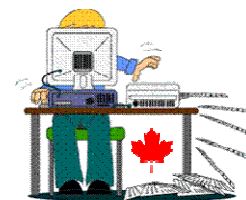


## Media Watch...

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

**Nudging is a tool of libertarian paternalism. It involves making use of certain psychological tendencies in order to help people make better decisions without restricting their freedom.**

'On nudging's supposed threat to rational decision-making' (p.8), in *Journal of Medicine & Philosophy*.

## Canada

**New poll shows that most people in Canada think it is important to do advance care planning, but only few did**

CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION | Online – 30 July 2019 – A national poll was commissioned by the 'Speak Up' advance care planning (ACP) in Canada initiative to identify people's current attitudes and behaviors towards planning for their future health and personal care. People in Canada were asked about ACP, which includes reflecting on and talking about their wishes for future care in the event they have a serious illness or health crisis. Respondents identified what makes it easier to have a conversation about their wishes and what makes it tough to plan ahead. While attitudes towards ACP are overall positive, behavior has not followed; 8 in 10 Canadians have given end-of-life care some thought, but less than 1 in 5 have an advance care plan. <http://bit.ly/2Ke37By>

### Specialist Publications

**'End-of-life care in individuals with respiratory diseases: A [Canadian] population study comparing the dying experience between those with chronic obstructive pulmonary disease and lung cancer'** (p.7), in *International Journal of Chronic Obstructive Pulmonary Disease*.

**'Request for medical assistance in dying after a suicide attempt in a 75-year-old man with pancreatic adenocarcinoma'** (p.15), in *Canadian Medical Association Journal*.

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<http://bit.ly/2ThiikC>

Noted in Media Watch 25 March 2019 (#607, p.1):

- ALBERTA | *The Lethbridge Herald* – 19 March 2019 – ‘**Local physician develops Plan Well Guide to help with end-of-life care.**’ Dr. Daren Heyland ... a critical care doctor at Kingston General Hospital ... conducted research on 120 random patients around the age of 65 ... to test his Plan Well Guide to help ease the stress of making end-of-life (EoL) decisions. The guide starts with being prescribed by the doctor for a patient to go online and go through the process of developing the plan. When individuals log into the site they are able to go through easy-to-understand information about the different types of care, serious illness decision making, understanding where their values are and developing the plan. <http://bit.ly/2Cn9wHl>

Noted in Media Watch 21 August 2017 (#526, p.1):

- ONTARIO | *The Kingston Herald* – 17 August 2017 – ‘**Queen’s University researcher seeks to improve end-of-life care.**’ Dr. Daren Heyland has developed new quality measures he hopes will be used to improve end-of-life care (EoLC) in Canada. These new measures came about from earlier research that showed a significant proportion of Canadians are unhappy or dissatisfied with their EoLC.<sup>1</sup> “Inadequate or poor communication and decision-making at the end of life is a major source of dissatisfaction with EoLC,” said Dr. Heyland. A questionnaire was issued to patients and their family members at 12 hospitals in Alberta, British Columbia, Manitoba and Ontario by Dr. Heyland and his team, collecting their opinions about advance care planning and goals-of-care discussions. <http://bit.ly/2Mw4Yoc>

1. ‘Validation of quality indicators for end-of-life communication: Results of a multicentre survey, *Canadian Medical Association Journal*, 2017;189(30):e980-e989. [Noted in 7 August 2017 issue of Media Watch (#524, p.9)] **Full text:** <http://bit.ly/2SVVmnV>

Noted in Media Watch 30 November 2015 (#438, p.1):

- *THE NATIONAL POST* | Online – 23 November 2015 – ‘**Third of dying hospital patients marked to receive CPR against their wishes, Canadian study says.**’ More than a third of elderly, gravely ill hospital patients are tagged to receive cardiopulmonary resuscitation (CPR) even though they don’t want the painful and usually futile measure, concludes a new Canadian study.<sup>1</sup> The authors call the unwanted orders for CPR on the sickest patients a type of medical error, and say it’s the result of a communications breakdown hospitals need to confront. Despite heroic depictions of emergency resuscitation in popular entertainment, attempts to restart an arrested heart rarely save anyone’s life. They also take a toll both on patients and the family members who have to watch. <http://bit.ly/2YlIQoL>

1. ‘The prevalence of medical error related to end-of-life communication in Canadian hospitals: Results of a multicentre observational study,’ *BMJ Quality & Safety*, published online 9 November 2015. [Noted in 16 November 2015 issue of Media Watch (#436, p.10)] **Abstract:** <http://bit.ly/2GG82KG>

## U.S.A.

### **Statewide coalition of non-profit hospices enhances delivery of patient care and end-of-life services**

CALIFORNIA | *Chestnut Post* – 1 August 2019 – The Elizabeth Hospice in San Diego, Mission Hospice & Home Care in San Mateo and Hospice of Santa Cruz County announced the formation of California Hospice Network (CHN) – a strategic partnership committed to sustaining local, non-profit, community-based hospice care throughout California. These organizations, respected healthcare leaders in their communities, are working, sharing and planning together to further enhance their local delivery of exemplary patient care and end-of-life (EoL) services. The vision of CHN is that every person in California has access to mission-driven, advanced illness and EoL care services that meet their needs as defined by them and their communities. Each member of the network will continue to operate as a distinct and independent non-profit hospice and palliative care organization while working with the other member partners to share best practices in patient care, maximize operational economies and efficiencies, and support local innovation. “While many for-profit hospices provide quality care, it is the non-profit community hospice that has

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continued to offer services that meet the unique needs of the communities, including grief support, education, complementary therapies and transitional care,” said Jan Jones, Chief Executive Officer of The Elizabeth Hospice who will also serve as Chief Executive Officer of CHN. “Non-profit hospices are facing increasing costs and decreasing revenues amidst a rapidly changing healthcare landscape. The CHN lets us focus on the unique needs of our communities while leveraging the strength of a statewide network to better prepare for the long term.” <http://bit.ly/315f4QI>

### Specialist Publications

**‘Managing palliative patients in inpatient rehabilitation through a short stay family training program’** (p.6), in *American Journal of Hospice & Palliative Medicine*.

