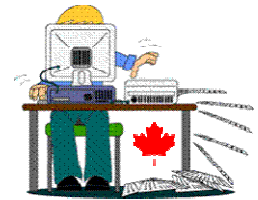


## Media Watch...

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

Facilitating patient-centred care: Scroll down to [Specialist Publications](#) and 'Social media in palliative medicine research: Jump into the cool water' (p.7), in *BMJ Supportive & Palliative Care*.

## Canada

### Most Canadian caregivers are paying too much tax. Here's how to remedy that

*THE GLOBE & MAIL* | Online – 22 August 2018 – While billions of dollars are spent every year by Canadians who are caring for ailing family members, more than 85% of them are leaving money on the table in possible tax breaks that could ease the financial burden for caregivers. One-third of Canadians currently provide caregiving support or expect to in the next five years – a number that increases to 40% among those aged 45 to 55, according to a recent Canadian Imperial Bank of Commerce poll. Yet, despite several tax credits available for those Canadians who financially contribute to the care of a loved one due to illness or advanced age, 43% of caregivers stated that they are not aware that they exist, and only 12% have ever used them. The low percentage of Canadians utilizing available tax credits is a surprising number that shows there is a greater need for education around what is available to caregivers... The costs of caring for an aging parent alone is estimated at \$33 billion annually in direct and indi-

rect costs, which can range from parking fees to personal-care workers to reduced hours at work... That figure is expected to jump by 20% over the next decade because of an aging population and increased demand for services. <https://goo.gl/xehtQM>

### [Specialist Publications](#)

'Caregivers for people at end of life in advanced age: Knowing, doing and negotiating care' (p.5), in *Age & Ageing*.

'Education, training, and mentorship of caregivers of Canadians experiencing a life-limiting illness' (p.5), in *Journal of Palliative Medicine*.

'Psychological morbidity and general health among family caregivers during end-of-life cancer care: A retrospective census survey' (p.5), in *Palliative Medicine*.

**N.B.** Selected articles on job protection and income security for family caregivers in Canada noted in the 28 December 2016 issue of Media Watch (# 442, pp.1-2). See also Compassionate Care Benefit, Government of Canada: <https://goo.gl/yGFoYQ>

## U.S.A.

### Families should talk about end-of-life care early, experts say

CABLE NEWS NETWORK | Online – 24 August 2018 – Senator John McCain and his family have made the difficult decision to discontinue treatment for McCain's terminal brain cancer. Legendary singer Aretha Franklin also decided to discontinue treatment toward the end of her life. How patients and families do this kind of risk-benefit analysis about end-of-life decisions involves a complicated and emotional conversation that experts say you should have as early as possible when someone is seriously ill. Oncologist Dr. Otis Brawley said he still finds shocking a conversation he had 30 years ago with the daughter of a terminally ill cancer patient he treated. He remembers asking the daughter whether they should stick with what he called "reasonable care" for the woman. "When I used that term, I was thinking about comfort measures, but the daughter told me, 'Dr. Brawley, everything is reasonable,'" he recalled. But "everything" is not always the best option, said Brawley, the chief medical and scientific officer for the American Cancer Society. "Then what typically happens is, you end up with a patient on a ventilator, in intensive care, with all kinds of drugs to support their blood pressure and other body functions," Brawley said. "The quality of that person's life for their final days is absolutely awful." Doctors are under no legal obligation to help you with these questions, but there is a general consensus, according to the American Medical Association, that doctors should have conversa-

tions with patients and their families about quality of life using various treatments and should be truthful about if there are no treatment options left. <https://goo.gl/5gsxn6>

N.B. Senator McCain died 25 August.

#### Specialist Publications

'Quality improvement initiatives to reduce mortality: An opportunity to engage palliative care and improve advance care planning' (p.6), in *American Journal of Hospice & Palliative Medicine*.

'End-of-life care, not end-of-life spending' (p.11), in *Journal of the American Medical Association*.

'Patient, caregiver and taxpayer knowledge of palliative care and views on a model of community-based palliative care' (p.10), in *Journal of Pain & Symptom Management*.

'Hospice underutilization in the U.S.: The misalignment of regulatory policy and clinical reality' (p.11), in *Journal of Pain & Symptom Management*.

'Caregivers' experiences with medical aid-in-dying in Vermont: A qualitative study' (p.16), in *Journal of Pain & Symptom Management*.

