

## 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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The illness experience: Scroll down to [Specialist Publications](#) and 'Compassion in palliative care: A review' (p.8), in *Current Opinion in Supportive & Palliative Care*.

## Canada

### How close is your death? New algorithm can tell patients how long they have to live

ONTARIO | *The Ottawa Citizen* – 12 October 2018 – Researchers at Ottawa's National Centre for Individualized Health have developed an algorithm that predicts how many months, or years, patients near the ends of their lives have to live. It is information some people might not be comfortable with, acknowledged Dr. Peter Tanuseputro, an investigator at the Bruyère Research Institute and family doctor who offers house calls to his palliative patients. But he believes many elderly patients will want to know exactly how long they have to live, information not currently available for most. He also said everyone deserves access to the information, based on an individual's health information and data collected across Ontario. Among other things the end-of-life calculator can lead to is more appropriate care and more people benefiting from palliative care. Only 15% of Canadians receive palliative care, according to recent data released from the Canadian Institute for Health Information.<sup>1</sup> Even those who do often get it too late, said Tanuseputro. "In Canada, we don't like to talk about death and dying," he said. "We think patients have the right to their own information to tell them about what is going to happen to them. We still live in a paternalistic society

where we don't think the patient can handle that information or don't think they should have this information." The algorithm was developed using data collected through the province's health system. <https://goo.gl/5M24Nu>

### [Specialist Publications](#)

'Does informal care impact utilisation of home-based formal care services among end-of-life patients? A decade of evidence from Ontario, Canada' (p.10), in *Health & Social Care in the Community*.

'Improving end-of-life care and advance care planning for frail older adults in Canada' (p.13), in *Journal of Frailty & Aging*.

'Medical assistance in dying: Canadian registry recommendations' (p.17), in *Alberta Law Review*.

'An ethical-legal analysis of medical assistance in dying for those with mental illness' (p.17), in *Alberta Law Review*.

1. 'Access to Palliative Care in Canada,' Canadian Institute for Health Information, 2018. [Noted in 24 September 2018 issue of Media Watch (#582, p.1)] **Download/view at:** <https://goo.gl/xSmLrB>

## New report highlights the lived experience of breast cancer patients across Canada

CANADIAN BREAST CANCER NETWORK | Online – 10 October 2018 – The report provides the comprehensive perspective of almost 500 Canadian women who have experienced a breast cancer diagnosis. Patients and survivors diagnosed with both early stage and metastatic (stage IV) breast cancer, share their experiences with the process of being diagnosed, making treatment decisions, accessing clinical trials, the psychosocial and financial impact, accessing palliative care [see sidebar] and managing survivorship challenges. Through their experiences, patients identify current gaps when it comes to meeting the needs of breast cancer patients. This is the first Canadian report to share the experiences of early stage patients in parallel with metastatic breast cancer patients; creating a greater understating of the similarities and differences between both groups. **Download/view at:** <https://goo.gl/fj5U3Y>

### ***Breast Cancer: The Lived Experience: Palliative care (pp.41-42)***

There is increasing evidence that demonstrates the importance of early access to palliative care (PC) to improve quality of life while living with metastatic breast cancer, not just at the end of life.<sup>1</sup> When asked if anyone from their health care team had spoken to them about PC 26% of respondents indicated that someone had this conversation with them; 73% of respondents answered no; and 1% of respondents didn't remember. When asked if they had accessed PC, 16% of respondents shared that they had, while 80% indicated they had not, and 4% didn't know.

1. 'Is palliative care support associated with better quality end-of-life care indicators for patients with advanced cancer? A retrospective cohort study,' *BMJ Open*, published online 31 January 2018. [This U.K. Study noted in 5 February 2018 issue of Media Watch (#549, p.6)] **Full text:** <https://goo.gl/Ha3vQU>

Noted in Media Watch 30 April 2018 (#561, p.12):

- *MEDSCAPE MEDICAL NEWS* | Online – 25 April 2018 – '**The palliative care questions to ask every advanced breast cancer patient.**' Despite the proven benefits of early palliative care (PC) for oncology patients, integration of PC remains a challenge. At Johns Hopkins Medicine, the Time, Education, Assessment & Management approach, which requires approximately one hour of additional time with the patient each month, is being used to improve oncology outcomes by incorporating PC in practice for patients with advanced breast cancer. **Full text:** <https://goo.gl/RQRSuo>

Noted in Media Watch 6 November 2017 (#537, p.7):

- *BREAST CANCER RESEARCH & TREATMENT* | Online – 30 October 2017 – '**The value of embedding: Integrated palliative care for patients with metastatic breast cancer.**' Little is known about palliative care (PC) among patients who die from metastatic breast cancer. In the 18-month study period, oncologists referred for PC 105 of their 515 patients; 59 patients were seen by a PC physician. Of the 38 referred patients who died, 23 were seen by embedded PC and all 23 received PC within 90 days of death. **Abstract (inc. list of references):** <https://goo.gl/TVuk7L>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | *The National Post* (Toronto) – 9 October 2018 – '**Toronto's Sick Kids hospital preparing policy for euthanasia for youth over 18 that could one day apply to minors.**' A team at Toronto's Hospital for Sick Children has developed a draft policy on doctor-assisted dying that applies to youth aged 18 and older – the legal age restriction for "medical-aid [*sic*] in dying," or MAiD, in Canada. However, the policy was also developed "with an eye to a future when MAiD may well become accessible to capable minors," the team of bioethicists, palliative care doctors and others report...<sup>1</sup> The Sick Kids' working group says the hospital has willing doctors who could "safely and effectively" perform euthanasia for terminally ill youth 18 and older who meet the criteria as set out in federal law, and that it would be "antithetical" to its philosophy of care to have to transfer these patients to a strange and unfamiliar adult hospital. But it is a suggestion that euthanasia might one day take place without the involvement of parents that has provoked fresh controversy in the assisted-death debate. <https://goo.gl/2GNjbm>

1. 'Medical assistance in dying at a paediatric hospital,' *Journal of Medical Ethics*, published online 21 September 2018. [Noted in 24 September 2018 issue of Media Watch (#582, p.18)] **Abstract:** <https://goo.gl/VEogod>

## U.S.A.

### Medicare may be spending far less on end-of-life patients than we think

*FORBES* | Online – 11 October 2018 – One-quarter of Medicare spending is for patients in the last year of life. It is cited as a major reason for excessive medical spending in the U.S. and leads to a widely-accepted conclusion: If only we would stop “wasting” dollars on futile care for those who soon will die anyway, we could significantly slow medical cost growth. But what if the entire premise of this argument is wrong? What if Medicare spends just a small fraction of its resources on those who are expected to die? An important study concludes that only 5% of Medicare dollars – not 25% – is spent on individuals who were predicted to die.<sup>1</sup> Thus, controlling end-of-life (EoL) costs may do much less to reduce projected medical spending in the U.S. than conventional wisdom claims. The research ... provides important statistical support to buttress an argument that a handful of health policy experts ... have been making for years: Using spending in the last year of life as a proxy for futile care is deeply flawed – because we are very bad at predicting who is going to die and who is not. As the authors write, the “common interpretations of EoL spending flirt with a statistical fallacy: Those who end up dying are not the same as those who were sure to die.” Thus,

much of the care we provide in what turns out to be the last year of life may not be futile at all, based on what doctors know at the time they are treating their patients. Many who are expected to die within, say, a year, don't. And many who are not expected to die within that time frame do. <https://goo.gl/shmmwv>

#### Specialist Publications

**'Predictors of reliably high-value end-of-life care'** (p.8), in *Current Opinion in Supportive & Palliative Care*.

**'How much end-of-life care is of low value?'** (p.10), in *Internal Medicine Journal*.

**'Palliative care: Medically futile and potentially inappropriate therapies of questionable benefit'** (p.16), in *UpToDate*.