Noted in Media Watch 15 April 2019 (#610, p.2):

- **HOSPICE NEWS** | Online – 10 April 2019 – **‘Non-profit hospices fight to compete with for-profit chains.’** Non-profit hospices have been bleeding market share for several years – but are not going gentle into that good night. Rather, many non-profits are adapting to compete with large for-profit providers that are entering the space in greater numbers. In the 1980s and 1990s non-profits provided virtually all hospice care in the U.S., but the balance has shifted. In 2016, 67% of Medicare-certified hospices were for-profit, and only 20% were non-profits, according to the National Hospice & Palliative Care Organization. <http://bit.ly/2FZXG72>

### **Why “Right-to-Try” created to help terminal patients hasn’t worked**

OHIO | WKRC Radio (Cincinnati) – 24 July 2019 – Experts say more than a year after the passage of the national “Right-to-Try” Act, little has changed. Dr. Arthur Caplan, a bioethicist at New York University Langone Health, considers “Right-to-Try” nothing more than feel-good politics, calling the law meaningless, “They promise what doesn’t happen. Caplan says ... the companies that make drugs still hold all the power. He would know. He currently sits on an independent committee which advises a major drug company on whether to approve requests for experimental treatments. He explained that while “Right-to-Try” did remove liability for companies that choose to make investigational drugs available, it did not create a requirement for them to say yes if there’s a request. “In our country, drug development is a private business. It’s their property. If the company doesn’t want to do it, you can’t get anything,” Caplan said. Experts with years of experience in the prior system that required Federal Drug administration approval say the new law hasn’t impacted them. <http://bit.ly/2T0R1zW>

**N.B.** Selected articles on “right-to-try” laws noted in 22 April 2019 issue of Media Watch (#611, p.7).

## International

### **End-of-life care facility in need of government support**

AUSTRALIA (Queensland) | *Noosa News* (Noosaville) – 2 August 2019 – A Sunshine Coast hospice centre shut their doors this week after unsuccessfully securing government funding to continue their end-of-life care. The temporary closure of Katie Rose Cottage’s three-bedroom, 24-hour service in Doonan is “disappointing” for the team with the hospice’s future now pending discussions with state and federal government. In the past nine months the hospice has served 30 patients aged between 36 to 98 live out their final days and in June this year the hospice received “accredited” status, a significant achievement for the hospice team, which ensured the ongoing, high quality care aligned with

the expectations and requirements established by the National Safety & Quality Health Service Standards. <http://bit.ly/2GJwH0L>

### Specialist Publications

**‘Clarity sought on medical cards for terminal patients’** (p.8), in *Irish Medical Times*.

**‘Integrating palliative care and symptom relief into responses to humanitarian crises’** (p.12), in *Medical Journal of Australia*.

## Care in dying days needs revamp: Research

AUSTRALIA | *The Canberra Times* (Australian Capital Territory) – 1 August 2019 – When Alan Bevan's wife was diagnosed with dementia, he imagined that when the end of her life neared, the care she deserved would be readily available. Looking back on Sue's final 10 days, Alan wishes he hadn't had to be grappling with thoughts such as whether his wife was getting the right care or how he could crack the system to get her some help. "I felt like the whole responsibility was still on my shoulders and that no one else was taking any particular notice." Stories such as Alan's are what new research suggests should play a greater role in shaping palliative care in Australia.<sup>1</sup> The Australian National University paper led by Dr. Brett Scholz suggests policymakers are not taking enough notice of those who have cared for dying loved ones. "We are missing out on a lot of the benefits of patients' point of view," Dr. Scholz said. "At the moment patient involvement is tokenistic and we are recommending real engagement." He believes carers should be involved in all levels of decision-making processes that health services offer and in helping to educate others, conduct research, and set policy agendas. <http://bit.ly/2MxLm2L>

1. 'Consumer and carer leadership in palliative care academia and practice: A systematic review with narrative synthesis, *Palliative Medicine*, published online 14 June 2019. [Noted in 17 June 2019 issue of *Media Watch* (#618, p.13)] **Abstract:** <http://bit.ly/2Xh60Ko>

### Related

- AUSTRALIA | ABC Radio News – 1 August 2019 – '**People who watched loved ones die can help with palliative care.**' Watching a loved one go through the final days of their life is one of the toughest experiences we can go through, but it also gives us a pretty clear idea of what works and doesn't work in end-of-life care. Now experts from the Australian National University say authorities responsible for how we provide palliative care need to start getting advice from people who have watched someone close to them go through the system. <https://ab.co/335PfSm>

## New survey sparks call from health charity for Lancashire residents to be more open about death

U.K. (England) | *The Lancashire Post* (Preston) – 31 July 2019 – A survey by charity Sue Ryder shows that, while people in Lancashire know how they would spend their last days on earth, few are preparing for them. While nine in 10 people ... knew what their last meal on earth would be, less than half this number (38%) have written a will, the figures show. A third of people in Lancashire ... did not know that they can plan where they want to die, and less than one in ten ... have made an advance care plan, a document which outlines a statement of preferences for end-of-life care. Less than a quarter ... have discussed their death with their loved ones, confirming that the stigma around the D-word remains. Just under two-thirds ... would want to spend their last day on earth in a familiar space, such as at home or place of worship and 17% would head straight to the seaside. However, the

reality is that their final days would likely take place in a hospital, a hospice or at home. According to the findings, people living in Lancashire are clear on whom they would like to spend their final hours with; over half ... would choose their partner, while almost one in five ... would choose to spend their final hours with a pet. <http://bit.ly/2SST1tF>



The findings reported in *The Lancashire Post* were extracted from a larger, national-wide survey, which can be **downloaded/viewed at:** <http://bit.ly/2Ywwhoz>

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Noted in Media Watch 4 November 2013 (#330, p.7):

- U.K. (England) | ITV News – 28 October 2013 – ‘**Cancer patients in Lancashire denied wish to die at home.**’ Almost three quarters of cancer patients in England who die in hospital beds wanted to die at home – an estimated 890 people in Lancashire each year, according to figures released by Macmillan Cancer Support.<sup>1</sup> The vast majority of health professionals agree access to social care services is crucial for keeping people out of hospital. However, two years after the Palliative Care Funding Review recommended social care should be free for those at the end of life thousands of cancer patients are still spending their last remaining days and hours on a hospital ward.<sup>2</sup> <http://bit.ly/2K72rPx>
  1. ‘Time to Choose: Making Choice at the End of Life a Reality,’ Macmillan Cancer Support, October 2013. Download/view at: <http://bit.ly/2K7OgK7>
  2. ‘Funding the Right Care & Support for Everyone: Final Report of the Palliative Care Funding Review,’ July 2011. [Noted in 4 July 2011 issue of Media Watch (#208, p.4)] <http://bit.ly/2ynrCH4>

## Specialist Publications

### **The key aspects of online support that older family carers of people with dementia want at the end of life: A qualitative study**

*AGING & MENTAL HEALTH* | Online – 29 July 2019 – Most carers interviewed had positive views of receiving support online via a website. Participants described a series of challenges they felt online support could address and help support them with when caring for someone with dementia towards the end of life (EoL): 1) Feeling prepared and equipped; 2) Feeling connected and supported; 3) Balancing their own needs with those of the individual; and, 4) Maintaining control and being the coordinator of care. However many valued a mix of technology and human interaction in receiving support. This study has identified the key challenges for carers at the EoL that could be met by online support.

