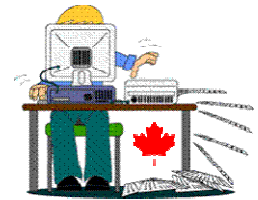


## Media Watch...

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

**Navigating the illness experience: Scroll down to [Specialist Publications](#) and ‘The need for flexibility when negotiating professional boundaries in the context of home care, dementia and end of life’ (p.4), in *Ageing & Society*.**

## Canada

### The bereaved, better-informed, no longer always do what they are told or pay whatever they are asked

ONTARIO | *The Economist* – 12 April 2018 – America’s 2.7 million-odd deaths a year underpin an industry worth \$16 billion in 2017, encompassing over 19,000 funeral homes and over 120,000 employees. In France the sector is worth an estimated €2.5 billion (\$3.1 billion). The German market was worth €1.5 billion in 2014 and employed nearly 27,000 people, a sixth of them undertakers. In Britain the industry, estimated to be worth around £2 billion (\$2.8 billion), employs over 20,000 people, a fifth of them undertakers. As baby-boomers hit old age, the annual death rate will climb from 8.3 per 1,000 people today to 10.2 by 2050 in America, from 10.6 to 13.7 in Italy, and from 9.1 to 12.8 in Spain. Spotting the steady rise in clientele, money managers – from risk-seeking venture capitalists to boring old pension funds – have been getting into the death business. Last year the Ontario Teachers Pension Fund bought one of Spain’s largest funeral businesses from 3i Group, a British private-equity firm, for £117 million, and increased its stake in a French equivalent. The dead-body business is seen as highly predictable, uncorrelated with other industries, inflation-linked, low-risk and high-margin. In North America the modern under-taker’s job is

increasingly one of event-planning, says Sherri Tovell, an undertaker in Windsor, Canada. <https://goo.gl/1Z76jp>

### Specialist Publications

**‘Community readiness and momentum: Identifying and including community-driven variables in a mixed-method rural palliative care service siting model’** (p.5), in *BMC Palliative Care*.

**‘Barriers to and enablers of advance care planning with patients in primary care’** (p.11), in *Canadian Family Physician*.

**‘New dimensions in palliative care cardiology’** (p.7), in *Canadian Journal of Cardiology*.

**‘Teaching residents about medical assistance in dying’** (p.14), in *Canadian Family Physician*.

**‘A response to popular arguments against permitting medical assistance in dying (MAiD) where mental illness is the sole underlying condition’** (p.14), in *Canadian Journal of Psychiatry*.

## U.S.A.

### **Our surprise finding: Whatever a doctor's political views, end-of-life care is the same**

USA TODAY | Online – 12 April 2018 – As Americans have grown ideologically segregated, so too have doctors. A generation ago, most doctors were Republicans. Today, they're split evenly between the parties and cluster along familiar lines: men, older physicians and higher-paid specialists favor Republicans, while women, younger doctors and lower-paid specialists lean Democrat. These political affiliations influence how doctors feel about a variety of health issues, including gun control, abortion, the Affordable Care Act and whether the medical profession is obligated to care for the uninsured. What does this mean for how patients and families are cared for? In a new study<sup>1</sup> ... we analyzed whether doctors' political preferences affect the care patients receive at the end of life – a heavily politicized and value-laden area of medicine and one that prior research has shown is influenced by how doctors counsel patients.<sup>2</sup> Let's say you're admitted to the hospital with a terminal condition. You and your family are trying to make important, agonizing decisions about what you want in your final days – weighing complex trade-offs of quality and quantity of life. The doctor caring for you is either strongly Democrat or strongly Republican and has donated to political candidates in recent elections.

Are you more or less likely to get a breathing tube? To be admitted to the ICU or, instead, be discharged to hospice? To receive a feeding tube for artificial nutrition? Will the health system spend any more or any less? The answer to each of these questions is: No. <https://goo.gl/jDjgJV>

#### Specialist Publications

**'Facilitating home hospice transitions of care in oncology: Evaluation of clinical pharmacists' interventions, hospice program satisfaction, and patient representation rates'** (p.5), in *American Journal of Hospice & Palliative Medicine*.

**'Interprofessional training: Geriatrics and palliative care principles for primary care teams in an Accountable Care Organization'** (p.8), in *Gerontology & Geriatrics Education*.

**'Defining death: Making sense of the case of Jahi McMath'** (p.9), in *Journal of the American Medical Association*.

**'Health sciences library outreach to family caregivers: A call to service'** (p.9), in *Journal of the Medical Library Association*.

1. 'Physicians' political preferences and the delivery of end-of-life care in the U.S.: Retrospective observational study,' *British Medical Journal*, published online 11 April 2018. **Full text:** <https://goo.gl/jDjgJV>
2. 'Physician characteristics strongly predict patient enrolment in hospice,' *Health Affairs*, 2015;34(6):993-1000. [Noted in the 15 June 2015 issue of *Media Watch* (#414, p.30)] **Abstract (w. notes):** <https://goo.gl/QYxsUr>

### **Survey: More families having “the conversation” about end of life**

THE CONNECTICUT POST (Bridgeport) | Online – 10 April 2018 – Not only are more than half of Americans open to talking about end-of-life (EoL) decisions with a loved one, but more people are actually having those conversations, compared to just five years ago. That's according to a national survey by the Conversation Project, a Boston-based program dedicated to helping people talk about their wishes for EoL care. The data show that 53% of the roughly 1,000 Americans polled said that they would feel relieved if a loved one started a discussion about how they want to live at the end of their lives, and that 32% of those polled are actually having these conversations. The last Conversation Project survey, done in 2013, showed that more than 90% of Americans thought it was important to have the conversation, but only 27% had done it. <https://goo.gl/jH91Bi>