**'Advance directives for refusing life-sustaining treatment in dementia'** (p.17), in *The Hastings Report*.

1. 'Predictive modeling of U.S. health care spending in late life,' *Science*, 2018;360(6296):1462-1465. [Noted in the 2 July 2018 issue of *Media Watch* (#570, p.3)] **Abstract:** <https://goo.gl/LioPPT>

Noted in *Media Watch* 10 July 2017 (#520, p.10):

- *HEALTH AFFAIRS*, 2017;36(7):1211-1217. **'End-of-life medical spending in last twelve months of life is lower than previously reported.'** The authors used detailed health care data for the period 2009-2011 from Denmark, England, France, Germany, Japan, The Netherlands, Taiwan, the U.S., and the Canadian province of Quebec to measure the composition and magnitude of medical spending in the three years before death. Data suggests that high aggregate medical spending is due not to last-ditch efforts to save lives, but to spending on people with chronic conditions, which are associated with shorter life expectancies. **Full text:** <https://goo.gl/7dBtVi>



#### 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>

## Texas judge denies order to keep nine-year-old girl on life support

TEXAS | KGNS-TV News (Fort Worth) – 11 October 2018 – The parents of a nine-year-old girl who was declared brain dead by a Fort Worth hospital have been denied a temporary restraining order extension that would keep their daughter on life support. A judge ruled the hospital will not be forced to keep the little girl's ventilator on after Monday; however, her fate remains unclear. Nine-year-old Payton Summons has been on life support at Cook Children's Medical Center for over two weeks after she went into cardiac arrest. Doctors say they also found a tumor in her chest when she was brought into the hospital. Payton's parents say she still has a heart-beat, and that she is still alive. An attorney that represents the hospital says she is brain dead

which means she is legally dead and argues that she should be removed from the ventilator. However, a temporary 14 day restraining order issued 1 October has prevented them from doing so. The hospital has been looking for another facility for Payton to go to during this time; so far, they have contacted 28 facilities, all of which have declined. <https://goo.gl/VVde9c>

### [Specialist Publications](#)

'Unilateral withdrawal of life-sustaining therapy in a severely impaired child' (p.15), in *Pediatrics*.

Noted in Media Watch 8 October 2018 (#584, p.3):

- TEXAS | *The Texas Tribune* (Austin) – 3 October 2018 – **'The hospital says she's brain-dead. Her parents say she's alive. Who decides when to take her off the ventilator?'** If 9-year-old Payton Summons were lying in a hospital bed in Oklahoma, her parents would have more control over the ventilator that's currently breathing for her. But 100 miles south in Fort Worth, it's largely left up to her doctors. Summons' doctors want to take her off the ventilator. Her parents are adamantly opposed. And Texas law favors the positions of the doctors. <https://goo.gl/kVBcyM>

## Lessons Learned from Payer-Provider Partnerships for Community-Based Palliative Care

CALIFORNIA HEALTH CARE FOUNDATION | Online – Accessed 10 October 2018 – Despite evidence of the benefits of community-based palliative care (CBPC) and data indicating that our current capacity is insufficient to meet the need, growth of these services has likely been slowed by the lack of adequate, defined funding streams. To address this challenge, from 2014 to 2017, the Foundation supported a planning and implementation process for six teams of payer and provider organizations committed to strengthening and spreading CBPC services in California. Participating providers included large academic medical centers, hospices, and a specialty palliative care practice, while the payers included national insurers, regional insurers, and a Medicaid managed care plan. Payer-provider teams participated in a six-month planning process during which they developed operational and financial plans for delivering palliative care services in community settings (clinics, patient homes, and tele-visits), followed by a 24-month implementation phase where contracts were executed and services were launched. This kind of collaboration between payers and providers is an emerging trend in CBPC, and our grantees were among the first to participate in such efforts. Lessons learned from the initiative that address the process of developing and enacting an agreement to deliver CBPC are reviewed. **Download/view at:** <https://goo.gl/CSgeKr>



## The cost of not talking about death to dying patients

WASHINGTON DC | *The Hill* – 8 October 2018 – Will you know when it is your time to die? It is a question that has permeated my mind since 14 July 2017. This was the day my mother died. It was a sad day, but it pales in comparison to the months preceding it. A breast cancer that had returned aggressively, a hasty port placement to receive chemotherapy that was too late and an intensive care unit admission that began many futile interventions that never saved her life, but prolonged my mother's suffering. As a registered nurse, I watched a scene unfold that I swore to myself I would never let happen to anyone I loved.

Cont.

Yet, there I was listening to an oncologist discuss a 30% chance she would respond to chemo (which did not mean she would be cured) and choosing this inappropriate treatment for my critically-ill mother. I was party to these decisions when my mother couldn't make them and when she made some recovery in her mental status, she also chose to continue treatments. Were these decisions well founded? They were missing a key piece of information, that even with my training, I failed to see. My mother was dying. She was dying and none of my mother's care providers were able to say those words. Would my family have chosen a different path for my mother, if there had been a more explicit conversation? If my mother's healthcare providers would have had a deliberate discussion about her impending death my family would never have chosen chemotherapy and instead chose to initiate hospice care. <https://goo.gl/GX6cu2>

Noted in Media Watch 19 February 2018 (#551, p.8):

- **BMJ SUPPORTIVE & PALLIATIVE CARE** | Online – Accessed 17 February 2018 – ‘**End-of-life chemotherapy: A prisoner's dilemma?**’ Despite much attention focused on end-of-life chemotherapy, many patients continue to receive chemotherapy late into their illness, providing minimal benefit and potentially causing harm. The authors describe the prisoner's dilemma, in the context of palliative oncology, as a framework to partially explain this finding. They believe that this novel perspective will provide valuable and interesting insights to practising clinicians. Almost 10% of patients receive chemotherapy within two weeks of dying of cancer, and 60% receive treatment within two months of death. **Introductory paragraphs:** <https://goo.gl/HUUD2A>

Noted in Media Watch 18 September 2017 (#530, p.12):

- **EXPERT REVIEW OF QUALITY OF LIFE IN CANCER CARE** | Online – 11 September 2017 – ‘**Gaps in patients' understanding of palliative chemotherapy. Can we better communicate that treatment is not curative?**’ Misunderstanding in cancer patients receiving chemotherapy is common; 50% of cancer chemotherapy is given with palliative intent. Many patients receiving chemotherapy for incurable cancer may not understand that chemotherapy is unlikely to be curative. Cancer patients expect to share treatment decisions with their oncologist. Provision of a question prompt list and endorsement by physicians enhances patient participation in consultations and promotes patient questions about prognosis. **Abstract (w. link to references):** <https://goo.gl/9bsihL>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- **WASHINGTON DC | The Daily Caller** – 10 October 2018 – ‘**Family physicians association breaks ranks, no longer opposed to assisted suicide.**’ The American Academy of Family Physicians (AAFP) announced that it no longer opposes physician-assisted suicide (PAS), instead taking a neutral position on the matter. AAFP's adoption of “engaged neutrality” regarding PAS signals a marked split from the American Medical Association.<sup>1</sup> AAFP president Michael Munger announced the change. The committee also recommended the procedure be referred to as medical-aid-in-dying as opposed to PAS.<sup>2</sup> “Through our ongoing and continuous relationship with our patients, family physicians are well-positioned to counsel patients on end-of-life care, and we are engaged in creating change in the best interest of our patients,” Munger said in a statement. California, New Mexico, New York and Washington Academies of Family Physicians have introduced the measure that AAFP delegates approved. Any resolution departing from AMA's Code of Ethics requires a two-thirds vote by the Academy's Congress of Delegates. <https://goo.gl/VcsWk2>



