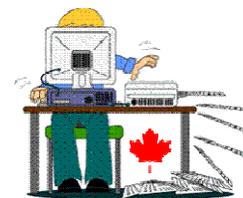


## **Media Watch...**

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**

**'Quality improvement priorities for safer out-of-hours palliative care: Lessons from a mixed-methods analysis of a national incident-reporting database' (p.12), in *Palliative Medicine*.**

**Media Watch will not be published the w/o 24 December 2018.  
The next issue of the weekly report will be on 31 December 2018.**

## **Canada**

### **Ontario family's legal fight to keep daughter on life support could change how death is defined across Canada**

ONTARIO | *The Globe & Mail* (Toronto) – 12 December 2018 – Though at least five examining physicians have declared Taquisha Deseree McKitty brain dead, her family's refusal to discontinue life support kicked off a labyrinthine legal dilemma, which they're taking to the Ontario Court of Appeal... If they're unsuccessful, Mr. Stewart would consider applying for their case to be heard in the Canadian Supreme Court. Ontario has no statutory definition of death; nor do most Canadian provinces and territories. The determination is instead left up to physicians. Doctors use one of two sets of criteria to declare a patient dead: either a stopped heart or a deceased brain. A brain-dead patient no longer has the capacity for consciousness, and is unable to breathe on their own – much less cough, gag, or blink. Some Christians, Muslims, Orthodox Jews and members of other religions feel that "brain death" doesn't align with their definition of life's end, especially if technology can preserve tissue, send swells of air into lungs and keep a heart beating. In recent years, families around the world have sought legal protection for these views. A Supreme Court ruling would establish uniformity in the way brain death is approached across the country. Currently, the federal government only defines death if the case pertains to criminal law, federal pensions or income tax... In provinces like Ontario, death is governed by a patchwork of rules around organ donation and vital statistics. Only Manitoba, Prince Edward Island, Nova Scotia and Northwest Territories have a legislative definition. In Manitoba, death is an "irreversible cessation" of all brain function. In Prince Edward Island and the Northwest Territories, brain death must be declared by "generally accepted" medical criteria. In Nova Scotia, death is the end of a person functioning as a whole, determined by an irreversible loss of the brain's ability to control and co-ordinate critical functions. To be heard in Supreme Court, a case has to demonstrate public importance in Canada. <https://goo.gl/vNtK8P>

Cont.

Noted in Media Watch 22 October 2018 (#586, p.16):

- *SEMINARS IN NEUROLOGY*, 2018;38(05):576-582. ‘**Contentious ethical and legal aspects of determination of brain death.**’ Although the concept of death by neurologic criteria is accepted throughout much of the world ... the process is fraught with contentious ethical and legal controversies. The author explores historic and contemporary ethical and legal disputes about determination of death by neurologic criteria including the need for consent from patients’ surrogates prior to determination of death, the role of religion in determination of death, management of objections to determination of death by neurologic criteria, the approach to patients who are dead by neurologic criteria but are pregnant, and gamete retrieval after determination of death. **Full text:** <https://goo.gl/cpTwnJ>

Noted in Media Watch 27 August 2018 (#578, p.12)

- *MEDSCAPE* | Online – 21 August 2018 – ‘**Are docs giving patients the wrong idea about brain death?**’ When doctors discuss brain death with families, the doctors have to be very clear to use the term “dead” instead of “brain-dead.” If someone wants to know how [to be] sure that a relative, loved one, or child has died, you don’t start off with the concept of brain death, because they hear that differently. People confuse coma with brain death. They think the doctor said, “He might be permanently unconscious,” and they equate that with brain death because that may be something they have heard about or seen in the media. Everybody needs clarity. There’s only one condition between life and death. **Full text:** <https://goo.gl/3Hdpuh>

**N.B.** Additional articles on defining “brain death” noted in this issue of Media Watch.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE GLOBE & MAIL* | Online – 12 December 2018 – ‘**Long-awaited reports highlight challenges of broadening assisted-dying law.**’ Canada would be venturing into barely charted waters if it were to expand its assisted-dying law to cover young teenagers and patients with mental illness or severe dementia, according to three long-awaited reports exploring how other countries handle ethically challenging requests for the procedure. The trio of independent reports<sup>1</sup> ... were prepared at the request of the federal government after the Liberals passed their assisted-dying law in June 2016. Although deeply researched and hundreds of pages long, the reports reveal just how little international experience Canada would have to draw upon if it chose to broaden the law. The reports do not contain any specific recommendations on how – or even if – Canada should change the legislation that allows doctors to help qualifying patients end their lives. The federal government asked the Council of Canadian Academies a non-profit evidence-gathering organization, to study and sum up all that is known about how Canada and a handful of other countries treat requests for three kinds of patients currently excluded from Canada’s law. <https://goo.gl/WBTcDA>

1. ‘Medical Assistance in Dying,’ Expert Panel on Medical Assistance in Dying, Council of Canadian Academies, December 2018. **Download/view at:** <https://goo.gl/3oJCEa>

- *BRITISH COLUMBIA* | *The Vancouver Sun* – 11 December 2018 – ‘**Assisted death transfers declining: Local health authorities.**’ Local health regions are making significant progress in boosting the number of patients dying in place rather than being moved to facilities to obtain medical assistance in dying (MAiD). The Fraser Health region, where palliative care hospices have been especially resistant to providing MAiD on site because of philosophical opposition, has drastically reduced the number of patients transferred to other facilities on their last day or days of their lives, going from 27 transfers in 2017 and part of 2016 to only six in 2018, according to new data provided by the health authority. Between the time when MAiD was legalized midway through 2016 to 31 October 2018, 257 medically assisted deaths were provided in Fraser Health. <https://goo.gl/LsSQoL>

### [Specialist Publications](#)

‘**Reflections and Learnings – Assisted dying in Canada and the U.S.,**’ a new report from Palliative Care Australia. Scroll down to ‘Assisted dying’s impact on palliative care explored in new reports,’ (p.6).