**N.B.** The Conversation Project website: <https://goo.gl/shJnuM>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- WASHINGTON DC | *The Washington Post* – 10 April 2018 – ‘**A year after D.C. passed its controversial assisted suicide law, not a single patient has used it.**’ Nearly a year after the District enacted a law allowing terminally ill patients to end their lives – over the objections of congressional Republicans, religious groups and advocates for those with disabilities – not a single patient has used it. And just two of the approximately 11,000 physicians licensed to practice in the District have registered to help patients exercise their rights under the law. Only one hospital has cleared doctors to participate. The bill ... allows patients with less than six months to live to receive a fatal dose of drugs after making two requests at least 15 days apart. Two witnesses must attest that the requesting patient was of sound mind, and patients must take the medication without assistance. DC health officials added requirements when implementing the law ... including psychological evaluations for patients, registration for doctors, and online training for patients and doctors. <https://goo.gl/LzdDKN>

## International

### Charity removes “hospice” from name to avoid putting off beneficiaries

U.K. (England) | Civil Society Media (London) – 11 April 2018 – A care providing charity has removed the word “hospice” from its name after finding the term was putting off potential beneficiaries from accessing its services. Compton Care today announced its rebrand from Compton Hospice after conducting research that found people were fearful of accessing its services. The Wolverhampton-based charity found a large number of patients, staff and supporters associate the word “hospice” with being “a place you go to die.” According to the £9 million charity, this negative perception has contributed to people often becoming fearful of accessing its care, as well as healthcare professionals making referrals only in the final weeks or days of a person’s life. <https://goo.gl/4GLTLz>

### High court judge backs end-of-life care plan for toddler on life support

U.K. (England) | *The Guardian* (London) – 11 April 2018 – A high court judge has endorsed an end-of-life care plan for a 23-month-old boy who has been at the centre of a life-support treatment legal battle. Mr. Justice Hayden said the details of provisions for the final stage of Alfie Evans’s life could not be made public. Alfie’s parents, Tom Evans and Kate James, from Liverpool, have lost treatment fights in the high court, court of appeal, supreme court and European court of human rights. In February, Hayden had ruled that doctors at Alder Hey children’s hospital in Liverpool could stop treating Alfie against the wishes of his parents following hearings in the family division of the high court in London and Liverpool. He endorsed a detailed plan put forward by Alder Hey doctors for withdrawing life-support treatment during a follow-up hearing in London. <https://goo.gl/jhU7y7>

**N.B.** Earlier news media coverage of the Alfie Evans case noted in the 2 April 2018 issue of Media Watch (#557, p.6).

### Specialist Publications

‘**What is the cost of palliative care in the U.K.? A systematic review**’ (p.12), in *BMJ Supportive & Palliative Care*.

‘**End-of-life care in ICUs in East Asia: A comparison among China, Korea, and Japan**’ (p.7), in *Critical Care Medicine*.

‘**Access to strong opioid analgesics in the context of legal and regulatory barriers in eleven Central and Eastern European countries**’ (p.10), in *Journal of Palliative Medicine*.

‘**The first unified official regulation of how to organize palliative care in Romania**’ (p.11), in *Paliatia*.

‘**What readers thought about the *BMJ*’s articles on assisted dying**’ (p.14), in *British Medical Journal*.

## Four out of five Swiss support palliative care

SWITZERLAND | Swiss Broadcasting Corporation (Bern) – 10 April 2018 – Most Swiss are in favour of palliative care being made available to terminally ill and dying people, a study by the Federal Office of Public Health has found. More than two thirds of survey respondents said they had already concretely thought about the type of treatment and care they would like to receive at the end of their lives. Half of all respondents believed it was important to address these topic at an early stage, when they still felt healthy. Some 8% of respondents had already spoken to health professionals about their treatment plan wishes. The study also examined how well-known the term “palliative care” was among the Swiss. It found that the percentage of people who have heard of the term rose from 48% to 59% compared to data collected nine years ago. <https://goo.gl/aD2xof>

**N.B.** Additional articles on palliative care in Switzerland noted in the 6 February 2017 issue of Media Watch (#498, p.16).

## Specialist Publications

### **The need for flexibility when negotiating professional boundaries in the context of home care, dementia and end of life**

AGEING & SOCIETY | Online – 10 April 2018 – Professional boundaries may help care staff to clarify their role, manage risk and safeguard vulnerable clients. Yet there is a scarcity of evidence on how professional boundaries are negotiated in a non-clinical environment (e.g., the home) by the home-care workforce in the context of complex care needs (e.g., dementia, end-of-life care). Findings from this study indicate that home-care workers and their managers have clear perceptions of job role boundaries, yet these are modified in dementia care, particularly at end of life (EoL), which routinely requires adaptability and flexibility. As a lone worker in a client's home, there may be challenges relating to safeguarding and risk to both clients and workers. The working environment exacerbates this, particularly during EoL care where emotional attachments to both clients and their family may affect the maintenance of professional boundaries. There is a need to adopt context-specific, flexible and inclusive attitudes to professional boundaries, which reconceptualise these to include relational care and atypical workplace conventions. Pre-set boundaries which safeguard clients and workers through psychological contracts may help to alleviate to some extent the pressure of the emotional labour undertaken by home-care workers. **Abstract (w. link to references):** <https://goo.gl/oHZX9q>

#### **From the archives:**

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2012;8(1):10-28. **‘Exploring professional boundaries in end-of-life care: Considerations for hospice social workers and other members of the team.’** Hospice social workers and members of the interdisciplinary team develop close therapeutic relationships with patients and families as they journey toward death. During this process, situations can develop that challenge professional boundaries and blur the line between a professional and personal relationship.. **Abstract (w. link to references):** <https://goo.gl/aWFqGh>