#### Related

- CALIFORNIA | *The San Diego Union-Tribune* – 25 August 2018 – **'Why hospice care should start sooner rather than later.'** As much as we need celebrities and respected persons to announce their decision to seek hospice or palliative care, the gap between "enters hospice care" and "dies after a battle with X" is too often way too short: Harmon Killebrew, four days; Lari White, three days; Joan Mondale, one day; B.B. King, 10 days; George McGovern, five days; Jarrod Lyle, six days; and, Barbara Bush, two days. With luminaries like these passing in days, and the median length of stay in hospice just a little over three weeks, the public could be forgiven for thinking that "hospice is where you go to die." <https://goo.gl/eS2zya>
- WASHINGTON DC | *Slate* – 24 August 2018 – **'Palliative care is still medical treatment.'** The idea that McCain is no longer receiving medical treatment is simply incorrect. What he has announced is what we in medicine call a change in his goals of care... It means that instead of continuing with treatments designed to cure or prolong life, you transition to care designed only to alleviate suffering, meaning palliative care (PC) and hospice care. Unfortunately, many patients conflate accepting PC with "giving up," when in fact, it is no different than any other kind of medicine. Palliative and hospice care are not a discontinuation of medical treatments, but rather an escalation of treatments focused on the actual problems at hand – the extremely difficult tasks of being terminally ill and of dying – even if we wish the salient problems were different. <https://goo.gl/K7zkyp>

## **A late-life surprise: Taking care of frail, aging parents**

**KAISER HEALTH NEWS** | Online – 23 August 2018 – As life spans lengthen, adult children ... in their 60s and 70s are increasingly caring for frail, older parents – something few people plan for. “When we think of an adult child caring for a parent, what comes to mind is a woman in her late 40s or early 50s,” said Lynn Friss Feinberg, senior strategic policy adviser for American Association for Retired Person’s Public Policy Institute. “But it’s now common for people 20 years older than that to be caring for a parent in their 90s or older.” A new *[sic]* analysis from the Center for Retirement Research<sup>1</sup> ... is the first to document how often this happens. It found 10% of adults ages 60 to 69 whose parents are alive serve as caregivers, as do 12% of adults age 70 and older. The analysis is based on data from 80,000 interviews (some people were interviewed multiple times) conducted from 1995 to 2010 for the Health & Retirement Study. About 17% of adult children care for their parents at some point in their lives, and the likelihood of doing so rises with age, it reports. That’s because parents who’ve reached their 80s, 90s or higher are more likely to have chronic illnesses and related disabilities and to require assistance, said Alice Zulkarnain, co-author of the study. The implications of later-life caregiving are considerable. <https://goo.gl/yP1y5c>

1. ‘How much long-term care do adult children provide?’ Center for Retirement Research, Boston College, Massachusetts, June 2017. **Download/view at:** <https://goo.gl/2Zcpu2>

## **Hospices need to redefine themselves**

**FLORIDA** | *Citrus County Chronicle* (Crystal River) – 21 August 2018 – November was National Hospice Month and officials with Hospice of Citrus and the Nature Coast (HoCNC) were pictured all smiles receiving the proclamation from the county commission. But all is not rosy in hospice-land, according to HoCNC’s chief operating officer and a board member. They told the *Chronicle* in late November about the \$3.5 million in federal fines the company is facing, which has forced it to sell properties in its 12-county service area and lay off dozens of employees, 27 in Citrus County alone. HoCNC’s settlement agreement with the Office of Inspector General (OIG) dates from late 2015, and it has until 2020 to complete the payments. Local hospice officials blame over-eager federal contractors acting on behalf of the federal OIG, which is charged with investigations under the Health Care Fraud & Abuse Control Program. It looks for fraud and abuse of Medicaid and Medicare, which provides the lion’s share of hospice funding nationwide. In fiscal year 2015, the OIG said, “the government recovered \$2.4 billion as a result of health care fraud judgments, settlements and additional administrative impositions in health care fraud cases and proceedings. Since its inception in 1997, the program has returned more than \$29.4 billion to the Medicare Trust Funds.” Hospice of Citrus and the Nature Coast says it hopes to keep the doors open despite the fines and a dwindling patient count – barely 250 now, down from 600. <https://goo.gl/kMBHpQ>

- N.B.** See ‘Vulnerabilities in the Medicare Hospice Program Affect Quality Care and Program Integrity...,’ Office of Inspector General, U.S. Department of Health & Human Services, July 2018. [Noted in the 6 August 2018 issue of *Media Watch* (#575, pp.3-4)] **Download/view at:** <https://goo.gl/DPTmw9>

## **Saginaw hospice care facility closing due to lack of patients**

**MICHIGAN** | *MLive* (Saginaw) – 20 August 2018 – Cartwright Hospice Residence is closing ... because of the low number of residents admitted to the care facility. “We’ve really been evaluating this over multiple years,” said Diane Glasgow, director of the Covenant Visiting Nurse Association. “The amount of patients was decreasing year by year. There’s been times where we’ve closed.” Glasgow said that over the last few months they averaged about 1.8 residents a day and with a staff that included six full-time employees and part time employees it did not make it feasible. One reason numbers are low, she said, is because more people prefer to die at home instead of a facility... <https://goo.gl/kL5Nqt>

- N.B.** See ‘Site of death, place of care, and health care transitions among U.S. Medicare beneficiaries, 2000-2015,’ *Journal of the American Medical Association*, 2018;320(3):264-271. [Noted in the 2 July 2018 issue of *Media Watch* (#570, p.4)] **Full text:** <https://goo.gl/TpgfZk>

