliative expertise and oversight is valuable and appreciated. Based on a review of literature and three decades of clinical experience with over a hundred patients and their families, this article provides an overview of the PC issues confronted when attending these patients and their families. <https://goo.gl/1hsxTT>

#### **Selected articles on palliative care for patients and family living with Huntington's disease**

- *TREMOR & OTHER HYPERKINETIC MOVEMENTS* | Online – 11 April 2017 – '**Palliative care in Huntington's disease: Personal reflections and a review of the literature.**' Beyond its application at the end of life, little is known about the role of palliative care in Huntington's disease. [Noted in Media Watch 17 April 2017, #508 (p.13)] <https://goo.gl/HpvS9H>
- *JOURNAL OF HUNTINGTON'S DISEASE* | Online – 25 September 2014 – '**Perhaps the subject of the questionnaire was too sensitive: Do we expect too much too soon?**' Wishes for the end of life in Huntington disease – the perspective of physicians in 15 European countries. No abstract available. [Noted in Media Watch 6 October 2014, #378 (p.13)] <https://goo.gl/P9KwDG>
- *JOURNAL OF MEDICAL ETHICS* | Online – 22 December 2012 – '**A plea for end-of-life discussions with patients suffering from Huntington's disease: The role of the physician.**' From a qualitative study ... several ethical issues emerged. Consideration of these leads to a discussion about the role of a physician in relation to the personal autonomy of a patient. Such a discussion can raise awareness that talking about end-of-life wishes with an Huntington's disease patient is part of the legal, professional and moral responsibility of the physician. [Noted in Media Watch 24 December 2012, #285 (p.11)] <https://goo.gl/LK4EGS>

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BIOETHICS*, 2017;31(6):422-423. **'New frontiers in end-of-life ethics (and policy): Scope, advance directives and conscientious objection.'** ...the arguments against medically assisted suicide and voluntary euthanasia have lost their case, not only in peer reviewed journals, but also as far as public opinion, in most liberal Western democracies, is concerned. More jurisdictions will introduce these end-of-life options, because evidence from jurisdictions that have decriminalized shows that there has been no slippery slope to abusive practices, and because the much-maligned respect for citizens' autonomous choices turns out to be something to which we do actually ascribe high importance in liberal polities. Skirmishing activities involving vague terminology such as "human dignity" or "vulnerability" as justifications for the continuing criminalization of assisted dying have not been terribly successful. However, it would be premature to conclude that all arguments are settled now, if not in politics and law, and that, certainly in ethics, nothing much original could be added to the existing corpus of critical analysis and argument. In fact jurisdictions considering the decriminalization of medical aid in dying are grappling today with three issues that deserve further analysis. <https://goo.gl/CqMZY4>

## Worth Repeating

### **Patient-satisfaction surveys on a scale of 0 to 10: Improving health care, or leading it astray?**

*THE HASTINGS REPORT* | Online – 6 March 2015 – The current institutional focus on patient satisfaction and on surveys designed to assess this could eventually compromise the quality of health care while simultaneously raising its cost. The authors offer an overview of the concept of patient satisfaction, which remains poorly and variously defined. They trace the evolution of patient-satisfaction surveys, including both their useful and problematic aspects. The authors then describe the effects of these surveys, the most troubling of which may be their influence on the behavior of health professionals. The pursuit of high patient-satisfaction scores may actually lead health professionals and institutions to practice bad medicine by honoring patient requests for unnecessary and even harmful treatments. Patient satisfaction is important, especially when it is a response to being treated with dignity and respect, and patient-satisfaction surveys have a valuable place in evaluating health care. Nonetheless, some uses and consequences of these surveys may actively mislead health care. A critique of patient-satisfaction surveys takes into consideration three different ways patients may be "satisfied." First is the provision of medically necessary care that actually improves their outcomes. The second concerns interventions that patients or families want but that are medically unnecessary and may negatively affect health outcomes. The third category – comprising factors that are less likely to affect health outcomes but may certainly contribute to a sense of dignity and well-being – includes "humanistic" aspects of health care, such as good communication and treating patients with respect, as well as peripheral aspects, such as convenient parking and designer hospital gowns. [Noted in Media Watch 9 March 2015, #400 (pp.9-10)] <https://goo.gl/aeYW0i>

### 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.

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Cont.

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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.

### Media Watch: Online

#### **International**



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE:  
<https://goo.gl/UDj2iO>

IAHPC link updated 06.13.2017

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: <https://goo.gl/IXO4mD>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <https://goo.gl/JL3j3C>

#### **Canada**

ONTARIO | Acclaim Health (Palliative Care Consultation): <https://goo.gl/wGi7BD>  
[Scroll down to 'Additional Resources']

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <https://goo.gl/IOSNC7>

ONTARIO | Mississauga Halton Palliative care Network: <https://goo.gl/ds5wYC>

#### **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/5d1l9K>

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

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