### 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>

## **Facilitating home hospice transitions of care in oncology: Evaluation of clinical pharmacists' interventions, hospice program satisfaction, and patient representation rates**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 April 2018 – A transitions of care pilot initiative was developed to streamline the transition for patients at end of life from inpatient cancer center care to home hospice. The initiative consisted of using a hospice discharge checklist, pharmacist-led discharge medication reconciliation in consultation with the primary team responsible for inpatient care, review of discharge prescriptions, and facilitation of bedside delivery of discharge medications. This well-received pilot initiative demonstrated an improvement in local hospice's perception of patient readiness for discharge and a high percentage of accepted pharmacist interventions during discharge medication reconciliation. **Abstract:** <https://goo.gl/DkoEVV>

Noted in Media Watch 29 August 2016 (#477, p.5):

- *AMERICAN JOURNAL OF HEALTH-SYSTEM PHARMACY*, 2016;73(17):1351-1367. '**American Society of Health-System Pharmacists Guidelines on the Pharmacist's Role in Palliative & Hospice Care.**' Despite representation within the first hospice demonstration project in the U.S., participation of the pharmacist as an essential member of the interdisciplinary team has been traditionally overlooked. Evidence of the pharmacist's contribution to the delivery of PC and supportive care services beyond the original role of medication dispensing and compounding has garnered growing recognition across numerous practice settings. **First page view:** <http://goo.gl/qV9VcJ>

**N.B.** Access the American Society of Health-System Pharmacists guidelines at: <https://goo.gl/X5xboF>

### **Palliative care in rural and remote regions of Canada**

#### **Community readiness and momentum: Identifying and including community-driven variables in a mixed-method rural palliative care service siting model**

*BMC PALLIATIVE CARE* | Online – 6 April 2018 – Health service administrators make decisions regarding how to best use limited resources to have the most significant impact. Service siting models are tools that can help in this capacity. The authors build on their own mixed-method service siting model focused on identifying rural Canadian communities most in need of and ready for palliative care (PC) service enhancement through incorporating new community-driven insights. They previously introduced the inclusion of a "community readiness" arm in the siting model. This arm is based on five community-driven indicators of PC service enhancement readiness and need. The current analysis underscore the importance of this arm of the model. However, the data also revealed the need to subjectively assess the presence or absence of community awareness and momentum indicators. Findings of this study point to factors such as educational tools, volunteers, and local acknowledgement of PC priorities as reflecting the presence of community awareness and factors such as new employment and volunteer positions, new care spaces, and new projects and programs as reflecting momentum. **Full text:** <https://goo.gl/Xyz16S>

Noted in Media Watch 5 March 2018 (#553, p.10)

- *JOURNAL OF RURAL & COMMUNITY DEVELOPMENT*, 2018;13(1):1-12. '**A case study exploring the implications of one Alberta rural community's experience with planning their own hospice care.**' This article describes how one community in rural Alberta, Canada, worked to plan for their rapidly increasing hospice care needs. The author's study advances understanding about how hospice care, a major health care service in high demand, is being provided by community members as a result of governments downloading health service planning onto the shoulders of local communities in the name of "community engagement." **Full text:** <https://goo.gl/3aURCH>

Cont. next page

Noted in Media Watch 22 August 2016 (#476, p.11):

- *HEALTH & PLACE*, 2016;41(9):19-23. **‘Revisiting the use of “place” as an analytic tool for elucidating geographic issues central to Canadian rural palliative care.’** In 2010, Castleden *et al* published a paper using the concept of “place” as an analytic tool to understand the nature of palliative care (PC) provision in a rural region in British Columbia, Canada.<sup>1</sup> The authors of this article revisit Castleden and colleagues’ original framework. Applying the concept of place to the full dataset confirmed the previously published findings, but also revealed two new place-based dimensions related to experiences of rural PC in Canada. **Abstract:** <http://goo.gl/13BJL1>

1. “It’s not necessarily the distance on the map...”: Using place as an analytic tool to elucidate geographic issues central to rural palliative care,’ *Health & Place*, 2010;16(2):284-290. [Noted in the 18 January 2010 issue of Media Watch (#132, p.6)] **Abstract:** <http://goo.gl/6im5qm>

**N.B.** Postings on the Rural Ontario Institute website offer a perspective on palliative and end-of-life care in remote and rural communities in Canada: 1) ‘End-of-life Care in Rural Communities’ <https://goo.gl/P4e4rn>; and, 2) ‘Survey: Urban vs. Rural Palliative Medicine’ <https://goo.gl/i5KcPZ>. The latter was conducted in 2015 by the Canadian Medical Association.

### End-of-life care in London, England

### The impact of Ceiling of Treatment plans in patients with Coordinate My Care

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 7 April 2018 – The aim of this evaluation is to describe the components and results of urgent care planning in Coordinate My Care (CMC), a digital clinical service for patients with life-limiting illness, for use if a patient is unable to make or express choices. Ceiling of treatment (CoT) plans were created detailing where the patient would like to receive their care and how aggressive medical interventions should be. Two-thirds of patients [i.e., of the patient population studied] had recorded decisions about CoT. Regardless of which CoT option was chosen, for most patients, place of death (PPD) was home or care home. Patients with a CoT plan were more likely to have a documented resuscitation status. This analysis demonstrates that a substantial proportion of patients are willing to engage in urgent care planning. Three facets of urgent care planning identified include PPD, CoT, and resuscitation status. **Full text:** <https://goo.gl/8Jh49a>