Online support offers a source of support to supplement face-to-face contact, as many carers still wish to talk to someone in person. **Abstract:** <http://bit.ly/2Yfp3Ga>

#### Publishing Matters

‘**American Medical Writers Association, European Medical Writers Association & International Society for Medical Publication Professionals joint position statement on predatory publishing**’ (p.16), in *Current Medical Research & Opinion*.

#### **Related**

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 2 August 2019 – ‘**Can persons with dementia meaningfully participate in advance care planning discussions? A mixed-methods study of SPIRIT.**’ Despite the importance of persons with dementia (PWDs) engaging in advance care planning (ACP) at a time when they are still competent to appoint a surrogate decision maker and meaningfully participate in ACP discussions, studies of ACP in PWDs are rare. SPIRIT engaged PWDs and surrogates in meaningful ACP discussions, but requires testing of efficacy and long-term outcomes. **Abstract:** <http://bit.ly/2GKHms3>

**N.B.** Additional articles on palliative and end-of-life care for people living with dementia noted in 29 July 2019 issue of Media Watch (#624, p.13).



#### 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.17.

## **Managing palliative patients in inpatient rehabilitation through a short stay family training program**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 1 August 2019 – Patients with terminal illnesses often have functional limitations that prohibit discharge home after hospitalization, but their condition limits their ability to participate in rehabilitation in an inpatient setting. After a needs assessment, an interdisciplinary team developed an Short Stay Family Training (SSFT) program to empower patients, caregivers, and family members by giving them the tools to be independent in caring for a patient with a life-limiting condition. Patients qualifying for the program were tracked in terms of acute care physical therapy and occupational therapy discharge recommendations, diagnosis, inpatient rehabilitation unit length of stay (LoS), caregiver involvement, and discharge location. Data were retrospectively analyzed from patients over the first 16 months. Since program implementation, 30 patients and their family members participated in the program. **Abstract:** <http://bit.ly/2KlByq8>

## **Expressive writing as a therapeutic intervention for people with advanced disease: A systematic review**

*BMC PALLIATIVE CARE* | Online – 2 August 2019 – Expressive writing involves writing about stressful or traumatic experiences. Despite trials in people with advanced disease, no systematic review to date has critiqued the evidence on expressive writing in this population. Although the trial results suggest there is no benefit in expressive writing for people with advanced disease, the current evidence is limited. There is a need for more rigorous trials. It would be of benefit first to undertake exploratory research in trial design including how best to measure impact and in tailoring of the intervention to address the specific needs of people with advanced disease. **Full text:** <http://bit.ly/2MAa42H>

## **Making end-of-life care decisions for older adults subject to guardianship**

*ELDER LAW JOURNAL*, 2019;27(1):1-34. The authors present current definitions of hospice and palliative care and describes several common EoL disease trajectories. This background information introduces the diverse contexts in which guardians may find themselves when making EoL care decisions. The next section of the article sets forth results of the authors' recent research focusing on EoL care for unbefriended adults subject to guardianship. "Unbefriended" adults are those who lack decision-making capacity, have no advance directive, and have no family or friends to serve as a surrogate decision-maker. As such, professional guardians may be appointed when healthcare decisions are needed. Making healthcare decisions for such adults, particularly EoL care decisions, can be challenging. Little to nothing may be known about the person's values prior to guardianship and the patient may be unable to convey his or her wishes and goals to the guardian. The third section of the article provides practical guidance to guardians. The authors discuss the assessment of values – with some thoughts about what to do when it is not possible to assess values. Finally, they discuss several common EoL healthcare decisions that may confront guardians – a code status change, a do not transfer order, and deescalating care within an intensive care unit. For these situations, the authors provide information from the perspective of their interdisciplinary team for the purposes of supporting guardians who face these challenging decisions. **Abstract (via PubMed):** <http://bit.ly/2K8LKIG>

**N.B.** Access the full text of this article at the journal's website: <http://bit.ly/2YdOecu>

Noted in Media Watch 22 July 2019 (#623, p.11):

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 13 July 2019 – '**End-of-life decision making and treatment for patients with professional guardians.**' Concerns have repeatedly been raised about end-of-life (EoL) decision making when a patient with diminished capacity is represented by a professional guardian (PG), a paid official appointed by a judge. Such guardians are said to choose high-intensity treatment even when it is unlikely to be beneficial or to leave pivotal decisions to the court. EoL decision making by PGs has not been examined systematically, however. **Abstract:** <http://bit.ly/30yw6Xu>

Cont.

Noted in Media Watch 5 February 2018 (#549, p.9):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 1 February 2018 – ‘**Medical decision-making for adults who lack decision-making capacity and a surrogate: State of the science.**’ The main findings of this study include: 1) Various terms were used to refer to adults who lack decision-making capacity and a surrogate; 2) The number of unbefriended adults was sizable and likely to grow; 3) Approaches to medical decision-making for this population in healthcare settings varied; and, 4) Professional guidelines and laws to address the issues related to this population were inconsistent. **Abstract:** <http://bit.ly/31sParj>

Noted in Media Watch 22 January 2018 (#547, p.11):

- *CANADIAN JOURNAL ON AGING* | Online – 17 January 2018 – ‘**Going it alone: A scoping review of unbefriended older adults.**’ The purpose of this study was to review the peer-reviewed and grey literature to determine the scope of available research on unbefriended older adults in Canada and the U.S. The authors found limited research examining unbefriended older adults. No Canadian studies or reports were located. These findings demonstrate a stark scarcity of studies on unbefriended older adults. **Abstract:** <http://bit.ly/2wSHuQQ>

**N.B.** Scroll down to ‘On the likelihood of surrogates conforming to the substituted judgment standard when making end-of-life decisions for their partner’ (p.11), in *Medical Decision Making*.