1. ‘Physician-Assisted Suicide,’ American Medical Association. **Download/view at:** <https://goo.gl/JxYPkm>
2. ‘Congress of Delegates addresses medical-aid-in-dying,’ American Academy of Family Physicians, 10 October 2018. <https://goo.gl/YviDVn>

Noted in Media Watch 18 June 2018 (#568, p.3):

- U.S. | *The Washington Post* – 11 June 2018 – ‘**American Medical Association to keep reviewing its opposition to assisted death.**’ Following a debate on whether the nation's most prominent doctors' group should revise its Code of Medical Ethics, the House of Delegates voted by a margin of 56 to 44% to have the Association's Council on Ethical & Judicial Affairs keep studying the current guidance. <https://goo.gl/reRY19>

## International

Extract from an interview with palliative care specialist Amin Lamrous

### **Palliative care: “Our mission is also to alleviate suffering”**

MÉDECINS SANS FRONTIÈRES (MSF) | Online – 12 October 2018 –Because of the type of organisation we are, we work in very difficult contexts – in armed conflicts, on frontlines, in emergencies. In addition, in many of these contexts, people already struggle to access or can’t access the healthcare they need. Suffering is the order of the day. Our teams witness that suffering, and on many occasions they can’t do much in the curative sense. But we can’t close our eyes either. PC is part of our response, as an organisation, to that suffering. Of course, we need to keep improving what we do, we need to put pressure on others to achieve changes that will improve the lives of these people, we need to explain what happens to them. But we must also do something for those who are already sick and have no other options. The objective of humanitarian aid is to save lives, but also to alleviate suffering. For example, imagine a man with advanced cancer who lives in a remote village in South Sudan and arrives at the MSF hospital in the area. Normally, the patient would be referred to a hospital in the capital. But if we know that the curative surgery that he would need is not available even in the capital, what do we do? Do we refer him anyway, knowing the suffering he and his family will face? In our hospital, we can provide psychological support to both him and his family, we can offer treatment to relieve pain, etc. What we can’t do is close our eyes and simply send him to the hospital in the capital to avoid having to deal with such a painful situation. <https://goo.gl/XVSP73>



Noted in Media Watch 1 October 2018 (#583, p.6):

- WORLD HEALTH ORGANIZATION | Online – Accessed 25 September 2018 – ‘**Integrating palliative care and symptom relief into responses to humanitarian emergencies and crises.**’ Current responses to humanitarian emergencies and crises rightfully focus on saving lives, but for both ethical and medical reasons the prevention and relief of pain, as well as other physical and psychological symptoms, social and spiritual distress, also are imperative. Therefore, palliative care (PC) should be integrated into responses to humanitarian emergencies and crises. Principles of humanitarianism and impartiality require all patients receive care and should never be abandoned for any reason, even if they are dying. There is significant overlap in the principles and mission of PC and humanitarianism: relief of suffering; respect for the dignity of all people; support for basic needs; and, accompaniment during the most difficult of times. **Download/view at:** <https://goo.gl/tdnWUB>

**N.B.** Additional articles on the provision of palliative care during humanitarian crises or natural disasters noted in this issue of Media Watch.

### End-of-life care in South Korea

#### **Over 20,000 refuse life-prolonging treatment since law change**

SOUTH KOREA | *The Chosunilbo* (Seoul) – 10 October 2018 – More than 20,000 Koreans have chosen to refuse life-prolonging treatment since the law changed to permit living wills to that effect earlier this year after a three-month trial run. The Ministry of Health & Welfare reports that 20,742 people opted to discontinue life support treatment from February until last Wednesday [3 October 2018]. One out of three patients gave doctors permission to discontinue life support when their illnesses became terminal, and the families of two out of three terminally ill patients chose death with dignity for their loved ones. The rest had made a living will in advance. Yun Young-ho at Seoul National University’s College of Medicine said; “The changes are interesting, but the numbers are insufficient to say that death with dignity has taken root in this country.” <https://goo.gl/M22M8S>

## End-of-life care in Ireland

### **Voluntary hospice calls for guaranteed minimum State funding**

IRELAND | *The Irish Times* (Dublin) – 8 October 2018 – Voluntary hospices should be guaranteed minimum State funding to meet the growing palliative care (PC) needs as people are living longer with terminal diseases, according to a leading hospice. The Marymount Hospice in Cork helped 1,500 people in 2008, but it is now treating 3,000 people, according to the hospice's chief executive Sandra McCloskey. By 2021, the number of over-65s will have grown by 36%, she said, leading to increased demand for PC. "We are living longer with higher levels of chronic illness," she said. "Our ageing population will drive a large increase in the number of new cancers leading to increased need to access specialist PC." Hospices are "genuinely indebted" to

voluntary fundraisers, who raise up to a third of their spending annually, said Dr. McCloskey. "Each hospice currently raises a minimum of between €2 million and €4 million each year for operations. Without reaching this target, services would have to be curtailed." <https://goo.gl/fqYYj1>

#### [Specialist Publications](#)

'Improvements are needed in end-of-life care: Ombudsman' (p.11), in *The Irish Medical Times*.

'Providing hospice care to Ireland's children' (p.12), in *The Irish Medical Times*.

## End-of-life care in England

### **Hospices care for 200,000 people a year, but they're powered by voluntary effort**

U.K. (England) | *The Guardian* (London) – 8 October 2018 – Hospice Care Week ... is at least as much a fundraiser as a celebration: although hospices have made themselves indispensable providers of free palliative and end-of-life care, they continue to rely on the goodwill of their local communities to keep going. On average, they receive only a third of their funding from the state; children's hospices get even less. And for most, that contribution has been shrinking. In 2016-2017, two in three hospices in England reported that their state funding, which comes typically from local National Health Service commissioners, had been frozen or cut. Almost 80% said they had been forced to rely more on charitable giving, and more than half had dipped into reserves. A third had resorted to imposing a pay freeze on staff. Jonathan Ellis, director of advocacy and change at Hospice UK, which represents more than 200 hospice services, says that while the sector does not expect (or indeed want) full funding, it needs a better balance of statutory and voluntary income. "It staggers even ministers when we say our members have to fundraise £1 billion every year just to maintain their services." <https://goo.gl/AnkCfU>

**N.B.** Embedded in the article posted on *The Guardian* website is a link to an undated Hospice UK document, 'Commissioning and statutory funding arrangements for hospice and palliative care providers in England 2017.' To access click on the phrase "two in three hospices in England reported."