## U.S.A.

### Who cares for volunteer caregivers when they get sick?

*THE WASHINGTON POST* | Online – 11 December 2018 – The American healthcare system is difficult to navigate for the sickest patients, with family and other informal caregivers bearing a significant amount of this load. For the substantial number of these nearly 44 million caregivers who have major medical problems of their own, this work comes at a particularly high cost, providing a stark example of how our health system can doubly fail the sickest of the sick. Unpaid, untrained caregivers navigate mazes of clinicians, home healthcare agencies, pharmacies and nursing homes. They buy groceries, keep track of medications, administer injections, provide comfort, and schedule and sit in on medical appointments. They are most often women, and they face significant barriers – and consequences – when doing this work. This was confirmed in a recent survey of some of the sickest patients in the U.S....<sup>1</sup> Nearly two out of three patients in the survey faced problems such as fragmented care, high costs or medical errors. Most of them – 86% – relied on friends and family for help. More than a third of respondents reported their caregivers struggled with the burden of that role. Nearly 1 in 3 said their caregivers found this work emotionally stressful, while 1 in 4 said their caregivers found it physically stressful.

Other research has found caregivers have a higher risk of such medical issues as depression, anxiety, social isolation, and financial strain from out-of-pocket costs and lost income. <https://goo.gl/gmBWMc>

#### Specialist Publications

**'Engaging the African American church to improve communication about palliative care and hospice: Lessons from a multi-level approach'** (p.9), in *Journal of Palliative Care*.

**'Evidence-based review of trauma center care and routine palliative care processes for geriatric trauma patients...'** (p.10), in *Journal of Trauma & Acute Care Surgery*.

**'More physicians support assisted suicide...'** (p.12), in *Becker's Hospital Review*.

**'Reflections and Learnings – Assisted dying in Canada and the U.S.,'** a new report from Palliative Care Australia. Scroll down to 'Assisted dying's impact on palliative care explored in new reports,' (p.6).

1. 'Being Seriously Ill in America Today,' Commonwealth Fund, Harvard TH Chan School of Public Health & *The New York Times*, October 2018. **Download/view at:** <https://goo.gl/4FTrSs>



#### 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>



Media Watch: Behind the Scenes  
<http://goo.gl/XDjHxz>

## International

### **New rules spell out when doctors can let patients with brain damage die**

U.K. (England & Wales) | *The Guardian* (London) – 12 December 2018 – It is estimated that there are up to 16,000 patients in the U.K. in a vegetative state – where they are awake but show no signs of awareness – and perhaps three times that number in a minimally conscious state, where patients have clear but minimal awareness, such as occasionally being able to move a finger. People in these conditions are severely brain damaged and as time goes on, even partial, let alone full recovery, is unlikely. The only thing keeping them alive are their feeding tubes. But until now, the only way to allow them to die was to go to court for permission to withdraw all nutrition and hydration, after which they would die within two or three weeks. Such decisions have been possible since 1993, when a landmark court case ruled that Anthony Bland, a victim of the Hillsborough disaster, could be allowed to die. Since that ruling, clinically assisted nutrition and hydration has been defined as a medical treatment. If it is not in the patient's best interests to continue it, doctors can withdraw food and water. Since then, around 100 cases have gone to court. Now, families no longer need to embark on a legal process to

stop life-prolonging treatment, after the supreme court ruled in July that if doctors and relatives agreed that withdrawing life support is in the patient's best interests, a court order was not needed. The British Medical Association, the Royal College of Physicians and the General Medical Council have jointly published guidance for health professionals, and information for loved ones, on the rules governing how and in what circumstances food and water can be withheld.<sup>1</sup> <https://goo.gl/F3QpZa>

#### **Specialist Publications**

**'Evaluating the impact of national education in pediatric palliative care: The Quality of Care Collaborative Australia'** (p.6), in *Advances in Medical Education & Practice*.

**'How we improved end-of-life care in our practice'** (p.9), in *GP*.

**'Quality improvement priorities for safer out-of-hours palliative care: Lessons from a mixed-methods analysis of a national incident-reporting database'** (p.12), in *Palliative Medicine*.