### **Value-based medicine and palliative care: How do they converge?**

*EXPERT REVIEW OF PHARMACOECONOMICS & OUTCOMES RESEARCH* | Online – 1 August 2019 – Sick persons need doctors who understand their pathology, know how to treat their problem, and accompany them through their illness. This study aimed to synthesize the state of knowledge regarding the concept of value-based medicine (VBM) through an integrative literature review, and establish how VBM can be applied in palliative care. Ten articles met the authors’ eligibility criteria. VBM combines the highest level of technical-scientific data with patients’ values. It is defined as the combination of evidence-based medicine, patient-centered care, and cost-effectiveness. Patients’ values are a set of preferences, concerns, and expectations that contribute toward accommodating their needs in the treatment clinic. Like VBM, PC focuses on patients’ values and quality of life, respecting natural limits. The early development of a care plan with active participation of the patient in the face of life-threatening diseases should be encouraged and can bring peace and comfort in a person’s final moments. **Abstract:** <http://bit.ly/2yjuXD5>

### **End-of-life care in individuals with respiratory diseases: A [Canadian] population study comparing the dying experience between those with chronic obstructive pulmonary disease and lung cancer**

*INTERNATIONAL JOURNAL OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE* | Online – 31 July 2019 – The authors conducted this population-based study to: 1) Describe the health service use and costs in the last 90 days of life, as well as place of death among individuals with chronic lung diseases such as chronic obstructive pulmonary disease (COPD) and/or lung cancer; 2) Identify predictors of receiving home palliative care (PC); and, 3) Assess benefits associated with PC in these populations. Their findings from a large population-based study suggest that home PC services were underutilized in both COPD and lung cancer populations, and that increased use of home PC services in the last three months of life has the potential to reduce costs and influence the place of death. To the authors’ knowledge, this study is the first large population-based study to report the predictors of PC use among decedents with COPD and/or lung cancer and assess the benefits associated with PC at the population level for both diseases across health sectors. **Full text:** <http://bit.ly/2LSbxlt>

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Would this article be of interest to a colleague?

Noted in Media Watch 21 January 2019 (#598, p.6):

- *BMC PALLIATIVE CARE* | Online – 19 January 2019 – ‘**Integrated respiratory and palliative care leads to high levels of satisfaction: A survey of patients and carers.**’ Core components of new integrated respiratory and palliative care (PC) services should ideally include: access to PC activities (but not necessarily PC personnel if the respiratory team can provide this care), health and self-management information and education, and home support. Importantly, multi-site controlled trials are still required to examine on a larger scale the effectiveness (including cost-effectiveness) of integrated PC for patients with advanced respiratory disease.. **Full text:** <https://goo.gl/nRJcK6>

Noted in Media Watch 22 October 2018 (#586, p.9):

- *BMC PALLIATIVE CARE* | Online – 15 October 2018 – ‘**Attitudes to specialist palliative care and advance care planning in people with chronic obstructive pulmonary disease: A multi-national survey of palliative and respiratory medicine specialists.**’ Respiratory doctors reported being comfortable providing a palliative approach and acknowledged the role of both specialist palliative care and advance care planning, yet in reality people with advanced obstructive pulmonary disease (COPD) rarely access these elements of care. Additionally, current models of care for people with COPD were considered inadequate and fragmented. **Full text:** <http://bit.ly/2BnwEFh>

### Clarity sought on medical cards for terminal patients

*IRISH MEDICAL TIMES* | Online – 24 July 2019 – Confused messaging on medical cards causing untold anxiety to patients approaching end of life (EoL). The Irish Hospice Foundation (IHF) has called on the Health Service Executive (HSE) to highlight the special application process for medical cards allocated to people without a means test who have a limited prognosis and are approaching EoL. The Foundation is seeking greater clarity on eligibility and accessibility to the special application process on the HSE website, and in other appropriate publications. “Above all it must clarify the exact criteria which apply to eligibility in these circumstances,” the Foundation urged. Inconsistency in messaging and operation of the scheme had been causing untold anxiety for such people. “We are deeply disappointed to learn that despite a concerted advocacy campaign by IHF, and political assurances to the contrary dating back to 2014, people who receive medical cards on this basis are still being sent means test forms to complete after they have had the card after six months.” Contradictory and confused messaging from the HSE about the application process only added insult to injury. The Foundation advises patients who have a terminal illness with a limited prognosis that they can receive an Emergency Medical Card and describes this as a “most positive and appropriate” provision by the State to support people within their last months of life. It was most unfortunate that it was becoming burdensome and clouded by confusion for the very people it sought to help, stated the Foundation... **Full text:** <http://bit.ly/2GxAcHQ>



### On nudging’s supposed threat to rational decision-making

*JOURNAL OF MEDICINE & PHILOSOPHY*, 2019;44(4):403-422. Nudging is a tool of libertarian paternalism. It involves making use of certain psychological tendencies in order to help people make better decisions without restricting their freedom. However, some have argued that nudging is objectionable because it interferes with, or undermines, the rational decision-making of the nudged agents. Opinions differ on why this is objectionable, but the underlying concerns appear to begin with nudging’s threat to rational decision-making. Those who discuss this issue do not make it clear to what this threat to rationality amounts. In this article, the author evaluates what effect nudging has on decision-making and argues that it does not typically interfere with rationality in a problematic way. Perhaps nudging is objectionable for other reasons, but we should not argue that nudging is objectionable based on concerns about rational decision-making. **Full text:** <http://bit.ly/2LQ8t9g>

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Noted in Media Watch 8 January 2018 (#545, p.6):

- *BIOETHICS* | Online – 28 December 2017 – ‘**Manipulation, salience, and nudges.**’ Not surprisingly, healthcare practitioners and public policy professionals have become interested in whether nudges might be a promising method of improving health-related behaviors without resorting to heavy-handed methods such as coercion, deception, or government regulation. Many nudges seem unobjectionable... Other nudges influence decision-making in ways that do not involve providing more and better information. Nudges of this sort raise concerns about manipulation. **Abstract:** <http://bit.ly/2ZlneUD>

Noted in Media Watch 1 October 2018 (#583, p.18):

- *PLOS ONE* | Online – 19 September 2018 – ‘**Perspectives on using decision-making nudges in physician-patient communications.**’ The use of “nudges” may assist patients in making complex decisions. However, nudging patients may be perceived as inappropriate influence on patients’ choices. The authors sought to determine whether key stakeholders, physicians, and laypersons without clinical training consider the use of nudges to be ethical and appropriate in medical decision making. **Full text:** <http://bit.ly/2ZmBwo0>