Noted in Media Watch 16 April 2018 (#559, p.12):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 April 2018 – '**What is the cost of palliative care in the U.K.? A systematic review.**' The data are limited, and the heterogeneity is such that it is not possible to provide an aggregate cost of palliative care (PC) in the U.K. It is notable that the costs of hospice care and informal care are often neglected in economic studies. Further work is needed to address methodological and practical challenges in order to gain a more complete understanding of the costs of PC. **Abstract:** <https://goo.gl/RVeYX7>



#### 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.19.

## Specialist Publications

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

#### **Predictors of reliably high-value end-of-life care**

*CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE* | Online – 8 October 2018 – This review demonstrates the efficacy of a range of approaches to improve value of care at the end of life (EoL), both within the health system and across public policy sectors. Care near the EoL is expensive and frequently not aligned with the expressed preferences of decedents, creating an opportunity to improve value, or increase quality while lowering cost. This review examines publications from 2017 and 2018 on interventions and policies associated with high-value EoL care. Innovations in video and web-based advance care planning are promising to improve preference-congruent care at low cost. The patterns of care within hospice and in particular increased investment in patient care in hospice are shown to improve value. A meta-analysis demonstrated the role of inpatient palliative care (PC) consultations in decreasing hospitalization costs, as did several studies on inpatient PC units. Internationally, a range of home-based PC programs, implemented at the population level, demonstrated cost savings and reduced intensive care near the EoL. Finally, public policies that funded medical and long-term care and address broader inequalities were demonstrated to decrease low-value care near the EoL. **Abstract:** <https://goo.gl/wX9KoE>



#### **Compassion in palliative care: A review**

*CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE* | Online – 8 October 2018 – This article provides a general review of the current understanding of compassion in palliative care (PC) and summarizes emergent compassionate initiatives in PC at three interdependent levels: compassion for patients, compassion in healthcare professionals, and compassionate communities at the end of life (EoL). Compassion is a constructive response to suffering that enhances treatment outcomes, fosters the dignity of the recipient, and provides self-care for the giver. Patients and healthcare professionals value compassion and perceive a general lack of compassion in healthcare systems. Compassion for patients and for professionals' self-care can be trained and implemented top-down (institutional policies) and bottom-up (compassion training). "Compassionate communities" is an important emerging movement that complements regular healthcare and social services with a community-level approach to offer compassionate care for people at the EoL. Compassion can be enhanced through diverse methodologies at the organizational, professional, and community levels. This enhancement of compassion has the potential to improve quality of PC treatments, enhance healthcare providers' satisfaction, and reduce healthcare costs. **Abstract:** <https://goo.gl/zDrX8F>

Noted in Media Watch 2 July 2018 (#570, p.10):

- *JOURNAL OF MEDICAL ETHICS* | Online – 28 June 2018 – '**Psychological perspective on compassion in modern healthcare settings.**' The typical organisational set-up of a modern healthcare setting seriously undermines compassionate care. Organisational features frequently associated with uncompassionate care include understaffing of hospital wards, excessive working shift patterns and the dogged focus on achieving service efficiencies – each contributes to the alarming breakdown of compassionate care at the centre of several healthcare failings. **Abstract:** <https://goo.gl/NPTnCp>

Noted in Media Watch 28 Mat 2018 (#565, p.15):

- *PLOS ONE* | Online – 17 May 2018 – '**The colours and contours of compassion: A systematic review of the perspectives of compassion among ethnically diverse patients and healthcare providers.**' Synthesis of the literature identified the perspectives, facilitators and barriers of compassion in healthcare within different ethnic groups. Compassion was described as being comprised of healthcare provider virtues (honesty, kindness, helpful, non-judgment) and actions (smile, touch, care, support, flexibility) aimed at relieving the suffering of patients. **Full text:** <https://goo.gl/LyayzV>



## Palliative care teaching shapes medical undergraduate students' professional development: A scoping review

*CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE* | Online – 8 October 2018 – To study palliative care (PC) teaching medical undergraduate students' learning experiences, the authors employed the medical teaching concept, "hidden curriculum," as a way of describing attitudes and behavior conveyed implicitly by PC educators. Fifteen studies were selected: ten of those studies used a qualitative approach; two are theoretical explanations of the topic explored, one guideline, one review and just one quantitative study, made up the review. Medical undergraduate students reported that after PC teaching, they felt they had acquired better attitudes for effective integration with the patient, such as empathy or holistic care; ethical principles, such as respect or humanization of their clinical practice; and commitment to an improvement in competences, such as self-awareness or self-esteem. They also reported improved behavior in effective integration with patients, such as communication, caring for patients' families, and when addressing psychosocial, cultural and spiritual aspects; their commitment to improvement in competences, such as dealing with emotions and uncertainty; they learned team work as an effective way to interact within the health system; and to become more reliable, making themselves more available and dedicating enough time to each patient. **Abstract:** <https://goo.gl/ZBXwwZ>

## Danish medical schools do not meet international recommendations for teaching palliative medicine

*DANISH MEDICAL JOURNAL*, 2018;65(10);A5505. Denmark has been ranked low regarding the extent of teaching in palliative care (PC) at medical schools, although the Danish Health Authority recommends that all doctors have basic knowledge of PC. The authors investigated the contents of and time spent on teaching in PC at the four Danish medical schools and compared results with recommendations from the European Association of Palliative Care (EAPC). Teaching in palliative medicine is generally sparse and mainly deals with pain management and general aspects of PC. Compared to EAPC recommendations [see sidebar], teaching in, for example, ethics, spirituality, teamwork and self-reflection is lacking. Furthermore, PC training does not reach the recommended minimum of 40 hours, and examinations in PC are not held. As from the autumn of 2017, the University of Southern Denmark has offered a course that expands teaching in PC and thereby improves compliance with EAPC recommendations; the remaining three medical schools do not, to the authors knowledge, have any specific plans to increase the extent of teaching activities in palliative medicine. **Full text:** <https://goo.gl/thzjNH>

The European Association of Palliative Care recommendations	
<i>Domains</i>	
I	Basics of palliative care
II	Pain and symptom management
III	Psychosocial and spiritual aspects
IV	Ethical and legal issues
V	Communication
VI	Teamwork and self-reflection
<i>Learning goals</i>	
1.	To show that medical treatment is far beyond diagnostic investigations and healing, the patient is meant to be considered, cared for and treated holistically
2.	To show how to relieve symptoms (pain and others) by pharmacological and non-pharmacological means
3.	To show that palliative care of patients and their relatives is a process that does not only include crisis intervention but also includes anticipatory treatment and attention
4.	To show that care and treatment have to be adopted to meet the individual needs, wishes and values of individual patients and their relatives
5.	To show that the quality of end of life care for patients will only succeed if the attending doctors are able to reflect upon their own attitude towards disease, dying, death and mourning
6.	To show that the quality of medical treatment cannot only be improved by enlarging knowledge but also by the competence of team-working, communication and the willingness to discuss ethical issues

Noted in Media Watch 23 October 2017 (#535, p.4):

- DENMARK | *The Copenhagen Post* – 20 October 2017 – 'People increasingly prefer to die at home, study shows.' Figures revealed in *Momentum*, the newsletter sent out by Kommunernes Landsforening, the umbrella organisation for municipalities, show that the number of Danes dying in hospital or a hospice over the last 35 years has fallen from 54 to 43%. More specifically, the figure for people dying at home, in an old peoples' home, or other place outside hospital, was 57% in 2016. Experts feel that the health system and the municipalities can do a lot more to assist people with a dignified death in familiar surroundings. <https://goo.gl/h9ypF5>

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Noted in Media Watch 5 June 2017 (#515, p.13):