**N.B.** Coordinate My Care website: <https://goo.gl/62eGWZ>

Noted in Media Watch 12 June 2017 (#516, p.5):

- *CLINICAL MEDICINE*, 2017;17(3):s29. **‘First do no harm: Changing culture surrounding ceilings of treatment in end-of-life care.’** 90% of doctors and 73% of nurses [i.e., survey respondents] witnessed patients undergoing treatments they considered to be futile or burdensome. 71% of doctors and 77% of nurses have been left unsure what active interventions a patient is still considered for. After educational events and the addition of the Ceiling of Treatment (CoT) form, the number of patients with a clear CoT identification has risen from 12% to 53%. Patients documented as “do not attempt CPR” have had improved CoT identification from 35% to 92%. **Abstract:** <https://goo.gl/CMkGTh>

Noted in Media Watch 26 November 2012 (#281, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2012;2(4):301-307. **‘Coordinate My Care: A clinical service that coordinates care, giving patients choice, and improving quality of life.’** Coordinate My Care (CMC) is a service dedicated to preserving dignity and autonomy at the end of life. Its care pathways enable health professionals from primary and secondary care to put the patient at the centre of health care delivery. This service is underpinned by an electronic solution. The CMC record can be accessed 24/7 by all health and social care professionals who have a legitimate relationship with the patient. **Abstract:** <https://goo.gl/VHXzj3>



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

## New dimensions in palliative care cardiology

*CANADIAN JOURNAL OF CARDIOLOGY* | Online – 6 April 2018 – Advances have unquestionably improved the prognosis with advanced cardiovascular illnesses. However, they have also changed patient and family attitudes about death and dying, to the point where we have effectively “medicalized our mortality.” The importance of introducing palliative care (PC) to the cardiac patient population is now well-recognized, with the major cardiovascular societies incorporating PC principles into their guideline and consensus statement documents. However, despite this recognition, few cardiac patients get access to PC and other resources such as hospice. The authors review the existing literature on this topic and discuss opportunities for developing and fostering a more collaborative relationship between the disciplines of cardiology and PC. **Abstract (w. link to references):** <https://goo.gl/KUdhWU>

### Social worker-aided palliative care intervention in high-risk patients with heart failure...

*JAMA CARDIOLOGY* | Online – 11 April 2018 – Can routine initiation of goals of care discussions by a palliative care (PC) social worker bridging inpatient to outpatient care facilitate greater patient-physician engagement around PC considerations in high-risk patients hospitalized with decompensated heart failure? In this randomized clinical trial, compared with usual care, patients allocated to the social worker-led intervention were more likely to have physician-level documentation of care preferences in the electronic health record and to have prognostic expectations aligned with their physicians without worsening of depression, anxiety, or quality-of-life scores. **Abstract:** <https://goo.gl/DweL15>

**N.B.** Additional articles on palliative care for people living with cardiovascular disease noted in the 29 January and 26 March 2018 issues of Media Watch (#548, p.9 and #556, p. 10, respectively).

#### Related

- *CIRCULATION* | Online – 9 April 2018 – ‘**Projected costs of informal caregiving for cardiovascular disease (2015 to 2035): A policy statement from the American Heart Association.**’ The costs of informal caregiving for patients with cardiovascular disease (CVD) were estimated to be \$61 billion in 2015 and are projected to increase to \$128 billion in 2035. Costs of informal caregiving of patients with stroke constitute more than half of the total costs of CVD informal caregiving (\$31 billion in 2015, \$66 billion in 2035). Costs of informal caregiving for patients with CVD represent an additional 11% of medical and productivity costs attributable to CVD. **Abstract:** <https://goo.gl/YLbjud>

## End-of-life care in ICUs in East Asia: A comparison among China, Korea, and Japan

*CRITICAL CARE MEDICINE* | Online – 6 April 2018 – Chinese [survey] respondents were least likely to apply do-not-resuscitate (DNR) orders, even if they existed. Japanese respondents were most likely to practice DNR for terminally ill patients during cardiac arrest, even when no such prior order existed. Korean respondents’ attitudes were in between those of Chinese and Japanese respondents as far as withdrawing total parenteral nutrition, antibiotics, dialysis, and suctioning was concerned. Chinese respondents were most uncomfortable discussing end-of-life (EoL) care issues with patients, while Japanese respondents were least uncomfortable. Chinese respondents were more likely to consider financial burden when deciding on limiting life-sustaining treatment. Japanese respondents felt least exposed to personal legal risks when limiting life-sustaining treatment, and the Korean respondents most wanted legislation to guide this issue. The respondents’ [specialists who are either intensivists or non-intensivist primary attending physicians in charge of patients; 195 in China, 186 in Korea, 224 in Japan] gender, religion, clinical experience, and primary specialty were also independently associated with the different perceptions of EoL care. Despite similarities in cultures and a common emphasis on the role of family, differences exist in physician perceptions and practices of EoL ICU care in China, Korea, and Japan. These findings may be due to differences in the degree of Westernization, national healthcare systems, economic status, and legal climate. **Abstract:** <https://goo.gl/RyuN9q>

## Sharing is caring: Minimizing the disruption with palliative care

*CUREUS JOURNAL OF MEDICAL SCIENCE* | Online – Accessed 12 April 2018 – When patients approach the end of life, they are often faced with a challenging multidimensional burden while navigating a complex health care system. Patients and families/caregivers are faced with daily decisions, often with little or no frame of reference or medical knowledge. The “what, how, when, and where” puzzle during this challenging time can be overwhelming for patients and their families, and when clinicians do not contemplate this, associated workload’s impact on patients and caregivers’ capacity for self-care, patients and caregivers scramble to find compensatory solutions, often putting their health care at lower priority. This consequently warrants the underlying importance of palliative care (PC) and integrating it into the patients’ health care plans earlier. There is increasing evidence from recent trials that supported implementing national policies regarding the early integration of PC and its role in improving the quality of life, increasing survival, and supporting patients’ and caregivers’ values when making decisions about their health care while possibly minimizing the burden of illness. **Full text:** <https://goo.gl/nqzweL>