1. 'Clinically-assisted nutrition and hydration (CANH): New guidance to support doctors making decisions about CANH for adults who lack capacity in England and Wales,' British Medical Association. **Download/view at:** <https://goo.gl/3kdZS8>

### **YouGov survey reveals startling attitudes towards death in U.K.**

U.K. | *Business Leader* – 11 December 2018 – Asking wide-ranging questions from live-streaming funerals to becoming a chatbot after death, the report disrupts not only the "death community" of funeral directors but also the general public to consider what decisions they would make for their burial, funeral, and digital legacy. The Changing Attitudes to Death 2018 report revealed that by the time we leave full-time education, 55% of us will have been bereaved, with 27% of us losing someone special between the ages of 11 to 17 – a critical time in our education. The report states that 1 in 10 under-65s in the U.K. want to be turned into a chatbot after they die so that their loved ones can still "talk to them," a technological advance that is still in its infancy. Age had a dramatic effect on attitudes towards burial, with statistics showing that 20% of 18-24 year olds would choose to donate their body to science: the most popular choice for what they would want to happen to their body after death, and the age group most likely to choose this option. In fact, donation to science (10%) is almost as popular as traditional burial (11%). Yet this liberal attitude is not restricted to the young in all areas. When asked whether assisted suicide should be legal in the U.K., only 60% of 18-24 year olds believed that it should be, whereas that percentage rose up to 73% for 55-64s. <https://goo.gl/LR7Jky>



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## Home care in England: Views from commissioners and providers

U.K. (England) | The King's Fund (London) – 11 December 2018 – Care is provided at home each year to more than 350,000 older people and 76,300 young people with disabilities. Commissioning and delivering the highest quality home care (HC) should be a significant objective of our health and social care system. Between 2016 and 2018, The King's Fund carried out three pieces of research exploring: 1) The factors driving commissioning adult social care; 2) The mechanisms of purchasing and delivery of HC; and, 3) Alternatives to traditional models of delivering care at home. This report draws together the findings of those research projects, which record the stated opinions of commissioners, providers and other stakeholders. Recruiting and retaining HC staff remains a fundamental challenge for providers, but the extent of the challenge varies greatly depending on geographical location, with those in some rural and also in some prosperous areas particularly struggling. Despite the challenges facing providers, most councils commissioning HC attempted to drive down the fees they pay. Commissioners and providers disagreed about whether quality of HC had declined in recent years and, if it had, the role of fees in that process. HC continues to be commissioned on a "time and task" basis rather than with a view to health and care outcomes. Nor is there much evidence that health and care providers are joining up commissioning of HC. Alternative approaches to HC provision have yet to demonstrate they can be scaled up effectively, while approaches using new technology have not yet had time to be properly evaluated. **Download/view at:** <https://goo.gl/wU2u7g>

**N.B.** No mention is made in The King's Fund report of the provision and delivery of home hospice or palliative care.

Noted in Media Watch 19 February 2018 (#551, p.9):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 14 February 2018 – '**Persistent inequalities in hospice at home provision.**' As the trend towards fewer people dying in hospital continues in many, though not all countries, services such as Hospice at Home (H@H), which exist to support carers and patients emotionally and physically to enable a natural acceptance and dignified end of life (EoL), are becoming an increasingly vital resource to allow people to die at home. This study identifies the important roles that a H@H service plays in the care of people approaching the EoL and in a detail that has not been reported before. It has also highlights a dismaying gap between demand for such a service and the available supply. **Full text:** <https://goo.gl/5XvdgS>

## Care Committed to Me

U.K. (England) | Voluntary, Community and Social Enterprise Health and Wellbeing Alliance – 10 December 2018 – Sharing learning from a range of approaches including outreach models, training programmes and information resources, along with insights from the research literature and lived experiences, this project highlights a variety of work which is under way to improve access to personalised end-of-life care (EoLC) for gypsies [i.e., Roma] and travellers, LGBT people and people experiencing homelessness. Case studies, considered alongside feedback from a workshop and focus groups underline five key principles which are critical to success: 1) Good communication, which includes engaging with people in a way that is meaningful for the individual and so enables people to make informed decisions about their care; 2) An approach founded on dignity and respect, and investing in a relationship of trust; 3) The provision of workforce training and support; 4) Enabling partnership working at a strategic level; and, 5) Recognising that people are all different so inclusive, equitable care is not about treating everybody the same way. Furthermore, the case studies demonstrate a requirement for strategic ongoing commitment with support from senior management, and continuity measures to ensure the work remains visible and present should critical staff members leave the organisation. It is also clear that although there are commonalities (for example, in terms of a need for better data and in support of collaborative cross-sectoral working), there may be different emphases in the design and delivery of personalised care to support a reduction in inequalities in EoLC. **Download/view at:** <https://goo.gl/FQVUBt>



**N.B.** Selected articles on different perspectives on end of life and end-of-life care noted in past issues of Media Watch: Romani (i.e., gypsy, travellers), #530, pp.18-19; LGBT persons, #591, p.14 and #593, p.4 & p.14, respectively; and, the homeless, #587, p.7.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA | Palliative Care Australia (PCA) – 10 December 2018 – ‘**Assisted dying’s impact on palliative care explored in new reports.**’ The Association has released two documents looking at the impact of assisted dying on palliative care (PC) services in countries where it is legal. The first report, ‘Reflections and Learnings – Assisted dying in Canada and the U.S.,’ was written following a PCA delegation visit to Canada and the U.S. in October. The second report, ‘Experience internationally of the legalisation of assisted dying on the PC sector,’ was commissioned by PCA to look at the literature and research surrounding the intersection of PC and assisted dying. **Download/view reports at:** <https://goo.gl/UVpGbm>

## Specialist Publications

### Evaluating the impact of national education in pediatric palliative care: The Quality of Care Collaborative Australia