- *ACTA ONCOLOGICA* | Online – 30 May 2017 – ‘**Admittance to specialized palliative care of patients with an assessed need: A study from the Danish palliative care database.**’ Admittance to specialized palliative care (SPC) has been discussed in the literature, but previous studies examined exclusively those admitted, not those with an assessed need for SPC, but not admitted. Admittance was higher for younger patients (e.g., 50-59 versus 80+ years). This first nationwide study of indicates prioritization of limited resources means certain sub-groups with a documented need have reduced likelihood of admission to SPC. **Full text:** <https://goo.gl/2AjSJK>

**N.B.** Denmark was ranked 19th of 80 countries surveyed in the ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit. [Noted in 12 October 2015 issue of Media Watch (#431, p.6)] **Download/view at:** <https://goo.gl/PPu7rG>

### **Lessons from filial piety: A social-life-span approach to building the connection that survives death**

*DEATH STUDIES* | Online – 8 October 2018 – The purpose of this article is to unpack concepts surrounding “the connection that survives death” between living people and the deceased. The study was designed as the qualitative arm of an integrated project on filial piety in contemporary times, and data were collected from 17 interviews with Korean human service professionals from Australia, New Zealand and Korea. The findings from the study indicate that the connectedness with the dead is an important part of the participants’ mental and social lives, and this post-mortem relationship can be embodied through practising “memorial piety” and “memorial work.” **Abstract:** <https://goo.gl/rd73RW>

### **Does informal care impact utilisation of home-based formal care services among end-of-life patients? A decade of evidence from Ontario, Canada**

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 11 October 2018 – This article aims to assess the relationship between informal and formal home care among home-based end-of-life (EoL) patients and how this relationship has changed over the last decade and over the EoL trajectory. The authors focus on informal care provided by family members or friends, and three types of home-based formal care services: care by personal support workers, physician visits, and nurse visits. Using survey data collected in a home-based EoL care programme in Ontario, Canada from 2005 to 2016, they build a two-part utilisation model analysing both the propensity to use each type of formal care and the amount of formal care received by patients. The results suggest that informal care is a substitute for care by personal support workers, but a complement to physician visits and nurse visits. In the case of nurse visits, an increased complementary effect is observed in more recent years. For home-based physician and nurse visits, the complementary effect grows with patient’s proximity to death. These findings highlight the complexity of the relationship between informal and formal care among home-based EoL patients. **Abstract:** <https://goo.gl/DiJLiq>

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

#### **How much end-of-life care is of low value?**

*INTERNAL MEDICINE JOURNAL*, 2018;48(10):1173-1174. A significant proportion of healthcare expenditure is spent on patients in their last year of life. In the U.S., such patients accounted for 25% of the Medicare budget in 2009, with more recent data from 2009 to 2011 from nine developed countries showing the share of total healthcare spending incurred ranging from 8.5% in the U.S. to 11.2% in Taiwan. In Australia, hospital care for the last year of life for those aged 65 years and over constitutes around 9% of all inpatient costs. A rising concern is how much of this relatively expensive end-of-life (EoL) care is of low value, that is, ineffective or even harmful. In one study, 12% of admissions to three Australian tertiary hospitals involving patients at the EoL involved the administration of futile care, as defined by audit cri-

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teria and expert consensus. A systematic review of 38 studies found that on average one in three older patients in the last 6 months of life received interventions in hospital that were very unlikely to confer benefit. These included dialysis, radiotherapy, transfusions, antibiotics, life support treatments and unnecessary and often invasive investigations. The same review found non-beneficial intensive care unit admission involved one in 10 patients. Surveys of older patients in the U.S. indicate receiving inappropriate care with its unintended consequences is perceived as more of a problem than being denied appropriate care. In most cases, beneficent intent, death denial, mass marketing of modern healthcare technologies, which raises expectation of miracles, and a host of cognitive biases constitute the drivers of “do everything” care. However, although the notion of low-value care at EoL is easy to accept, the problem comes when some assert that avoiding such care could save money which could then be redirected to care of higher value. This raises the disquieting topic of rationing care and assuming clinicians can accurately predict who will live or die, regardless of the care received. **Full text:** <https://goo.gl/FjmNbl>

Noted in Media Watch 5 February 2018 (#549, p.14):

- *PERSPECTIVES IN BIOLOGY & MEDICINE*, 2018;60(3):331-335. ‘**Futile treatment and conquering death.**’ Pragmatically speaking, there is a stronger case for using the language of “futility” than “potentially appropriate” for end-of-life care. The latter obscures the reality of death as a part of human life. Do patients die because death always wins in the end? Or do they die because physicians run out of ways to treat them? In the end, modern medicine has made the conquest of death its *de facto* goal. That is a fundamental error, one which the language of “potentially appropriate” is unwittingly supportive of. **Abstract/First page view:** <https://goo.gl/Dp2phL>

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

#### **Improvements are needed in end-of-life care: Ombudsman**

*THE IRISH MEDICAL TIMES* | Online – 11 October 2018 – Hospital and hospice staff need to improve the way they deal with dying patients and recently bereaved families, a report from the Ombudsman has found.<sup>1</sup> The report ... is a follow-up to Ombudsman Peter Tyndall’s 2014 report, which described some of the issues raised in complaints he received about end-of-life care.<sup>2</sup> Although Tyndall acknowledged that the majority of health workers communicate with the dying and bereaved “in a kind, compassionate and caring way”, he said that sometimes “staff did not appear to have much time to talk to them.” In his report, which was ... Tyndall said that the introduction of two new training schemes, the ‘Final Journeys’ workshop and the ‘Breaking Bad News’ [*sic*] training programme,<sup>3,4</sup> were “giving staff the confidence to hold compassionate and sensitive conversations with dying patients and their families.” He added: “Poor communication is a regular feature of complaints to the Ombudsman. “Conversations about diagnosis, prognosis, ceilings of care or decisions about resuscitation all need to be had with sensitivity, in a way that patients and families can understand. Many bereaved relatives who contributed to the Survey of Bereaved Relatives: Voices MaJam (which was launched in 2017) reported that hospital staff communicated with them in a kind, compassionate and caring way,” Tyndall continued. “However, some survey respondents said that staff did not appear to have much time to talk to them, that doctors gave bad news in a blunt way in front of patients, or that patients were told about their diagnosis, without the option of family members being present to support them.” The complaints made to the Ombudsman, he said, highlight the need for continuous training for hospital staff in this regard. **Full text:** <https://goo.gl/zxgVF8>

1. ‘A Good Death Progress Report: Developments in End-of-Life Care in Irish Hospitals since the publication of the Ombudsman’s report in 2014,’ Office of the Ombudsman, September 2018. [Noted in the 24 September 2018 issue of Media Watch (#582, p.5)] **Download/view at:** <https://goo.gl/5Mh9D2>
2. ‘A Good Death: A Reflection on Ombudsman Complaints about End-of-Life Care in Irish Hospitals,’ Office of the Ombudsman, June 2014. [Noted in 30 June 2014 issue of Media Watch (#364, p.6)] **Download/view at:** <https://goo.gl/kkM5Xd>
3. ‘Final Journeys,’ Irish Hospice Foundation. <https://goo.gl/RmKK3c>
4. ‘Delivering Bad News,’ Irish Hospice Foundation. <https://goo.gl/Q8h5Fk>