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

#### **Interprofessional training: Geriatrics and palliative care principles for primary care teams in an Accountable Care Organization**

*GERONTOLOGY & GERIATRICS EDUCATION* | Online – 9 April 2018 – The authors developed an adaptable curriculum around commonly encountered topics in palliative care (PC) and geriatrics that can be delivered to multidisciplinary clinicians in primary care settings. Participants were part of an Accountable Care Organization and were motivated to improve to care for complex older adults. A needs assessment was performed on each practice or group of learners and the curriculum was adapted accordingly. With the use of patient education and screening tools with strong validity evidence, the participants were trained in the principals of geriatrics and PC with a focus on advance care planning and assessing for frailty and functional decline. Comparison of pre- and post-test scores demonstrated increased confidence and knowledge in goals of care and basic geriatric assessment. **Abstract:** <https://goo.gl/LKuMyG>

Noted in Media Watch 9 October 2017 (#533, p.16):

- *CURRENT ONCOLOGY REPORTS* | Online – 2 October 2017 – ‘**Using geriatric assessment strategies to lead end-of-life care discussions.**’ Developing a roadmap for these conversations can be challenging. Patients and caregivers may have expectations that are not concordant with what is reasonably achievable if the patient is frail. Measuring baseline cognition, nutritional status, and physical function and discussing goals of care are all essential pieces of information that can be obtained through a comprehensive geriatric assessment. **Full text:** <https://goo.gl/7C7x1J>

Noted in Media Watch 17 April 2017 (#508, p.7):

- *CLINICS IN GERIATRIC MEDICINE* | Online – 6 April 2017 – ‘**Integrating quality palliative and end-of-life care into the geriatric assessment.**’ Integrating quality palliative and end-of-life care (P&EoLC) into geriatric assessment can be a tremendous benefit to older adult patients and their families. Although the quality of P&EoLC for older adults has improved greatly, there are still many opportunities to improve the quality of life and function for older adult patients in the last few years of their life. **Abstract (w. link to references):** <https://goo.gl/5vhdzr>

**N.B.** Noted in the 6 February 2017 issue of Media Watch (#498, p.6) additional articles on the common ground shared by geriatric and palliative medicines.



### Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.15.



## Defining death: Making sense of the case of Jahi McMath

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 9 April 2018 – Cases like that of Jahi McMath cause great angst because they seem to cast doubt on the ability of the medical profession to distinguish between the living and the dead. The confusion disappears, however, with the recognition that law and biology function differently. The law necessarily depends on bright-line determinations to standardize many important societal distinctions, such as when a person becomes an adult, when a person is blind, and when a person is dead. However, failure to appreciate this distinction has also led to some factually inaccurate comments from prominent bioethicists about the McMath case... Comments like these, in the face of clear evidence to the contrary, erode the confidence of the public in the truthfulness and candor of the medical profession. The Uniform Determination of Death Act [adopted by most states in the U.S.] has served its purpose well. By drawing a bright line at the level of permanent unconsciousness and ventilator dependence, the Act has defined when a person should be considered dead, making it permissible for the person to be an organ donor if they wish and making it permissible for the health care system to refuse to continue to provide the patient with life support. Like many other legal bright lines, it is a social construction based on biological reality but not completely defined by it. Although the line is necessarily somewhat arbitrary, it represents a meaningful threshold, which over several decades has had widespread societal acceptance. **Full text:** <https://goo.gl/CZdnG4>

Noted in Media Watch 5 February 2018 (#549, p.4):

- U.S. (California) | *The New Yorker* – 5 February 2018 – **‘What does it mean to die?’** When Jahi McMath was declared brain-dead by the hospital her family disagreed. Her case challenges the very nature of existence. Like all states, California follows a version of the 1981 Uniform Determination of Death Act, which says someone who has sustained the “irreversible cessation of all functions of the entire brain, including the brain stem, is dead.” California law requires that hospitals permit “a reasonably brief period of accommodation” before disconnecting a ventilator – long enough to allow family to gather, but not so long that hospitals neglect the “needs of other patients and prospective patients in urgent need of care.” <https://goo.gl/qYchgD>

**N.B.** Additional articles on defining “brain dead” noted in the 20 November 2017 issue of Media Watch (#539, p.1).

## Health sciences library outreach to family caregivers: A call to service

*JOURNAL OF THE MEDICAL LIBRARY ASSOCIATION*, 2018;106(2):251-258. Receiving emotional support and authoritative information from librarians, who are part of the health care team, uplifts and unleashes the resourcefulness, resilience, and strengths of family caregivers. As proactive members of the health care team, librarians can embrace and honor family caregivers and their care recipients through expanded library outreach and information services. The recommendations for health sciences library outreach services build family caregiver strengths. Family empowerment, personhood, problem-solving, and a positive outlook are beneficial outcomes for caregivers, who are fully accepted as part of the patient’s care team and are offered unconditional support and acknowledgment. Health sciences librarians can creatively address caregiving challenges, introduce a wide range of practical solutions to address problems, focus mindfully on the present moment, support the establishment of a broad “circle of care” and social safety network, and advance the vision of a better world filled with hope and compassion for family caregivers, their loved ones, their health care teams, our local communities, and ourselves as librarians. Three strategies are recommended for developing health sciences library outreach services to family caregivers. **Full text:** <https://goo.gl/6YGRv7>