*ADVANCES IN MEDICAL EDUCATION & PRACTICE* | Online – 14 December 2018 – The Quality of Care Collaborative Australia (QuoCCA) provided pediatric palliative care (PC) education across Australia with the aim of improving the quality of services. The education was delivered through a collaboration of six tertiary pediatric PC services, through funding for Nurse Educators, Medical Fellows, a National Allied Health Educator, and national project staff. Education was provided to over 5,500 health and human service professionals in 337 education sessions across Australia between May 2015 and June 2017. Paired pre- and post-surveys were completed by 969 participants and showed a significant improvement in all the domains measured. Those with no experience in caring for children receiving PC showed greater improvement following QuoCCA education compared to those with experience, although the latter had higher scores both before and after education. Similarly, those with no previous education showed greater improvement, but those with previous education showed higher scores

overall. Participants in full-day and half-day sessions showed greater improvement than those in short day sessions. Thus, the dosage of education in the length of the sessions and prior attendance impacted knowledge and confidence. Topics requested by the participants were analyzed. Educator learnings were that education was more effective when tailored to the needs of the audience, was interactive, and included story-telling, case studies, and parent experiences. **Abstract:** <https://goo.gl/ZkJU56F>

#### Publishing Matters

‘**Reporting guidelines: Doing better for readers**’ (p.13), in *BMC Medicine*.

‘**RE: How predatory journals leak into PubMed**’ (p.13), in *Canadian Medical Association Journal*.

‘**Too much academic research is being published**’ (p.13), in *International Higher Education*.

#### Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 11 December 2018 – ‘**Indicators used to assess the impact of specialized pediatric palliative care: A scoping review.**’ The authors identified 82 different indicators grouped into 14 domains. The most common included: location of death, length of stay in hospital, and number of hospital admissions. Only 22 indicators were defined identically in at least 2 studies. Only one included children’s perspectives in assessing indicators. Many indicators were used to assess program outcomes with little definition consensus across studies. Development of a set of agreed-upon indicators to assess program impact concurrent with family and patient input is essential to advance research and practice in pediatric palliative care. **Abstract:** <https://goo.gl/tt9qWF>

Cont.

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 11 December 2018 – ‘**Perceptions of a good death in children with life-shortening conditions: An integrative review.**’ Analysis of articles yielded a dynamic and layered narrative about a good death that revolved around three themes: 1) Level of needs: includes both practical support and aspirational goals such as “do everything”; 2) The composite experience: whether positive or negative adds to produce a sense of suffering; and, 3) Control (preservation and letting go): moving from maintaining *status quo* to acceptance of the child’s death, the experience of which also contributes to suffering. A concept map that interprets a good death in children with life-shortening conditions is represented. **Abstract:** <https://goo.gl/e19tnz>
- *PALLIATIVE MEDICINE* | Online – 12 December 2018 – ‘**Specialized pediatric palliative care services for children dying from cancer: A repeated cohort study on the developments of symptom management and quality of care over a 10-year period.**’ Parents’ perception of symptom occurrence, symptom burden, and effectiveness of symptom-related treatment remained stable over the 10-year period. Over time, the availability of pediatric palliative care as well as quality and satisfaction ratings of care increased significantly. **Abstract (w. list of references):** <https://goo.gl/vGmyFS>

### **Withholding and withdrawing treatment for cost-effectiveness reasons: Are they ethically on par?**

*BIOETHICS* | Online – 7 December 2018 – In healthcare priority settings, early access to treatment before reimbursement decisions gives rise to problems of whether negative decisions for cost-effectiveness reasons should result in withdrawing treatment, already accessed by patients. Among professionals there seems to be a strong attitude to distinguish between withdrawing and withholding treatment, viewing the former as ethically worse. In this article the distinction between withdrawing and withholding treatment for reasons of cost effectiveness is explored by analysing the doing/allowing distinction, different theories of justice, consequentialist and virtue perspectives. The authors do not find any strong reasons for an intrinsic difference, but do find some reasons for a consequentialist difference, given present attitudes. However, overall, such a difference does not, all things considered, provide a convincing reason against withdrawal, given the greater consequentialist gain of using cost-effective treatment. As a result, patients should be properly informed when given early access to treatment, that such treatment can be later withdrawn following a negative reimbursement decision. **Abstract:** <https://goo.gl/exsNML>

#### **Related**

- *CURRENT OPINION IN ANESTHESIOLOGY* | Online – 10 December 2018 – ‘**Withholding or withdrawing life support versus physician-assisted death: A distinction with a difference?**’ Withholding or withdrawing life-sustaining therapy is generally differentiated from physician-assisted suicide (PAS) or euthanasia based on the distinction between intention and foresight. The authors reviewed the literature surrounding the validity of this distinction. They conclude that the moral permissibility of withholding or withdrawing life-sustaining therapy does not necessarily entail the moral permissibility of PAS or euthanasia. **Abstract:** <https://goo.gl/nVEcgg>

### **Moving from heart failure guidelines to clinical practice: Gaps contributing to readmissions in patients with multiple co-morbidities and older age**

*CLINICAL MEDICINE INSIGHTS: CARDIOLOGY* | Online – 4 December 2018 – The authors outline important gaps in guidelines for patients with multiple co-morbidities and the elderly. Congestive heart failure (CHF) diagnosis manifests as a three-phase journey between the hospital and community, during acute, chronic stable, and end-of-life (palliative) phases. This journey requires in variable intensities a combination of multidisciplinary care within tertiary hospital or ambulatory care from hospital outpatients or primary health services, within the general community. Management goals are uniform, i.e., to achieve the lowest New York Heart Association class possible, with improvement in ejection fraction, by delivering gold standard therapies within a CHF program. Co-morbidities are an important common denominator that influences outcomes. Co-morbidities include diabetes mellitus, chronic obstructive airways disease, chronic renal impairment, hypertension, obesity, sleep apnea, and advancing age. Geriatric care includes the latter as well as syndromes such as frailty, falls, incontinence, and confusion. Many systems still fail to comprehensively achieve all aspects of such programs. **Full text:** <https://goo.gl/FrdtYr>

Cont.