### **Impact of poetry on empathy and professional burnout of healthcare workers: A systematic review**

*JOURNAL OF PALLIATIVE CARE* | Online – 29 July 2019 – Narrative medicine (NM) interventions have positively influenced empathy and burnout to varying degrees in healthcare workers. There is evidence that poetry as part of a NM intervention may increase empathy and limited evidence that it may reduce professional burnout among healthcare workers. Of the 401 abstracts independently screened for inclusion by two reviewers, two quantitative, three qualitative studies, and one research letter were included. One research letter, focusing on the use of poetry, found it to increase empathy as measured by a non-validated questionnaire. All other studies used mixed NM interventions: two quantitative studies, using validated surveys, showed an increase in empathy and two qualitative studies showed limited to a prominent finding of increased empathy. There were no studies that used poetry exclusively to assess impact on professional burnout. One quantitative study, utilizing a validated survey, revealed no overall reduced burnout among residents... **Abstract:** <http://bit.ly/2LLv07p>

**N.B.** Selected articles on burnout (i.e., compassion fatigue) noted in 15 April 2019 issue of Media Watch (#610, pp.6-7).

### **Top ten tips palliative care clinicians should know about caring for patients in the emergency department**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 29 July 2019 – Palliative principles are increasingly within the scope of emergency medicine (EM). In EM, there remain untapped opportunities to improve primary palliative care (PC) and integrate patients earlier into the palliative continuum. However, the emergency department (ED) differs from other practice environments with its unique systemic pressures, priorities, and expectations. To build effective, efficient, and sustainable partnerships, palliative clinicians are best served by understanding the ED’s practice priorities. The authors, each EM and Hospice & Palliative Medicine board certified and in active practice, present 10 high-yield tips to optimize the ED consultation by PC teams. **Abstract:** <http://bit.ly/2OsR1dm>

Noted in Media Watch 24 June 2019 (#619, p.6):

- *EMERGENCY NURSE* | Online – 18 June 2019 – ‘**Person-centred end-of-life care in an emergency department. A quality improvement project.**’ Supporting and managing end of life (EoL) in emergency departments (EDs) is often difficult and is becoming increasingly commonplace. Patients who present at the EoL are often triaged as low priority as their signs and symptoms are not considered life-threatening and they are often exposed to unnecessary and inappropriate tests and investigations. This results in increased stress and distress for patients and their family and carers in an environment that is not suited to this type of care. There are few specified palliative care pathways that provide the level of care required by these patients. **Abstract:** <http://bit.ly/2RIKNcU>

Cont.

Noted in Media Watch 6 May 2019 (#613, p.7):

- *EMERGENCY MEDICINE AUSTRALASIA* | Online – 1 May 2019 – ‘**Goals-of-care discussions for adult patients nearing end of life in emergency departments: A systematic review.**’ There was no consensus on the meaning of goals-of-care, which is often confused with advanced care planning and treatment limitation. Emergency clinicians can identify most patients needing discussions following training. There was no evidence for how to involve stakeholders, nor how to adapt conversations to meet cultural and linguistically diverse needs. Expert panels have suggested requirements and content for conversations with little supporting evidence. There was no evidence for how emergency conversations differ to those in other settings... **Abstract:** <http://bit.ly/2vwqFdR>

Noted in Media Watch 11 February 2019 (#601, p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 5 February 2019 – ‘**Emergency department-based palliative interventions: A novel approach to palliative care in the emergency department.**’ Patients with palliative care (PC) needs were identified using an abbreviated 5-question version of the screen for palliative and end-of-life care needs in the emergency department (ED). These patients were flagged for an ED-based palliative intervention (EPI) as determined by their identified need. The primary outcome was the prevalence of PC needs among patients with active cancer. Secondary outcomes were the rate of EPI services successfully delivered to ED patients with unmet PC needs, ED length of stay (LoS), and repeat ED visits within the next 10 days. **Abstract:** <http://bit.ly/2Suram4>

### **Global scientific outputs of brain death publications and evaluation according to the religions of countries**

*JOURNAL OF RELIGION & HEALTH* | Online – 17 July 2019 – In 1950s, the concept of brain death, which began to be discussed primarily in terms of medicine and then in terms of religion, law, and ethics, became a central topic in all world countries as it was an early diagnosis of death. Despite the fact that brain death (BD) diagnosis is of importance for benefitting from organ and tissue transplantation of patients in the world, the literature still involves no bibliometric studies that made a holistic evaluation of the publications about this issue. This study aimed to investigate the top-cited articles about BD published between 1980 and 2018, identify the citation collaboration of the journals, demonstrate the collaboration between the countries, define the relationship between organ transplantation and BD, and reveal the latest developments and trend topics about this issue. In addition, the authors aimed to investigate the relationship between religions of countries and brain death publication productivity. The U.S. was the top country in terms of publication productivity, which was followed by developed countries such as Germany, Japan, France, and Spain. However, the contribution of the undeveloped or developing countries such as China, Brazil, Turkey, Iran, and South Africa was found to be considerably important. **Abstract (w. list of references):** <http://bit.ly/2yiATA7>

**N.B.** Additional articles on the ethical and legal aspects of determination of brain death noted in 17 December 2018 issue of Media Watch (#594, p.1).

### **Go in peace: Brain death, reasonable accommodation and Jewish mourning rituals**

*JOURNAL OF RELIGION & HEALTH* | Online – 6 July 2019 – Religious objections to brain death are common among Orthodox Jews. These objections often lead to conflicts between families of patients who are diagnosed with brain death, and physicians and hospitals. Israel, New York and New Jersey (among other jurisdictions) include accommodation clauses in their regulations or laws regarding the determination of death by brain-death criteria. The purpose of these clauses is to allow families an opportunity to oppose or even veto (in the case of Israel and New Jersey) determinations of brain death. In New York, the extent and duration of this accommodation period are generally left to the discretion of individual institutions. Jewish tradition has embraced cultural and psychological mechanisms to help families cope with death and loss through a structured process that includes quick separation from the physical body of the dead and a gradual transition through phases of mourning... This process is meant to help achieve clo-

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sure, acceptance, support for the bereaved, commemoration, faith in the afterlife and affirmation of life for the survivors. The authors argue that the open-ended period of contention of brain death under the reasonable accommodation laws may undermine the deep psychological wisdom that informs the Jewish tradition. By promoting dispute and conflict, the process of inevitable separation and acceptance is delayed and the comforting rituals of mourning are deferred at the expense of the bereft family. **Abstract (w. list of references):** <http://bit.ly/2YpXpXh>

### **On the likelihood of surrogates conforming to the substituted judgment standard when making end-of-life decisions for their partner**