Palliative Care Network

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

## **Mediating systems of care: Emergency calls to long-term care facilities at life's end**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 April 2018 – The findings of this study illuminate how pre-hospital providers become mediators between nursing homes and emergency departments by managing tension, conflict, and challenges in patient care between these systems and suggest the importance of further exploration of interactions between long term care (LTC) staff, pre-hospital providers, and emergency departments. Enhanced communication between LTC facilities and pre-hospital providers is important to address potentially inappropriate calls and transport requests and to identify means for collaboration in the care of sick frail residents. **Abstract:** <https://goo.gl/pR9Bjp>

## **Factors associated with early referral to palliative care in outpatients with advanced cancer**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 April 2018 – The authors conducted a retrospective review of 337 patients with advanced cancer referred to outpatient palliative care at a comprehensive cancer center. 232 (69%) referrals were late, 60 (18%) intermediate, and 45 (13%) early. On multivariable analysis, earlier referral was associated with earlier primary cancer diagnosis, and referral for pain and symptom management. Patients who were referred late had worse overall Edmonton Symptom Assessment System distress scores, as well as worse tiredness, nausea, drowsiness, appetite, and wellbeing. A longer disease course and referral for symptom management were associated with earlier referral, whereas overall symptom burden was higher for late referrals. **Abstract:** <https://goo.gl/dY8igr>

## **Access to strong opioid analgesics in the context of legal and regulatory barriers in eleven Central and Eastern European countries**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 6 April 2018 – In 2011-2013, 95% of the global opioid analgesics consumption occurred in three regions, accounting for 15% of the world population. Despite abundant literature on barriers to access, little is known on the correlation between actual access to opioid analgesics and barriers to access, including legal and regulatory barriers. In this study, no correlation was found, which indicates that other factors besides potential legal and regulatory barriers play a critical role in withholding prescribers and patients essential pain medication in the studied countries. **Abstract:** <https://goo.gl/urBsHq>

## **What is 'The Pause'? Taking a moment to address pain, profundity, and palliative care**

*MD MAGAZINE* | Online – 9 April 2018 – The team was not unfamiliar with the vacuous feeling that often accompanies a patient's passing. Every one of them had lost dozens of patients before and were not ignorant of the fact that death is always looming in the emergency department. For Jonathan Bartels RN, though, this time was different. Slowly and with confidence, a chaplain sauntered to the bedside and asked the staff in the room to stop what they were doing. A soft silence fell on the room. The chaplain began uttering a brief prayer over the patient's body. It honored the patient's life and the practitioners who had struggled to delay her death. The staff in the room reflected, and not long after, dispersed almost in unison. Bartels began conducting 'The Pause' – an increasingly common custom where hospital staff takes a moment to honor the life of a deceased patient – regularly with his colleagues at the University of Virginia Health System. As the then-unnamed, localized act of respect gained momentum, Bartels secularized it to fit the diversity of the patients and practitioners it served. Then, he published an editorial ... giving a name to a practice that is now becoming a phenomenon across health systems.<sup>1</sup> **Full text:** <https://goo.gl/GJzVdf>

1. 'The Pause,' *Critical Care Nurse*, 2014;34(1):74-75. **Full text:** [goo.gl/ATR8o7](http://goo.gl/ATR8o7)

Noted in Media Watch 5 October 2015 (#430, p.4):

- U.S. | *Kaiser Health News* – 28 September 2015 – 'Hospital workers find solace in pausing after a death.' For trauma workers like Jonathan Bartels, a nurse who has worked in emergency care and palliative care, witnessing death over and over again takes a toll. Over time, they can become numb or burned out. But about two years ago, after Bartels and his team at the University of Virginia Medical Center tried and failed to resuscitate a patient, something happened. **Full text:** <https://goo.gl/RLYnfg>

## The first unified official regulation of how to organize palliative care in Romania

*PALIATIA*, 2018;11(2). For 26 years, since the establishment of the first palliative care (PC) service in the country, care for people suffering from progressive or incurable chronic diseases has developed along local initiatives, both in the public and the private system (as charity or private organizations), without the benefit of an organized framework and without being integrated into a coordinated development that provides unitary quality services. Due to this slow and random development of local PC initiatives, the degree of coverage of specialized PC services is still very low, while the need for it is high. Of the more than 172,000 cancer patients and other non-oncological patients who would need PC annually, only 9% now have access to these services. The Order of the Ministry of Health creates the premises for the implementation and development of the World Bank's program through which PC services will be expanded so that the real need can be covered as efficiently as possible throughout the country. The Order presents elements of a future development strategy for PC, so that the real need for PC services is covered as quickly and efficiently as possible in all counties. **Full text:** <https://goo.gl/RdLfrM>

**N.B.** Published in English and Romanian.

Noted in Media Watch 12 December 2016 (#491, p.10):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(6):278-280. '**Romanian National Association for Palliative Care: Quality assurance for palliative care in Romania.**' Since 1992, new palliative care (PC) services have been set up in both the public and private healthcare systems. The current legal framework and the funding mechanisms have been gradually encouraging the emergence of new PC services, particularly as inpatient units. Home-based PC services are still isolated private initiatives, and their funding through the health insurances system is low, despite the fact that 70% of people die at home in Romania and most of them wish to be looked after in their home environment at the end of life.