Noted in Media Watch 15 October 2018 (#585, p.14):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 11 October 2018 – ‘**Top ten tips for palliative care clinicians caring for heart failure patients.**’ 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. Management in hospice remains challenging, with a significant risk for readmission to the hospital. Almost a quarter of heart failure patients discharged to hospice from the hospital die in less than three days. **Abstract:** <https://goo.gl/Rdn6XK>

**N.B.** Additional articles on PC for heart failure patients noted in 22 October 2018 (#586, pp.15-16).

### Non-standard do-not-resuscitate orders

*CURRENT OPINION IN ANESTHESIOLOGY* | Online – 10 December 2018 – Tattoos and medallions are examples of non-standard do-not-resuscitate (DNR) orders that some people use to convey end-of-life (EoL) wishes. Studies show both providers and patients confuse the meaning and implication of DNR orders. In the U.S., out-of-hospital DNR orders are legislated at the state level. Most states standardized out-of-hospital DNR orders so caregivers can immediately recognize and accept the order and act on its behalf. These orders are complicated by the need to be printed on paper that does not always accompany the individual. Oregon created an online system whereby individuals recorded their EoL wishes that medical personnel can access with an Internet connection. This system improved communication of EoL wishes in patients who selected comfort care only. To improve conveyance of an individual's wishes for EoL care, the authors discuss nationwide adoption of Oregon's online registry where a person's account could comprehensively document EoL wishes, be universally available in all healthcare institutions, and be searchable by common patient identifiers. Facial recognition software could identify unconscious patients who present without identification. **Abstract:** <https://goo.gl/EZ4TcZ>

**N.B.** See ‘DNR tattoos: A cautionary tale,’ *Journal of General Internal Medicine*, 2012;27(10):1383. [Noted in 1 October 2012 issue of Media Watch (#273, p.9)] **Abstract:** <https://goo.gl/VkR6ct>; and, ‘An unconscious patient with a DNR tattoo,’ *New England Journal of Medicine*, 2017;377(22):2192-2193. [Noted in 4 December 2017 issue of Media Watch (#541, p.3)] **Full text:** <https://goo.gl/JU3b2r>

### Bereavement-related regrets and unfinished business with the deceased

*DEATH STUDIES* | Online – 12 December 2018 – Unresolved relational issues with the deceased have been considered a prominent risk factor for negative bereavement outcomes. However, this area of study has suffered from a lack of conceptual clarity, with some commentators focusing on bereavement-related regret and others focusing on “unfinished business,” or lingering or unspoken conflicts with the deceased. This study examined the two concepts in a sample of 229 bereaved individuals, finding them to be overlapping but distinct constructs. Unfinished business occurred more frequently with immediate family and friends and in cases of sudden and violent death of loved ones. Both forms of unresolved issues were associated with bereavement outcome, with the relation between distress over unfinished business and complicated grief symptomatology being particularly robust. **Abstract:** <https://goo.gl/udZn1U>

Noted in Media Watch 10 December 2018 (#593, p.10):

- *DEATH STUDIES* | Online – 4 December 2018 – ‘**The Unfinished Business in Bereavement Scale: Development and psychometric evaluation.**’ Although unresolved issues with the deceased are often targeted in bereavement interventions, understanding of this construct has been hampered by the lack of a psychometrically validated scale to assess it. To address this gap, the Unfinished Business in Bereavement Scale was developed and tested in two samples of bereaved adults... **Abstract:** <https://goo.gl/r8Bm96>

## How we improved end-of-life care in our practice

GP | Online – 11 December 2018 – As a large practice with over 58,000 patients and nine sites [in the County of York, England], any changes we make have the potential to make a big impact. I like to think that the care we were providing our patients approaching the end of life was good, but it was inconsistent and was almost exclusively focused on people with a cancer diagnosis. Three years on and we've significantly increased the number of patients on our palliative care register in the last 12 months, reduced avoidable hospital admissions and increased by a third the number of people we've enabled to die at home in line with their wishes. These are all significant changes of which we are proud. A mixture of the Gold Standards Framework and a lot of hard work are the two key ingredients for these successes, which have resulted in better outcomes for our patients as well as for our team. I knew that we'd be able to improve the care we provide for this patient group, I just didn't realise it would be quite as good as it has proved. **Full text:** <https://goo.gl/cKfqRi>



Noted in Media Watch 12 December 2016 (#491, p.9):

- *ST. CHRISTOPHER'S END OF LIFE JOURNAL* | Online – 9 December 2016 – **'Going for gold: The Gold Standards Framework programme and accreditation in primary care.'** The Gold Standards Framework (GSF) Quality Improvement Programmes have been influential in end-of-life care (EoLC) since 2000. The first 10 GP practices completing the updated programme and associated accreditation are demonstrating enhanced EoLC including earlier identification of patients, more advance care planning discussions, and improved outcomes for more patients. **Full text:** <https://goo.gl/GEpSpV>