*MEDICAL DECISION MAKING* | Online – 29 July 2019 – In this study, the authors examined how the likelihood of surrogates conforming to the substituted judgment standard varies with individual differences in mortality acceptance and confidence in their decision making. They recruited 153 participants in romantic relationships between 18 and 80 years old from the general population. The authors asked them to make hypothetical end-of-life (EoL) decisions for themselves and on behalf of their partner, as well as predict what their partner would do, and complete a series of questionnaires. Participants predicted that their partner would make similar decisions to their own but were more likely to accept a life-saving treatment that could result in reduced quality of life on their partner's behalf than for themselves. Decisions made by older adults were more likely to conform to the substituted judgment standard, which is encouraging given that they are more likely to be confronted with these decisions in real life, although this was not due to differences in mortality acceptance. Older adults were also more likely to have had previous discussions with their partner and thereby know that person's wishes and feel confident that they made the right decision, but these factors did not affect their likelihood of

conforming to the substituted judgment standard. This shows encouraging discussions about EoL among families would ease the decision process, but more work is needed to ensure that surrogates can adhere to the substituted judgment standard. **Full text:** <http://bit.ly/2Mpdp10>

#### **Loved ones with healthcare decision-making power often over-confident**

REUTERS | Online – 26 November 2018 – People entrusted with decision-making for incapacitated loved ones tend to believe they know what their loved ones would choose – but the vast majority of surrogate decision-makers in a recent study were wrong about loved ones' wishes.<sup>1,2</sup> <https://reut.rs/2Zo1CHA>

1. 'Assessment of surrogates' knowledge of patients' treatment goals and confidence in their ability to make surrogate treatment decisions,' *JAMA Internal Medicine*, **Abstract:** <http://bit.ly/2Z1AWk>
2. 'Preparing surrogates for complex decision making: The often neglected piece of the advance care planning equation,' *JAMA Internal Medicine*. **Abstract** <http://bit.ly/2Zmn4N9>

**N. B.** Reuters report noted in 3 December 2018 issue of Media Watch (#592, p.4).



#### **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://bit.ly/2RPJy9b>

## Integrating palliative care and symptom relief into responses to humanitarian crises


*MEDICAL JOURNAL OF AUSTRALIA* | Online – 1 August 2019 – Humanitarian crises often causes extensive loss of life and widespread suffering. Yet humanitarian crises response virtually never fully integrates palliative care (PC), the discipline devoted to preventing and relieving suffering. Recently, the World Health Organization (WHO) recognized the necessity of integrating PC and symptom relief into responses to humanitarian crises of all types and published a guide to this integration.<sup>1</sup> In this article, the authors summarize the WHO recommendations, explain why inclusion of PC is an essential part of humanitarian response is medically and morally imperative, and describe how to ensure that PC is accessible for those affected by humanitarian rises. **First page view:** <http://bit.ly/2GL2xKA>

1. 'Integrating palliative care and symptom relief into responses to humanitarian emergencies and crises,' World Health Organization, September 2018. [Noted in 1 October 2018 issue of Media Watch (#583, p.6).] **Download/view at:** <http://bit.ly/2T4AScC>

**N.B.** Additional article on integrating PC and symptom relief into responses to humanitarian emergencies and crises noted in 14 January 2019 issue of Media Watch, #597, p.5.

## Accessing palliative care for multiple sclerosis: A qualitative study of a neglected neurological disease

*MULTIPLE SCLEROSIS & RELATED DISORDERS* | Online – 20 July 2019 – Despite the global consensus on the importance of palliative care (PC) for patients with multiple sclerosis (MS), many patients in developing countries do not receive PC. Improving access to PC for MS requires a contextual understanding of how PC is perceived by patients and health professionals, the existing care pathways, and barriers to the provision of PC. Patients and neurologists [i.e., study participants] mostly associated PC with the end-of-life and struggled to understand the need for PC in MS. Another barrier was the lack of understanding about the PC needs of MS patients. PC physicians also identified the scarcity of resources and their lack of experience with MS as barriers. The current referral-based care pathway itself was found to be a barrier to the provision of PC. **Abstract:** <http://bit.ly/2Mnv2lj>



**Media Watch: On Humanitarian Crises**

Palliative care is entering the “culture” of humanitarian organizations. Morbidity and mortality caused by non-communicable diseases are about to overtake infectious diseases in adults, and the epidemiology of diseases is shifting toward chronic conditions even in low-income countries where disasters and armed conflicts are common. <http://bit.ly/2G8FVUb>

**N.B.** Scroll down to 'Media Watch: On Humanitarian Crises'

**Patient and caregiver involvement in formulation of guideline questions...**

*EUROPEAN JOURNAL OF NEUROLOGY* | Online – 23 July 2018 – Multiple sclerosis patients and their caregivers validated questions devised by the Academy's task force. They identified additional issues related to voluntary euthanasia and assisted suicide, sheltered housing or assisted living, case management, and client important overarching outcomes. **Full text:** <http://bit.ly/2OwWaRG>

**N.B.** This article noted in 30 July 2018 issue of Media Watch (#574, p.11). Additional articles on PC for people living with MS noted in the 10 December 2018 issue of the weekly report (#593, p.13).

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Closing the Gap Between Knowledge & Technology  
<http://bit.ly/2DANDFB>

Noted in Media Watch 21 January 2019 (#598, p.11):

- *MULTIPLE SCLEROSIS & RELATED DISORDERS*, 2019;28(1):290-304. **'Inequalities in access to health and social care among adults with multiple sclerosis: A scoping review of the literature.'** There was evidence of inequalities in access to services with a trend for worse access among men, older age groups, those from lower socio-economic groups or the least educated, non-Caucasians, those with mental health problems, and those from rural areas. On access to disease modifying treatments, older age and lower socioeconomic status were consistently associated with a lower rate of uptake, while race and gender were not. Inequalities or disparities in access to all levels of services and treatments will need to be addressed through a strategic research agenda with an emphasis on population-based studies and development and evaluation of interventions to reduce inequality. **Abstract:** <http://bit.ly/2YuZUmq>

**"It's just drug seeking behaviour isn't it?"**

### **Troubling the narratives surrounding substance use and pain management at the end of life**

*NURSING ETHICS* | In press – Accessed 28 July 2019 – The authors examine narrative positioning related to pain management for people who use substances at the end of life (EoL). They explore how dominant narrative genres associated with biomedicine, such as "restitution" and narratives common within the context of drug services such as "recovery" can hinder effective pain management within this population. The authors argue that these discourses can marginalise the ethical self-identity of patients who use substances at the EoL. It can also trouble health and social care professionals in supporting patients and generating counter-narratives that challenge those often associated with substance use. Stigma is a common experience for this population with stereotyping as "junkies" and associated with criminality. They are positioned as drug-seeking and this requires more surveillance at the EoL when opioid therapy is potentially more available and authorised. This can make it challenging to generate "companion" stories that are positive and maintain moral adequacy. Dominant biomedical narrative genres often prevent the recognition of the fractured stories that people using substances can often present with. This can lead to narrative silencing and to the under treatment of pain. **Abstract:** <http://bit.ly/2MnppDQ>

**N.B.** Additional articles on terminal ill patients with drug and alcohol addictions noted in 15 July 2019 issue of Media Watch (#622, pp.9-10).