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## Related

- *THE IRISH MEDICAL TIMES* | Online – 8 October 2018 – ‘**Providing hospice care to Ireland’s children.**’ Ireland’s only children’s hospice ... provides support and care to children from the moment of diagnosis of a life-limiting condition, which may be before they are born, to end-of-life. Care is currently being provided to 156 children nationally with life-limiting conditions as well as support to their families. A U.K. paediatrician looked at hospital inpatient data in 2012 under all the definitions and came up with the new prevalence data.<sup>1</sup> The children’s hospice has extrapolated the U.K. figures to the Irish context and estimate there are 3,840 children living in Ireland with life-limiting conditions and an estimated 720 children need hospice care at any given time. **Full text:** <https://goo.gl/mFk5ic>

1. ‘A cohort study of children and young people with progressive neuromuscular disorders: Clinical and demographic profiles and changing patterns of referral for palliative care,’ *Palliative Medicine*, 2012; 26(7):924-929. **Abstract:** <https://goo.gl/qZer5B>

## “We take care of patients, but we don’t advocate for them”: Advance care planning in prison or jail

*JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 9 October 2018 – The authors investigated correctional healthcare providers’ knowledge of and experience with advance care planning (ACP), their perspectives on barriers to ACP in correctional settings, and how to overcome those barriers. Participants in this study demonstrated low baseline ACP knowledge; 85% reported familiarity with ACP, but only 42% provided accurate definitions. Fundamental misconceptions included the belief that providers provided ACP without soliciting inmate input. Multiple ACP barriers were identified, many of which are unique to prison and jail facilities, including provider uncertainty about the legal validity of ACP documents in prison or jail, inmate mistrust of the correctional healthcare system, inmates’ isolation from family and friends, and institutional policies that restrict use of ACP. Clinicians’ suggestions for overcoming those barriers included ACP training for clinicians, creating psychosocial support opportunities for inmates, revising policies that limit ACP,

and systematically integrating ACP into health-care practice. **Abstract:** <https://goo.gl/y5WYMs>



### Prison Hospice: Backgrounder

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (last updated 1 August 2018) is available on request. Contact information at the foot of p.19.

Photo: Lori Waselchuk. Philadelphia, PA

Noted in Media Watch 2 July 2018 (#570, p.18):

- *JOURNAL OF CORRECTIONAL HEALTH CARE*, 2018;24(3):232-242. ‘**Preparing to die behind bars: The journey of male inmates with terminal health conditions.**’ Through collecting data during observation of facilitated advance care planning sessions, this qualitative study revealed four main themes: 1) Losing a piece of everything; 2) Not sure what to feel; 3) Where will I die; and, 4) Finding purpose in the midst of purposelessness. These themes characterize the central issues discussed by inmates as they considered death behind bars. **Abstract:** <https://goo.gl/4Fx1cf>

Noted in Media Watch 22 December 2014 (#389, p.17):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2014;10(4):322-337. ‘**Barriers associated with the implementation of an advance care planning program in a prison setting.**’ Through the course of implementing an advance care planning (ACP) program for aging and dying offenders at a medical classification center, multiple barriers were identified that need to be addressed systematically to ensure the medical wishes of offenders were known and honored. This article outlines steps taken to create systems change to promote and sustain ACP. **Abstract:** <http://goo.gl/UKwomd>

## Improving end-of-life care and advance care planning for frail older adults in Canada

*JOURNAL OF FRAILITY & AGING*, 2018;7(4):240-246. The authors present five concepts that describe priorities for improving end-of-life care (EoLC) for frail older adults in Canada and recommendations based on each: 1) The EoLC system is focused on cancer, not frailty; 2) We need better strategies to systematically identify frail older adults who would benefit from a palliative approach; 3) The majority of palliative and EoLC will be, and should be, provided by clinicians who are not palliative care specialists; 4) Organizational change and innovative funding models could deliver far better EoLC to frail individuals for less than we are currently spending; and, 5) Improving the quality and quantity of advance care planning for frail older adults could reduce unwanted intensive care and costs at the end of life, and improve the experience for individuals and family members alike. **Abstract (via PubMed):** <https://goo.gl/uETNYq>

Noted in Media Watch 1 October 2018 (#583, p.9):

- *BMC MEDICINE* | Online – 21 September 2018 – ‘**Frailty trajectories to identify end of life: A longitudinal population-based study.**’ This longitudinal population-based study demonstrates that it is possible to use a frailty index calculated within electronic healthcare records to identify people who are at a higher risk of dying within one year. This has potential application in health services to support clinicians in identifying older adults dying with frailty who may have been overlooked by traditional approaches and to help ensure appropriate care is offered. **Full text:** <https://goo.gl/jJvfvU>

**N.B.** Selected articles on recognising older frail patients near the end of life noted in 8 January 2018 issue of Media Watch (#545, p.5).

## Providing palliative care at the end of life: Should health professionals fear regulation?

*JOURNAL OF LAW & MEDICINE*, 2018;26(1):214-245. Anecdotal evidence from Australia and abroad suggests that health professionals may fear potential legal and/or professional repercussions if their patient dies after receiving pain relieving medication at the end of life (EoL). As a result, patients may be under-medicated and their pain and other symptoms not adequately relieved. The regulatory repercussions from inappropriate administration of medications are potentially broad and include criminal charges, civil negligence claims, coronial investigations and disciplinary proceedings. But despite these potentially serious repercussions, a review of publicly available cases in Australia reveals there has been comparatively little judicial or quasi-judicial scrutiny where over-medication is alleged to have resulted in a patient's death. The authors describe the regulatory framework that governs this field of medical practice and analyse the extent to which the actions of health professionals have been scrutinised, and the consequences of that scrutiny. They identify a number of themes arising from this analysis and conclude that fears of legal or professional repercussions are largely unfounded, and that existing laws and other forms of regulation should not inhibit the prescription and administration of adequate pain and other symptom relief to people at the EoL. **Abstract (via PubMed):** <https://goo.gl/xc8Eyx>

## On the margins of death: A scoping review on palliative care and schizophrenia

*JOURNAL OF PALLIATIVE CARE* | Online – 10 October 2018 – From this scoping review, 342 unique titles and abstracts were identified through a search of 20 databases, including 11 social science databases, 6 medical databases, and 3 gray literature databases. A total of 32 articles met the inclusion criteria and the following 4 themes were identified: 1) Stigma affecting quality of care and access to care; 2) Issues related to consent and capacity for the patient's end-of-life care (EoLC) decisions and to appoint substitute decision makers; 3) Best practices for psychosocial interventions, pharmacology, family and healthcare collaborations, goals of care, setting, and smoking; and, 4) Barriers to care, including setting, communication, provider education, and access to care. The review suggests the importance of mandatory interdisciplinary training practices and policy standards outlining cooperative communication across healthcare providers. It highlights gaps in evidence-based research on psychosocial interventions and collaborative frameworks to enable the provision of quality EoLC for individuals with schizophrenia. **Abstract:** <https://goo.gl/SXxchu>

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Noted in Media Watch 2 April 2018 (#557, p.9):

- *BMC PALLIATIVE CARE* | Online – 27 March 2017 – ‘**Palliative care for people with schizophrenia: A qualitative study of an under-serviced group in need.**’ Barriers to palliative care (PC) are outlined, but more importantly facilitators to PC are presented that identify key indicators needed to ensure good care. These include identifying a carer or nominating an advocate for the person, case conferencing in multidisciplinary and cross sector teams, and building capacity within the pre-existing workforce and care providers through education and advocacy. **Full text:** <https://goo.gl/HxhSVC>

**N.B.** Additional articles on palliative care for people living with schizophrenia noted in this issue Media Watch.

### **Top ten tips for palliative care clinicians caring for heart failure patients**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 11 October 2018 – Heart failure (HF) is an increasingly prevalent condition with a very high symptom burden. To address challenges faced by palliative care clinicians, the journal assembled a team of experts to provide high-yield tips for the management of these patients. Prognosis is unpredictable in HF and many patients and physicians overestimate survival. Ejection fraction, notably, is not predictive of prognosis. It is important to have thorough discussions about implantable cardioverter defibrillators in terminally ill HF patients. Diuresis is the mainstay of managing volume overload and dyspnea in these patients and it is important to be aggressive and creative to achieve symptom relief. However, HF patients have a high burden of comorbidities and have many symptoms beyond dyspnea as well. Management in hospice remains challenging for these patients, with a significant risk for readmission to the hospital. Almost a quarter of HF patients discharged to hospice from the hospital die in less than three days. **Abstract:** <https://goo.gl/Rdn6XK>

**N.B.** Selected articles on palliative care in heart failure noted in 1 October 2018 issue of Media Watch (#583, pp.11-12).