**N.B.** GSF Primary Care Programme: <https://goo.gl/PUiVNZ>

## Temporising and respect for patient self-determination

*JOURNAL OF MEDICAL ETHICS* | Online – 10 December 2018 – The principle of self-determination plays a crucial role in contemporary clinical ethics. Somewhat simplified, it states that it is ultimately the patient who should decide whether or not to accept suggested treatment or care. Although the principle is much discussed in the academic literature, one important aspect has been neglected, namely the fact that real-world decision making is temporally extended, in the sense that it generally takes some time from the point at which the physician (or other healthcare professional) determines that there is a decision to be made and that the patient is capable of making it, to the point at which the patient is actually asked for his or her view. This article asks under what circumstances, if any, temporizing – waiting to pose a certain treatment question to a patient judged to have decision-making capacity – is compatible with the principle of self-determination. **Full text:** <https://goo.gl/HAEKfz>

## Engaging the African American church to improve communication about palliative care and hospice: Lessons from a multi-level approach

*JOURNAL OF PALLIATIVE CARE* | Online – 12 December 2018 – The authors' primary goal was to encourage churches to embrace palliative care and hospice (PCH) as acceptable alternatives for end-of-life care by creating venues to improve communications about PCH. This article compares their experience in five churches [in the Philadelphia region of Pennsylvania], revealing lessons learned and the challenges of engaging, implementing, and maintaining a multilevel approach in the churches, and the authors' strategies in response to those challenges. They created 1) A leadership-education program; 2) An intensive training program for church-based lay companions (health visitors); and, 3) Messages and materials to increase knowledge and influence attitudes about PCH. The authors impacted church structures and policies as shown by: integration of the project activities into existing church structures, new church-based programs dedicated to training lay companions and church leaders, new roles for church members (church liaisons) dedicated to this project, and new materials and messages focusing on PCH for the general congregation. **Abstract:** <https://goo.gl/Y1ebhk>

Cont.

Noted in Media Watch 8 February 2016 (#448, p.15):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2016;19(2):143-148. ‘**The impact of faith beliefs on perceptions of end-of-life care and decision making among African American church members.**’ African Americans underuse palliative care (PC) and hospice services because of a combination of factors including faith beliefs. As the spiritual family for many African Americans, the church presents an opportunity to improve communication about PC and hospice services and end-of-life decision making. **Abstract:** <http://goo.gl/hO0qUe>

### The therapeutic utility of the pregnant palliative care physician: A case series

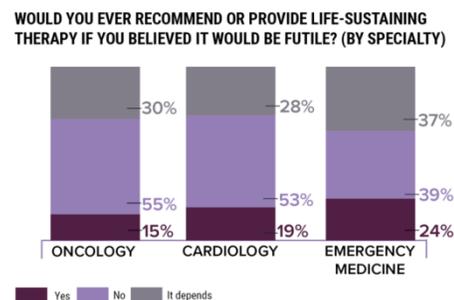
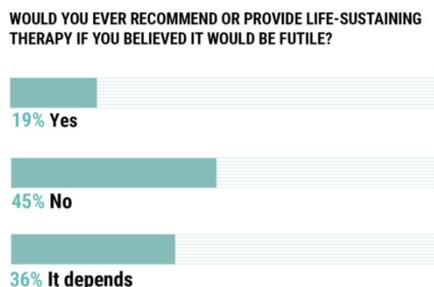
*JOURNAL OF PALLIATIVE MEDICINE* | Online – 11 December 2018 – Women physicians are becoming more numerous, with the majority of active hospice and palliative medicine physicians under the age of 50 being women. While this trend has appropriately led to discussions of supporting, recruiting, and retaining women physicians, there is little literature about the effect of women physicians on patients. In particular, little has been written about the effect of a physician’s pregnancy. Drawing on psychotherapeutic literature, the authors present seven cases illustrating how pregnancy of the palliative care (PC) physician affects patients and families. By recognizing the responses of patients and families and understanding the underlying meaning of the pregnancy, which drives those responses, PC physicians can utilize the pregnancy to select therapeutic interventions for the patient and family. **Abstract:** <https://goo.gl/W3Pz3R>

### Evidence-based review of trauma center care and routine palliative care processes for geriatric trauma patients: A collaboration from the American Association for the Surgery of Trauma (AAST) Patient Assessment Committee, the AAST Geriatric Trauma Committee, and the Eastern Association for the Surgery of Trauma Guidelines Committee

*JOURNAL OF TRAUMA & ACUTE CARE SURGERY* | Online – 6 December 2018 – Despite an aging population and increasing number of geriatric trauma patients annually, gaps in the understanding of best practices for geriatric trauma patients persist. Trauma center care improves outcomes for injured patients generally, and palliative care (PC) processes can improve outcomes for disease-specific conditions, and the authors’ goal was to determine effectiveness of these interventions on outcomes for geriatric trauma patients. They reviewed 7 articles relevant to trauma center care and 9 articles reporting results on PC processes as they related to geriatric trauma patients. Given data quality and limitations, the authors conditionally recommend trauma center care for the severely injured geriatric trauma patients, but are unable to make a recommendation on the question of routine PC processes for geriatric trauma patients. **Abstract:** <https://goo.gl/5NerGu>

### Medscape Ethics Report 2018: Life, Death, and Pain [in the U.S.]

*MEDSCAPE* | Online – 12 December 2018 – On a daily basis, physicians in the U.S. confront difficult decisions regarding patient care. Most often, the hardest choices come in weighing the life and death of a patient as well as dealing with their pain. No matter the specialty, making these judgement calls can challenge any healthcare professional. *Medscape* surveyed more than 5,200 physicians in over 29 specialties to find out how they feel about the key issues they wrestle with today, among them:

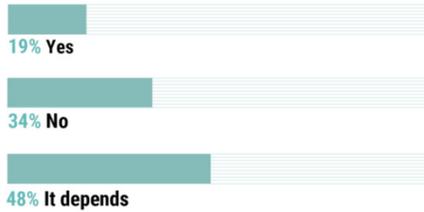


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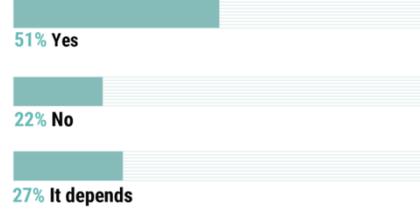
DO YOU THINK DECISIONS ARE BEING MADE TO WITHDRAW PATIENTS FROM LIFE SUPPORT TOO SOON?