**N.B.** Access to this article requires a subscription. Journal website: <https://goo.gl/qGVJCP>

## The engagement of young people in their own advance care planning process: A systematic narrative synthesis

*PALLIATIVE MEDICINE* | Inprint – Accessed 10 April 2018 –Current research about advance care planning (ACP) for young people indicates differing experiences for those involved. Understanding how far young people are engaged in their own ACP is important to shape future practice and facilitate young people's wishes. Most studies related to the engagement of young people were conducted in hospitals or other institutions. Research reported the aim to include young people in their own ACP, but also potential barriers to engagement. The latter included poor communication, conflict within relationships of those in the planning process, and patchy education and training for healthcare professionals. Some existing studies are characterised by a lack of rigorous, high quality, research, limiting their impact. Irrespective of setting, engagement of young people would benefit their ACP. More detailed, high-quality research is needed to understand the extent of the barriers to young people's engagement in their own ACP and how to facilitate their involvement. **Abstract:** <https://goo.gl/8EZ95F>

### Barriers to and enablers of advance care planning with patients in primary care

*CANADIAN FAMILY PHYSICIAN*, 2018;64(4):e190-e198. Family physicians and other primary care providers rated barriers related to patient characteristics and system factors the highest. Lack of time was the greatest barrier for family physicians, but not for allied health professionals. For allied health professionals, lack of knowledge about how to do advance care planning (ACP) and insufficient access to physicians to support ACP were among the greatest barriers. The recommendation of having ACP resources for the family practice and for patients was a main theme that emerged as an enabler. There is an opportunity to address physicians' lack of time for discussions and patients' lack of understanding of how treatment decisions are made by better preparing patients with accurate information and resources about ACP so that the time required for discussions could potentially be reduced. **Full text:** <https://goo.gl/ZTFXJ5>

Cont.

Noted in Media Watch 19 February 2018 (#551, p.13):

- *JOURNAL OF ADOLESCENT & YOUNG ADULT ONCOLOGY*, 2018,7(1):112-119. ‘**Advance care planning discussions with adolescent and young adult cancer patients admitted to a community palliative care service: A retrospective case-note audit.**’ This study indicates end-of-life care preferences for this unique cohort may differ from those of the adult population and need to be captured and understood. An advance care planning document incorporating a discussion regarding goals of care, preferred location of care, preference for place of death, and consent to future intervention, including cardiopulmonary resuscitation and prompts for review, could assist in pursuing this objective. **Abstract:** <https://goo.gl/s2bNfh>

### **Raise the bar, not the threshold value: Meeting patient preferences for palliative and end-of-life care**

*PHARMACOECONOMICS* | Online – Accessed 8 April 2018 – Despite increasing interest in economic evaluation of palliative and end-of-life care (P&EoLC), research on patients’ preferences and values to robustly inform such analysis in this setting is relatively scarce. In a special issue of *Palliative Medicine* on the economics of P&EoLC just one article focused on this controversial topic.<sup>1</sup> In large part this may be due to the complexities of palliative care (PC), which aims to improve “the quality of life of patients and families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” Clearly, PC is multidimensional and people value domains above and beyond health status. There is utility from the dying process; people have preferences for their place of care and place of death along the dying trajectory and derive benefit from preparing themselves and others for their impending death. Further, reducing families’ and carers’ distress and improving their well-being are integral aspects of care. People also value aspects such as not being a burden on family and friends, and receiving

high-quality healthcare as much as, or even more than, improvements in health status or extension of life when receiving PC. Yet, clinicians and decision makers don’t always accord the same value to these patient preferences. **Full text:** <https://goo.gl/WtP8Ln>

#### **What is the cost of palliative care in the U.K.? A systematic review**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 April 2018 – Little is known about the cost of a palliative care (PC) approach in the U.K., and there is an absence of robust activity and unit cost data. Ten papers met the authors’ inclusion criteria. The studies displayed significant variation in their estimates of the cost of PC, therefore it was not possible to present an accurate aggregate cost of PC in the U.K. The majority of studies explored costs from a National Health Service perspective and only two studies included informal care costs. Approaches to estimating activity and costs varied. Particular challenges were noted with capturing activity and cost data for hospice and informal care. Conclusion The data are limited, and the heterogeneity is such that it is not possible to provide an **Abstract:** <https://goo.gl/RVeYX7>

1. ‘An economic view on the current state of the economics of palliative and end-of-life care,’ *Palliative Medicine*, 2017;31(4):291-292. [Noted in the 20 March 2017 issue of Media Watch (#504, p.13)] **Full text:** <https://goo.gl/wMHxin>

**N.B.** Contents page of this special issue of *Palliative Medicine*: <https://goo.gl/sK9yLj>

Noted in Media Watch 12 March 2014 (#357, p.10):

- *EXPERT REVIEW OF PHARMACOECONOMICS & OUTCOMES RESEARCH* | Online – 2 May 2014 – ‘**Strategies for the economic evaluation of end-of-life care: Making sense for the capability approach.**’ The author examines different theoretical perspectives from which economic evaluation of end-of-life care could be conducted and argues for the application of a capability approach focusing on the opportunity for a good death. It then examines challenges with taking forward such an approach, including defining, measuring and valuing appropriate outcomes. It concludes that such an approach is viable, and explores how it might be taken forward to assist with resource allocation decisions. **Abstract (w. link to references):** <https://goo.gl/2DgzMQ>

## The codesign of an interdisciplinary team-based intervention regarding initiating palliative care in pediatric oncology

*SUPPORTIVE CARE IN CANCER* | Online – 7 April 2018 – Children with advanced cancer are often not referred to palliative or hospice care before they die or are only referred close to the child's death. Eleven pediatric oncology team members participated in four codesign sessions to discuss their experiences with initiating palliative care (PC) and to review the proposed intervention including patient case studies, techniques for managing uncertainty and negative emotions, role ambiguity, system-level barriers, and team communication and collaboration. The codesign process showed that the participants were strong supporters of PC, members of different teams had preferences for different materials that would be appropriate for their teams, and that while participants reported frustration with timing of PC, they had difficulty suggesting how to change current practices. The procedures and results of this project will be posted online so that other institutions can use them as a model for developing similar interventions appropriate for their needs. **Abstract (w. link to references):** <https://goo.gl/WG9Gjz>