### **Integration of pediatric palliative care into cardiac intensive care: A champion-based model**

*PEDIATRICS* | Online – 31 July 2019 – Timely referral to and integration of pediatric palliative care (PPC) into the traditionally cure-oriented cardiac ICU (CICU) remains variable. Despite dramatic declines in mortality in pediatric cardiac disease, key challenges confront the CICU community. Given increasing comorbidities, technological dependence, lengthy recurrent hospitalizations, and interventions risking significant morbidity, many patients in the CICU would benefit from PPC involvement across the illness trajectory. Current PPC delivery models have inherent disadvantages, insufficiently address the unique aspects of the CICU setting, place significant burden on subspecialty PPC teams, and fail to use CICU clinician skill sets. The authors propose a novel conceptual framework for PPC-CICU integration based on literature review and expert interdisciplinary, multi-institutional consensus-building. This model uses interdisciplinary CICU-based champions who receive additional PPC training through courses and subspecialty rotations. PPC champions strengthen CICU PPC provision by: 1) Leading PPC-specific educational training of CICU staff; 2) Liaising between CICU and PPC, improving use of support staff and encouraging earlier subspecialty PPC involvement in complex patients' management; and, 3) Developing and implementing quality improvement initiatives and CICU-specific PPC protocols. Our PPC-CICU integration model is designed for adaptability within institutional, cultural, financial, and logistic constraints, with potential applications in other pediatric settings, including ICUs. Although the PPC champion framework offers several unique advantages, barriers to implementation are anticipated and additional research is needed to investigate the model's feasibility, acceptability, and efficacy. **Abstract:** <http://bit.ly/2YAYRp4>

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## Related

- *ACADEMIC PEDIATRICS* | Online – 31 July 2019 – ‘**Pediatric resident experience caring for children at the end of life in a children's hospital.**’ Pediatric residents are expected to be competent in end of life (EoL) care. The authors aimed to quantify pediatric resident exposure to patient deaths, and the context of these exposures. Of 579 patients who died during the study period, 46% had resident involvement. Pediatric residents have limited but variable exposure to EoL care, with most exposures in the ICU after withdrawal of life-sustaining technology. Educators should consider how to optimize EoL education with limited clinical exposure, and design resident support and education with these variable exposures in mind. **Abstract:** <http://bit.ly/2YDmljU>
- *CURRENT ANESTHESIOLOGY REPORTS* | Online – 27 July 2019 – ‘**Pediatric palliative care in the perioperative period.**’ The purpose of this review is to familiarize anesthesiologists with the role of the subspecialty of pediatric palliative care (PC) and its potential contributions to the management of children with complex and life-threatening illnesses, many of whom may present for operative or diagnostic procedures requiring anesthesia. Recent publications highlight the benefits of PC to patients and families experiencing a wide variety of conditions along the continuum from prenatal application to the management of young adults. Retrospective reports highlight improved quality of life, improved symptom control, an impact on place of care... **Abstract (w. list of references):** <http://bit.ly/2Os4vFX>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 August 2019 – ‘**The influence of parents’ religiosity or spirituality on decision making for their critically ill child: An integrative review.**’ Religion and/or spirituality are important values for many parents of critically ill children; however, how religion and/or spirituality may influence which treatments parents accept or decline for their child, or how they respond to significant events during their child’s illness treatment, remains unclear. Twenty-four articles of variable methodological quality met inclusion criteria. Analysis generated three themes: parents’ religiosity or spirituality as 1) guidance during decision making, 2) comfort and support during the decision-making process, and 3) a source of meaning, purpose, and connectedness in the experience of decision making. **Abstract:** <http://bit.ly/2YI1TUA>

## Those 5 stages of grief: Does mourning really unfold like that?

*PSYCHCENTRAL* | Online – 30 July 2019 – Sometimes a psychological phenomenon becomes so well-known that even people with no training whatsoever in psychology are familiar with it. That’s true for the five stages of grief, as described by the psychiatrist Elisabeth Kübler-Ross back in 1969. When someone dies, she suggested, the first reaction of the loved ones left behind is denial. Anger comes next, then bargaining, then depression. Finally, after all those stages have passed, mourners experience some acceptance of their loss. Originally, Kübler-Ross formulated the stages of grief to describe the reactions of patients who had terminal illnesses. But she never conducted a systematic study of people’s reactions to the death of a loved one, and whether those reactions change over time in the way she predicted. Over the years, researchers have stepped in to try to see whether Kübler-Ross was right. They found that, with regard to the order in which various reactions peak over time, Kubler-Ross was spot on. She was wrong, though, about the frequency with which the bereaved experience different emotions. The most important conclusion of research on stages of grief, though, is that there is no one way to grieve. Different people mourn in different ways. Their stages may be different than the ones Kübler-Ross described, or they may not go through different stages at all. **Full text:** <http://bit.ly/2Yv7g9j>

## Related

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 31 July 2019 – ‘**Should we incorporate the work of Elisabeth Kübler-Ross in our current teaching and practice and, if so, how?**’ This article acknowledges the historical importance of the work of Elisabeth Kübler-Ross... Because her name and this model appear in many textbooks, professional educational programs, and popular culture, should we incorporate these subjects in responsible ways in our current teaching and practice? The answer proposed here is that we should incorporate these subjects, but only if: 1) We focus on her recommendations on behalf of active listening and learning from persons diagnosed with a terminal illness: 2) We

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limit ourselves to her descriptions of the individual reactions and responses experienced by her interviewees; 3) We acknowledge criticisms of the five stages model as a framework for understanding coping with life-threatening illness and dying; 4) We draw instead on alternative theories of coping with dying; and, 5) We recognize dangers in applying this model to issues involving loss, grief, and bereavement and do not do so. **Abstract:** <http://bit.ly/2yykico>