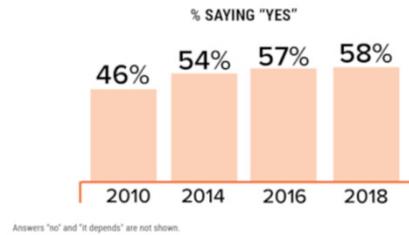
WOULD YOU GO AGAINST A FAMILY'S WISHES TO STOP TREATMENT AND CONTINUE TREATING A PATIENT WHOM YOU FELT HAD A CHANCE TO RECOVER?



SHOULD TERMINALLY ILL PATIENTS BE PERMITTED TO TRY ANY REMEDY OR POSSIBLE TREATMENT THEY WISH?



SHOULD PHYSICIAN-ASSISTED SUICIDE OR "PHYSICIAN-ASSISTED DYING" BE MADE LEGAL FOR TERMINALLY ILL PATIENTS?



Download/view *Medscape* report at: <https://goo.gl/gDSHmq>

### Palliative care in patients with hematological malignancies

*ONCOLOGY RESEARCH & TREATMENT*, 2018;42(1-2). Patients with hematologic malignancies (HM) nowadays rarely receive palliative or hospice care, and studies on potential effects of integrated palliative care are rare. This narrative review provides a comprehensive overview on their current end-of-life care, first data on integrated specialist palliative care (SPC) and potential barriers. Symptom burden and distress in patients with HM seem to be comparable to other cancer patients, but their performance status and specific symptoms are even worse. Prolongation of life usually remains the main focus until the last days or weeks of life. Their chance to die in hospital is twice as high, but their chance to receive specialist palliative or hospice care is only half of that of other cancer patients. Prospective studies indicate a high acceptability and positive effects of integrated SPC, e.g., clarification of treatment goals, stabilization of quality of life, decreased depression, anxiety, symptom burden, and post-traumatic stress disorders. Interdisciplinary cooperation, timely discussions about SPC referral and indicators to "flag" patients in need for SPC are important, but are largely missing. **Abstract (w. list of references):** <https://goo.gl/HbeW4V>

Noted in Media Watch 19 November 2018 (#590, p.9):

- *CURRENT ONCOLOGY REPORTS* | Online – 13 November 2018 – ‘**Palliative care in patients with leukemia: When and how?**’ Patients with hematologic malignancies get more aggressive treatment and the end-of-life, more ICU deaths, and prolonged hospital stays. In comparison to solid tumors, their access to palliative care and hospice is less. Multiple factors seem to play a role including curative goals, different treatment options, stronger relationship between patients and oncologist, symptom burden, and limitations of hospice care. **Abstract (inc. list of references):** <https://goo.gl/upc5sj>

Noted in Media Watch 9 July 2018 (#571, p.10):

- *THE HEMATOLOGIST* | Online – 6 July 2018 – ‘**Are transfusions a barrier to high-quality end-of-life care in hematology?**’ Unfortunately, evidence suggests that patients with hematologic malignancies are significantly less likely to use hospice care services than patients with solid tumors, instead receiving aggressive care at the end of life, including chemotherapy in the last 14 days, or spending time in a hospital, intensive care unit, or emergency department in their last month, sometimes even dying in the hospital. **Full text:** <https://goo.gl/k1dpoj>

## Quality improvement priorities for safer out-of-hours palliative care: Lessons from a mixed-methods analysis of a national incident-reporting database

*PALLIATIVE MEDICINE* | Online – 12 December 2018 – Patients receiving palliative care (PC) are often at increased risk of unsafe care with the out-of-hours setting presenting particular challenges. The identification of improved ways of delivering PC outside working hours is a priority area for policymakers. The authors analysed 1,072 patient safety incident reports involving patients receiving sub-optimal PC via the out-of-hours primary-care services. Incidents included issues with: medications; access to timely care; information transfer, and/or non-medication-related treatment such as pressure ulcer relief or catheter care. Almost two-thirds of reports described harm with outcomes such as increased pain, emotional, and psychological distress featuring highly. Commonly identified contributory factors to these incidents were a failure to follow protocol, lack of skills/confidence of staff, and patients requiring medication delivered via a syringe driver. Healthcare systems with primary-care-led models of delivery must examine their practices to determine the prevalence of such safety issues (communication between providers; knowledge of commonly used, and access to, medications and equipment) and utilise improvement methods to achieve improvements in care. **Abstract (w. list of references):** <https://goo.gl/TupK8m>