### Paediatric palliative care should focus on living as well as dying

*ACTA PAEDIATRICA* | Online – 14 April 2018 – During the last decade, paediatric palliative care (PC) has undergone a profound change in terms of diagnoses, goals and practices. It is no longer confined to end-of-life care (EoLC) and has gradually become an integral part of paediatrics. PC often starts at diagnosis, and in parallel with disease-directed therapy, to provide long-term quality of life. It therefore applies to any child with a life-threatening disease, such as a malignancy, severe malformation or neurological disorder. However, the general public is not aware of these changes and they are not widely recognised among healthcare professionals. The notion that PC is synonymous with EoLC still prevails, and this is a barrier to the acceptance of, and referrals to, paediatric PC. **Full text:** <https://goo.gl/D8qf7Q>

### Related

- *REVISTA BIOÉTICA*, 2018;26(1):127-134. **'Process of dying in a pediatric intensive therapy unit.'** The recurrent experience of the nursing team in a pediatric intensive care unit (ICU) is not enough to accept the death of a child, since they bring feelings like guilt, failure and denial of death. The objective of this study was to discuss how nursing professionals deal with the death and dying process, and identify the impacts caused during this process. There are some important gaps in the nursing process in dealing with death and dying in pediatrics. **Full text:** <https://goo.gl/qsnMt7>

**N.B.** Spanish language article. Check menu for links to English or Portuguese versions.

### Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BRITISH MEDICAL JOURNAL* | Online – 12 April 2018 – **'Why religious belief should be declared as a competing interest.'** People's faith can have a profound effect on their views on matters such as assisted dying and abortion, and disclosure is essential to provide full context for interpretation... "If in doubt, declare a competing interest" is standard teaching in ethics. Hiding a competing interest hints at dishonesty, raising doubts about the integrity of what has been written or said. It thus seems elementary that you should declare a religious competing interest because faith and other non-financial competing interests often have a profound effect on people's views. Yet people with deep religious beliefs and other non-financial competing interests often do not make such a declaration, perhaps believing it to be a private matter or because of the tendency to focus on financial conflicts of interest. **Introductory paragraph:** <https://goo.gl/Y1p6dH>

Cont.

- *BRITISH MEDICAL JOURNAL* | Online – 9 April 2018 – ‘**What readers thought about the *BMJ*’s articles on assisted dying.**’ The strongest argument against assisted dying, among more than 90 responses from readers to our recent cluster of articles<sup>1</sup> ... was that under no circumstances should doctors intentionally kill patients. Eunice Minford, consultant surgeon in Northern Ireland, quoted Elizabeth Butler-Sloss: “The law ... rests on the principle that we do not involve ourselves in deliberately bringing about the deaths of others. Once we start making exceptions based on arbitrary criteria such as terminal illness, the frontier becomes just a line in the sand, easily crossed and hard to defend.” Assisted suicide might also be open to abuse, some readers thought. Barry Cullen, retired GP from Fareham, Hampshire, asked, “Would there be the same level of support for physician assisted suicide if it were introduced as a cheaper alternative to palliative care in an National Health Service already starved of resources?” **Introductory paragraph:** <https://goo.gl/86RcC8>

1. *BMJ* articles on assisted dying (2013-2018): <https://goo.gl/vbBddx>

- *CANADIAN FAMILY PHYSICIAN*, 2018;64(4):315-316. ‘**Teaching residents about medical assistance in dying.**’ Family practice residents must understand how to discuss end-of-life care with patients and their families. This includes an understanding of and approach to the assessment and provision of medical assistance in dying (MAiD), so that they can offer correct information to their patients. Ideally, residents should be given the opportunity to witness an assessment and, if they are comfortable, a provision as well. Often the knowledge that MAiD is available allows patients to face their next treatment or their deaths with less anxiety and to help them feel more in control. This is true for the patients who receive MAiD and for those who only have conversations about it. **Full text:** <https://goo.gl/TQsRyy>
- *CANADIAN JOURNAL OF PSYCHIATRY* | Online – 10 April 2018 – ‘**A response to popular arguments against permitting medical assistance in dying (MAiD) where mental illness is the sole underlying condition.**’ Canada is approaching its federal government’s review of whether patients should be eligible for medical assistance in dying (MAiD) where mental illness is the sole underlying medical condition, and when “natural death” is not “reasonably foreseeable.” For those opposed, arguments involve the following themes: capacity, value of life, vulnerability, stigma, irremediability, and the role of physicians. It has also been suggested that those who are able-bodied should have to kill themselves, even though suicide may be painful, lonely, and violent. Opponents of MAiD for severe, refractory suffering due to mental illness imply that it is acceptable to remove agency from such patients on paternalistic grounds. After years of efforts to destigmatise mental illness, these kinds of arguments effectively declare all patients with mental illness, regardless of capacity, unable to make considered choices for themselves. The authors argue that decisions about capacity must be made on an individual-patient basis. Given the rightful importance granted to respect for patient autonomy in liberal democracies, the wholesale removal of agency advocated by opponents of a permissive MAiD regime is difficult to reconcile with Canadian constitutional values. Abstract (w. list of references): <https://goo.gl/R6y6tc>

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[January/February 2018 issue (Scroll down to 'Paediatric palliative care; the patient's voice')]

HUNGARY | Magyar Hospice Alapítvány: <https://goo.gl/3jnH7K>

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