### **Lancet Commission on the Value of Death**

*THE LANCET* | Online – 13 October 2018 – Without death every birth would be a tragedy. “We die so that others may live, we grow old so that others may be young”, writes the poet Kate Tempest. Yet medicine continues to strive to keep patients with life-limiting illnesses alive, often beyond the point of benefit. Many people in high-income countries, and those in poorer countries who are able to access quality health care, have an uneasy relationship with death, unlike some traditional societies. Serious people hold out the prospect of immortality, while dying baby boomers want as long a life as possible, symptom control, and a personalised death – a combination that may be unachievable. Yet many people around the world die without access to morphine or any care, illustrating the gross disparities that surround death. Has medicine gone wrong in the way it deals with death? *The Lancet* Commission on the Value of Death will explore the relationship of medicine to death, consider failures in the relationship, and share ideas on how it might be improved. **Full text:** <https://goo.gl/THVb33>

### **How funerals accomplish family: Findings from a mass-observation study**

*OMEGA – JOURNAL OF DEATH & DYING* | Online – 6 October 2018 – Contemporary Anglophone societies frame grief in terms of a unique personal connection to the deceased, yet hedged about by expectations that people will grieve certain family members more than others or more than friends, neighbors or colleagues. Only at the funeral are all relevant parties likely to find themselves physically in the same place, so it comprises a significant arena in which to explore this ambiguity. Funeral professionals often assert that the funeral is an occasion to express grief and to share sorrow, yet it is also an occasion typically controlled by close family who make the arrangements for the day, whatever their feelings or lack of feelings for the deceased. The funeral director contracts with just one person as client, typically a close family member. Critics of the mid-20th century American funeral denigrated the way it became an osten-

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tatious display of family status; more recent critics have observed how funerals can disenfranchise the grief of non-family; anecdotal observations by British mourners and funeral professionals, along with more systematic observation by researchers, indicate that close family always sit in the front row; and, soap operas portray funerals as dramatic family events. So there are reasons to think that British and American funerals may have as much to do with family as with personal feeling. **Full text:** <https://goo.gl/xz8CiD>

### Unilateral withdrawal of life-sustaining therapy in a severely impaired child

*PEDIATRICS* | Online – 12 October 2018 – An infant with complex congenital heart disease suffers a prolonged cardiac arrest with minutes of anoxia. He is left with severe brain damage and profound neurologic impairment. He no longer responds to caregivers. Much of the time, he cries and grimaces as if in pain. He has required increasing sedation to control these symptoms. His parents live hours from the hospital and seldom visit. When their infant's situation is explained to them over the telephone, they request that doctors "do everything to keep him alive." His bedside caregivers report high levels of moral and psychological distress and frequently discuss J.S.'s "suffering." An ethics consultation is requested, asking whether it is permissible to withdraw life support despite the parents' request that therapy continue. **Abstract:** <https://goo.gl/dM7BPG>

### Patient's rights to advance directives

*REVISTA BIOÉTICA*, 2018;26(3):440-450. This research identified the knowledge 55 patients with terminal diseases had about their diagnosis, prognosis, and the option to register their end-of-life (EoL) will in an advanced directive (AD). Only one patient had already registered their AD; three expressed their interest in registering them after the dialogue with the researcher. All the others subjects stated they did not have the opportunity to discuss the matter. Decisions regarding patients' EoL invariably make evident the lack of clarifying dialogue between doctor and patient. The study data suggest ADs, although constituting an instrument for the respect for the autonomy of will of patients with terminal diseases, are far from being effective in practice,

which leads to the need to improve the communication between doctors and patients regarding the process of reaching the EoL. **Full text:** <https://goo.gl/paBzZR>

## Revista **BIOÉTICA**

Articles in *Revista Bioética*, the journal of Brazil's Conselho Federal de Medicina (the Federal Council of Medicine), are published in Portuguese, Spanish and English. Click on the respective pdf icon to access the article in the language of choice.

### Related

- *REVISTA BIOÉTICA*, 2018;26(3):420-428. '**Terminality and living will: The knowledge of medical students.**' The results of this study show most of participants (72.1%) can differentiate euthanasia, dysthanasia and orthothanasia, but the knowledge about a living will (LW) and the resolution of the Brazilian Federal Council of Medicine that supports these is reduced. Only 22.4% of the students had contact with the subject in medical school. Regarding ethical decisions, 83.2% favor orthothanasia and 80.1% would respect the LW of the patient. The study is validated not only in the way it evaluates the perception of future physicians about the subject, allowing discussion about ethical decisions in relation to patients, but it also involves the informative and reflective nature of the research to the interviewees and readers, regarding the advance directives themselves. **Full text:** <https://goo.gl/tPif6n>



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## Palliative care: Medically futile and potentially inappropriate therapies of questionable benefit

UPTODATE | Online – Accessed 8 October 2018 – Modern controversies about medical futility arise when doctors and patients (or family members) disagree about whether a particular treatment is futile or inappropriate/inadvisable in a particular circumstance. Uncertainty about the appropriateness or benefit of interventions is a product of different perspectives on what constitutes benefit to patients and how individuals (patients/families as well as clinicians) can vary dramatically in how they define value as related to life. Medical interventions can sustain organ function, thereby prolonging life. However, at times, the quality of that life (e.g., lack of awareness of surroundings and/or inability to interact with surroundings without anticipated recovery) would lead many to determine that such a life lacks the quality or value warranting continued interventions to sustain it. In short, medical technological capacities collide with deeply ingrained moral and ethical beliefs and frameworks. This topic review covers the concept of medical futility as it applies to palliative care (PC) patients. Ethical issues related to futile and potentially inappropriate treatments that are specific to issues that arise in the intensive care unit from a critical care perspective are presented separately, as is a more extensive discussion of ethical issues that arise in PC. **Introduction (inc. list of references):** <https://goo.gl/3rMG4m>

Noted in Media Watch 25 June 2018 (#569, p.12):

- *JOURNAL OF CLINICAL ETHICS*, 2018;29(2):114-123. **‘Medical futility in concept, culture, and practice.’** This article elucidates the premises and limited meaning of medical futility in order to formulate an ethically meaningful definition of the term, that is, a medical intervention’s inability to deliver the benefit for which it is designed. It uses this definition to show the two ways an intervention could become medically futile, to recommend an even more limited usage of medical futility, and to explain why an intervention need not be futile in order to be withdrawn over patient-based objections. **Abstract:** <https://goo.gl/EcaVUN>

Noted in Media Watch 5 March 2018 (#553, p.5):