Noted in Media Watch 3 October 2016 (#482, p.11):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(5):244-245. **'End-of-life care at home out-of-hours: Think 3 a.m.'** The "in-hours" period is only between 9 a.m. and 5 p.m., or thereabouts, while the out-of-hours period represents all the rest; that is, approximately two thirds of the time. The same number of people die every hour, whether this is during the day or at night, during the week or at the weekend. Therefore, out of all people who die, two thirds die during the out-of-hours period. **Access to this article via journal website:** <https://goo.gl/tN4Ra6>

## People with advanced cancer: The process of living well with awareness of dying

*QUALITATIVE HEALTH RESEARCH* | Online – 12 December 2018 – Literature suggests that it is possible to live well with advanced cancer but little is known about the process. In this article, The authors present a secondary analysis of experiences of living with advanced cancer that refines the theory of "living well with chronic illness" for a different context and population. The refined theory explains the experience of living well with advanced cancer illuminating a five-phase iterative process: struggling, accepting, living with advanced cancer, sharing the illness experience, and reconstructing life. These five phases revolve around the core concept of *awareness of dying*, which varied from awareness of the possibility of dying, to accepting the possibility of dying, to acceptance that "I am dying." *Awareness of dying* led to a focus on living well with advanced cancer and movement towards living a life rather than living an illness. **Full text:** <https://goo.gl/F9o8WW>

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BECKER'S HOSPITAL REVIEW* | Online – 12 December 2018 – **'More physicians [in the U.S.] support assisted suicide...'** A new *Medscape* survey shows physician support for assisted suicide is growing and sheds light on physician beliefs on other ethical issues.<sup>1</sup> The survey of 5,200 U.S. physicians in 29 specialties found that more than half of them (58%) said they believe physician-assisted suicide or physician-assisted dying should be legal for terminally ill patients. That compares to 57% in 2016 and 46% in 2010. Forty-five percent of survey respondents said they believe physician-assisted suicide or physician-assisted dying should not be made legal for patients with incurable suffering, even if the disease isn't going to kill them right away. Twenty-seven percent said they believe it should be made legal, and 28% said, "it depends." **Full text:** <https://goo.gl/6oE7Yb>

1. 'Medscape Ethics Report 2018: Life, Death, and Pain,' December 2018. **Download/view at:** <https://goo.gl/QDR6gS>

## Publishing Matters

### Reporting guidelines: Doing better for readers

*BMC MEDICINE* | Online – 14 December 2018 – There is clear guidance on the responsibilities of editors to ensure that the research they publish is of the highest possible quality. Poor reporting is unethical and directly impacts patient care. Reporting guidelines are a relatively recent development to help improve the accuracy, clarity, and transparency of biomedical publications. They have caught on, with hundreds of reporting guidelines now available. Some journals endorse reporting guidelines while a smaller number have used various approaches to implement them. Yet challenges remain – biomedical research is still not optimally reported despite the abundance of reporting guidelines. Electronic algorithms are now being developed to facilitate the choice of correct reporting guideline(s), while other tools are being integrated into journal editorial management processes. Universities need to consider whether it is responsible to advance careers of faculty based on poorly reported research which is of little societal value. If journals embraced auditing of the quality of articles they publish this would give them and their readers essential feedback from which to improve their product. **Full text:** <https://goo.gl/8XCkG7>

### RE: How predatory journals leak into PubMed

*CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online – 10 December 2018 – The premise of the article by Manca *et al* is based on two of their previous studies,<sup>1</sup> in which they suggest that a high number of “predatory” journals are accepted for PubMed and PubMed PMC, and that the National Library of Medicine (NLM) should “raise the bar for journal inclusion.” However, Manca and colleagues have mistakenly characterized these journals as being included in PMC by conflating the appearance of one or more individual journal articles, which are included in PMC to support the public access policies of research funders, with the inclusion of articles from an accepted journal. A journal is considered “accepted” and added to PubMed only if it has been formally assessed and recommended for indexing in MEDLINE or archiving in PMC. Moreover, the authors make several incorrect statements about PubMed and NLM policies, most notably regarding journal selection criteria for PMC. In fact, journals that apply to be in PMC undergo a rigorous assessment of scientific and editorial quality, and the same assessment considerations are used to re-evaluate previously accepted journals. In addition, NLM reviews publishers of PMC and MEDLINE journals for ongoing conformance with publishing guidelines and best practices. **Full text:** <https://goo.gl/XrCequ>



### Too much academic research is being published

*INTERNATIONAL HIGHER EDUCATION*, 2019;96. There is a crisis in academic publishing and in the global knowledge-distribution system in general – there is too much pressure on top journals, there are too many books and articles of marginal quality, predatory journals are on the rise, and there is a tremendous pressure on academics worldwide to publish. We propose recognizing that most universities and most academics, globally, focus on teaching, and that the large majority of universities acknowledge their important roles as teaching-focused and do not seek to become research-intensive institutions. We call for quality, but also for control of what quality is, by the academic community instead of by nonacademic rankers, publishers, and citation and impact measurers. Quality – not quantity – should be the objective, in combination with an effort to bring quality control back into the academic community – while making sure that that control is not dominated by small groups in research universities in the rich countries. **Abstract:** <https://goo.gl/oZAah9>

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

1. 'How predatory journals leak into PubMed,' *Canadian Medical Association Journal*, 2018;190(35): E1042-E1045. [Noted in the 10 September 2018 issue of *Media Watch* (#580, p.12)] **Access options:** <https://goo.gl/2qVaDv>

## Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

## Distribution

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

## Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

## Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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



Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

## Media Watch: Access on Online

### **International**



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/S34vvs>

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

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

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

[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']

Cont.

## 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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