Noted in Media Watch 15 April 2019 (#610, p.8):

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 11 April 2019 – ‘**Elisabeth Kübler-Ross and the “five stages” model in a sampling of recent textbooks published in 10 countries outside the U.S.**’ A previous article in this journal examined some aspects of the enduring influence of Elisabeth Kübler-Ross’s “five stages” model through a sampling of recent American textbooks in selected academic disciplines and professional fields. This article offers a parallel sampling of 47 textbooks published in 10 different countries outside the U.S. The questions to be answered are as follows: 1) Does the “five stages” model appear without significant change in the textbooks described here?; 2) Is the “five stages” model applied in these textbooks to issues involving loss, grief, and bereavement as well as to those involving terminal illness and dying?; 3) Is the “five stages” model criticized in some or all of these textbooks?; 4) If so, is the criticism sufficient to argue that, while the “five stages” model might be presented as an important historical framework, it should no longer be regarded as a sound theory to guide contemporary education and practice? **Abstract:** <http://bit.ly/2KwyaMo>

**N.B.** Additional articles on “five stages” model noted in 19 November 2018 issue of Media Watch (#590, p.15).

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2019,191;(30):E838-E840. ‘**Request for medical assistance in dying after a suicide attempt in a 75-year-old man with pancreatic adenocarcinoma.**’ The term “wish to hasten death” does not have an established definition, and there is a divergence of opinion about what factors influence it. There is a consensus that this wish is a reaction to suffering in the context of a life-threatening condition, and arises when a person sees no other option than to accelerate their death. That is to say, intolerable suffering, or the anticipation of future intolerable suffering, is one of the key underlying drivers of wish to hasten death, which ultimately may manifest as a request for medical assistance in dying (MAiD), or in suicidal ideation and attempts. Suffering is defined as a state of distress that occurs when the intactness or integrity of the person is threatened or disrupted. Given the well-established connection between uncontrolled physical symptoms and desire for hastened death, every effort should be made to provide patients at the end of life with adequate pain and symptom management. However, assessing suffering means going beyond an inquiry into physical symptoms; the additional domains of emotional, spiritual and existential suffering should also be considered. Differentiation between these areas is often difficult, as each relates to and drives the other – hence, the involvement of three different clinical services (internal medicine, palliative care and psychiatry) in this case. **Full text:** <http://bit.ly/2YucoP8>
- *JOURNAL OF POLICY & PRACTICE IN INTELLECTUAL DISABILITIES*, 2019;16(2):96-98. **This special issue of the journal** is a contribution to stimulate discussion and debate in the community of scholars in the field of intellectual and developmental disability around the ethical issues of ending the lives of people with intellectual disabilities. It features a stimulus paper and then a series of invited commentaries. An initial, large monograph was shared with a group of scholars, scientists, and researchers in the global community who were invited to provide commentary. The monograph is available on the webpage of the International Association for the Scientific Study of Intellectual & Developmental Disability’s Ethics Special Interest Research Group. An abridged version of the monograph is published as the first article in this special issue. The review is in the commentaries that follow. A range of opinions and perspectives indicate the complexity of this important topic and the critical value of debate and discussion. **Journal contents page:** <http://bit.ly/2YsiDTG>



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**N.B.** Selected articles on palliative and end-of-life care for people living with intellectual and developmental disabilities noted in 6 May 2019 issue of Media Watch (#613, p.6).

- *MEDICAL HUMANITIES* | Online – 26 July 2019 – ‘**What is the cultural value of dying in an era of assisted dying?**’ Assisted dying is now a lawful and integral component of many societies “death system,” orienting individual and collective encounters with death and dying. While only a very small number of people living with terminal illness in these societies will opt for an assisted death, the choice, nevertheless, exists for those who satisfy the legal criteria. Theoretically, in these jurisdictions, this turns dying into an optional part of the human life cycle; a final phase of life that, until now, seemed a universal feature of life except in instances of sudden death. As anthropologists specialising in death and dying, the authors pose the question of how the various cultural scripts that have sought to give meaning to dying in post-industrial Western societies since the mid-20th century might be affected by the advent of assisted dying. They begin by building on both medical and social science literature to construct a working definition of “dying.” The authors then identify four dominant cultural scripts: psychological growth, preparation for death, the suffering experience and the caring experience. After outlining each script, they discuss how it may (or may not) be affected by the increase in assisted dying legislation. **Abstract:** <http://bit.ly/2Yt1w3U>

## [Publishing Matters](#)

### **American Medical Writers Association, European Medical Writers Association & International Society for Medical Publication Professionals joint position statement on predatory publishing**

*CURRENT MEDICAL RESEARCH & OPINION* | Online – 29 July 2019 – The three associations recognize the challenges to scientific publishing being posed by predatory journals and their publishers, which employ practices undermining the quality, integrity and reliability of published scientific research. The joint position statement complements several other sets of guidelines that have helped define the characteristics of a predatory journal. Predatory journals pose a serious threat both to researchers publishing the results of their work and to the peer-reviewed medical literature itself. These publications differ from legitimate open-access journals in that predatory journals subvert the peer-review publication system for the sole purpose of financial gain with little evident concern for ethical behavior. Harm to the scientific literature will be the ultimate result if predatory publishing proliferates. Legitimate research carried out with the best of intentions might be lost if it is not recorded, cited or made accessible in the long term, and the scientific record is at risk of being corrupted. But dangers to authors also exist in that their reputations can be damaged as a result of having their work published in predatory journals or being unknowingly “appointed” to their editorial boards. Furthermore, authors may find themselves trapped after they realize they have submitted an article to a predatory journal. There is a potential risk that some journals might not return submitted manuscripts or will publish a submitted paper even after an author has protested. **Full text:** <http://bit.ly/2YBcZOS>



Sample of press coverage of the associations' joint position statement:

- U.K. | *The Daily Mail* (London) – 30 July 2019 – ‘**Academics urged to stop submitting their papers to “predatory journals” motivated by money over fears they’re damaging the reputation of scientists.**’ Scientific journals which don’t properly review papers before publishing them are damaging the industry’s reputation, experts warn. The “predatory journals” are accused of having dangerously low standards and publishing papers simply to make money. Although they didn’t name the journals, the scientists listed red flags which should put researchers off using certain publications. Ones that have near-identical names to respected journals, those with shabby websites or with dubious contact details should be avoided, they said. <https://dailym.ai/2Ovtl7W>



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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.

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

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