- *POSTGRADUATE MEDICAL JOURNAL* | Online – 24 February 2018 – **‘Futility and appropriateness: Challenging words, important concepts.’** The factors that drive non-beneficial treatments include personal biases, patient-related pressures and institutional imperatives. Breaking loose from the perceived necessity to deliver non-beneficial treatment is a major challenge. Curative intent should give way to appropriateness such that curative and palliative interventions are valued equally. Goals of treatment should be shaped by illness trajectory, the risk of harms as well as potential benefits and patient preferences. **Abstract:** <https://goo.gl/3H5S51>

### Related

- *UPTODATE* | Online – Accessed 8 October 2018 – **‘Ethical issues in palliative care.’** There is often conflict between clinicians, nurses, other health care team members, patients, and family members about what constitutes appropriate care, particularly as patients approach death. This article discusses ethical issues in palliative care (PC). Other issues regarding the legal aspects of end of life (EoL) care, advance care planning, how to approach requests for potentially inappropriate and futile therapies, and discussing goals of care are discussed separately. In addition, issues related to specific symptoms for the patient in PC and/or at the EoL are discussed separately. **Introduction (inc. list of references):** <https://goo.gl/u3ivhv>



Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>



## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *ALBERTA LAW REVIEW*, 2018;56(1):55-72. **‘Medical assistance in dying: Canadian registry recommendations.’** Medical assistance in dying (MAiD) is a relatively new phenomenon in Canada, and is therefore a growing area of interest in the legal and medical communities. Research is hampered, however, by the lack of a standardized approach to collecting data on MAiD cases. The authors first discuss the importance of having comprehensive data to improving preventative and end-of-life care across Canada. The authors then canvas the existing framework for reporting MAiD cases in Canada before noting its deficiencies, most importantly, a lack of comprehensive, nation-wide data collection. The authors then propose a model for national data collection based on the existing Canadian cancer registry system. **Abstract:** <https://goo.gl/yrZWk5>

**N.B.** Additional articles on collecting data on medical assistance in dying in Canada, for example, regarding the role that social determinants of health, such as poverty, insecure housing, isolation or social stigma may play in motivating a request to die.

- *ALBERTA LAW REVIEW*, 2018;56(1):149-176. **‘An ethical-legal analysis of medical assistance in dying for those with mental illness.’** This article considers sources of opposition to allowing access to medical assistance in dying for individuals with mental illness. It originated with an observation by members of the University of Toronto Joint Centre for Bioethics that in mainstream Canadian culture – as well as in political, academic, and professional circles – such opposition remains widespread (and often reflexive). This opposition exists even in light of broad support for access to assisted dying for individuals with illness manifesting in physical suffering. Most Canadians treat the prospect of assisted dying for those with mental illness with suspicion, and it is worth exploring why this opposition persists, what arguments can be levelled to support it, and whether those arguments can be sustained. **Abstract:** <https://goo.gl/QpFdyw>

- *THE HASTINGS REPORT*, 2018;48(S3):S75-S79. **‘Advance directives for refusing life-sustaining treatment in dementia.’** Aid-in-dying laws in the U.S. have two important restrictions. First, only patients who are terminally ill, defined as having a prognosis of six months or less to live, qualify. Second, at the time the patients take the lethal medication, they must be competent to make medical decisions. This means that an advance directive requesting aid in dying for a later time when the patient lacks decision-making capacity would be invalid. However, many people are more concerned about avoiding living into severe dementia for years – a time when they will lack decision-making capacity – than they are about preventing suffering or the loss of dignity or autonomy for a few months at the end of life. **Full text:** <https://goo.gl/ykjlwL2>

**N.B.** Additional articles on advance directives for patients living with Alzheimer’s disease and other forms of dementia noted in 27 August 2018 issue of Media Watch (p.9).

- *UPTODATE* | Online – Accessed 8 October 2018 – **‘Physician-assisted dying: Understanding, evaluating, and responding to requests for medical aid in dying.’** Many physicians, particularly those in the fields of oncology and palliative care (PC), will be faced with a request for assistance in dying sometime in their professional lifetimes. No matter where clinicians stand ethically and morally on the permissibility of this practice, and regardless of whether these practices are legally permitted or prohibited in a given jurisdiction, clinicians have to carefully consider and decide how they will respond to these requests. The authors focus first on the background definitional and theoretical aspects of physician-assisted death, including the ethical, legal, and public policy issues surrounding euthanasia and assisted suicide, and then on clinical aspects of evaluating and responding to such requests, emphasizing the importance of full evaluation, including the adequacy of PC and the availability of alternative treatments to alleviate suffering, and finally on practical approaches that respect the values of the patient, the family, and the clinician, as well as the particular legal constraints under which they reside. **Introduction (inc. list of references):** <https://goo.gl/b21iLu>

## Publishing Matters

### How to write a thorough peer review

*NATURE* | Online – 8 October 2018 – Scientists do not receive enough peer-review training. To improve this situation, a small group of editors and the author developed a peer-review workflow to guide reviewers in delivering useful and thorough analyses that can really help authors to improve their papers.<sup>1</sup> We suggest that you perform three readings of a paper, concentrating on a different element each time. At every point, remember to classify your comments as major or minor flaws. Major flaws will need considerable time to explain or correct. The first reading is to get an overall impression of the paper and its aims. Take notes as you go. Make sure the paper is within the scope of the journal. It's unlikely that it won't be, but answering this question forces you to better understand the research and think about the paper's mission: what it's trying to achieve. Take particular note of the parts of the paper that your expertise speaks best to. Editors do not expect you to be an expert in absolutely every aspect of the paper, although they also don't want you to be a novice. Be upfront and honest with the authors and the editor about which scientific aspects you will focus on in your review. After the first reading, attempt to 'mirror' the article by writing down, in detail, your understanding of the science. This tells the authors how you – the reader – have interpreted the aims, results and novelty of their research. If they disagree with your analysis, they should, from your comments, be able to understand that this is not your fault. Your analysis is a clear message that the authors need to work on how they communicate their intentions. You might also notice a fatal flaw during your first reading. Forget minor or major flaws: a fatal flaw is one that stops the review process dead in its tracks. There's not much point in continuing the process if the method is fatally flawed, if an entire section is missing or if the paper is utterly unreadable. Describe all flaws in your review, and submit it. Depending on the journal, you might have the option to "reject, but resubmit." Otherwise, simply reject. There's no shame in it! **Full text:** <https://goo.gl/u5V8zn>

1. 'A Peer Review Process Guide,' **Download/view at:** <https://goo.gl/2AnGC1>

### 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.

Cont.

### 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.

[Search Back Issues of Media Watch @ http://goo.gl/frPgZ5](http://goo.gl/frPgZ5)

### Media Watch: Access on Online

#### **International**



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/xGvt2A>

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

PALLIATIVE CARE NETWORK: <https://goo.gl/YBP2LZ>

PALLIMED: <http://goo.gl/7mrqMQ>

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at <https://goo.gl/6vdk9v>]

#### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/ZRngsv>

[Scroll down to 'Resource Collection' and 'Media Watch Barry Ashpole']

#### **Canada**



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLgxy2>

[Scroll down to 'Are you aware of Media Watch?']

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>

#### **Europe**

HUNGARY | Magyar Hospice Alapítvány: <https://goo.gl/L7D2hw>

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

#### **South America**



Academia Nacional de Cuidados Paliativos (Brazil): <https://goo.gl/b5CV31>

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