## Veterans Affairs watchdog finds significant problems in caregiver program

WASHINGTON DC | *Roll Call* – 20 August 2018 – Family caregivers seeking help from the Department of Veterans Affairs (VA) encountered extended wait times and spotty aid from the agency, according to a report from the VA's Office of Inspector General (OIG). The OIG investigation found 65% of the more than 1,800 applicants between January and September 2017 were forced to wait longer than the required 45-day timeframe to be approved for the program. Fifty-five percent of the applicants waited between three and six months for approval, while 14% waited even longer... The problematic findings come as the VA ramps up resources to extend the program – which currently only applies to veterans who served after 9/11 – to veterans of all eras at a cost of \$21.4 billion over the next five years. <https://goo.gl/7ppnKw>

### Specialist Publications

**'Specialized palliative and hospice care and the importance of mourning our nation's veterans'** (p.6), in *American Medical Association Journal of Ethics*.

**'A comprehensive approach to eliciting, documenting, and honoring patient wishes for care near the end of life: The Veterans Health Administration's Life-Sustaining Treatment Decisions Initiative'** (p.6), in *The Joint Commission Journal on Quality & Patient Safety*.

## International

### Thousands died waiting for National Health Service funding decision

U.K. (England) | BBC News (London) – 24 August 2018 – More than three thousand people died in England last year awaiting an National Health Service (NHS) decision on their eligibility for home care funding. A charity said it was "tragic and ludicrous" that families learned the outcome after losing their relatives. One widow told the BBC a nurse came to assess her husband the day after he died. NHS England said improvements had been made but the process could be "more efficient." Continuing healthcare (CHC) is a funding package given to people with severe health and social care needs, such as Alzheimer's or Parkinson's, but who are not in hospital. Applications should take no longer than 28 days to deal with, but clinical commissioning groups (CCGs) revealed 3,400 people died in 2017-2018 while awaiting a decision on their application. The BBC obtained information from 185 out of 198 CCGs about the outcome of CHC applications received in the last financial year.

Figures from NHS England show that last year, nearly 150,000 CHC assessments were carried out. A third of assessments resulted in the applicant being told they were not eligible for funding. <https://goo.gl/oEa4iS>

### Specialist Publications

**"One day I will find the right words, and they will be simple" – Rethinking DNACPR at a national level'** (p.12), in *Journal of Public Health*.

**'Adaptation of the Ambulatory & Home Care Record for collecting palliative care service utilisation data from family carers in the U.K.: A pilot study'** (p.14), in *Pilot & Feasibility Studies*.

**'Advocating for end-of-life choice at home: A survey of rural Australian nurses'** (p.15), in *Rural & Remote Health*.



### 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.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NETHERLANDS | Dutch News* (Amsterdam) – 22 August 2018 – ‘**Living wills are often too old to sanction euthanasia: Research.**’ A large number of the euthanasia declarations signed by people in The Netherlands are useless because they have not been regularly updated, according to research by a Dutch family doctor. Matthijs van Wijmen has followed thousands of people who have set down their wish to die by euthanasia should they become senile, incapacitated or terminally ill. However, doctors cannot perform euthanasia on the basis of an old declaration, and fewer than half of people with a living will update it... Anyone can draw up a living will but the two Dutch voluntary euthanasia societies publish standard versions. However, just 42% of NVVE and 28% of NPV members had discussed their wishes with their family doctor within the six year period of the research, meaning their declarations were likely to be considered void, Van Wijmen found. There is no official guideline for determining how often a living will should be updated. However, earlier this year a doctor was reprimanded by the euthanasia regulatory body because she had carried out euthanasia on someone whose living will was five years old. <https://goo.gl/ztZWYd>
- U.K. | *The Economist* – 20 August 2018 – ‘**The case for and against assisted dying.**’ *The Economist* will run essays by people who are both for and against assisted dying. The magazine has a wide range of contributors: from doctors and lawyers who have fought for the right of patients or clients to die as they choose, to medical practitioners and atheists who are opposed to the idea. Contributions come from Guernsey (where a recent attempt to allow assisted dying was squashed), Britain, Canada, Switzerland and Belgium. *The Economist* will publish two to three articles each day this week; then, in the week beginning 27 August, some contributors will respond to one another. <https://goo.gl/9DRTv3>

## Specialist Publications

### Caregivers for people at end of life in advanced age: Knowing, doing and negotiating care

*AGE & AGEING* | Online – 25 August 2018 –The authors identify nine categories of care and argue the support and care provided by family should be understood as going beyond simple task-based transactions. They present a model of end-of-life (EoL) care describing and explaining inter-related aspects of knowing, doing and negotiating care tasks. This work furthers current understandings of care as multifaceted and negotiated and has practical implications for thinking about how best to support the complex EoL caregiving work of people caring for a person in advanced age. **Abstract:** <https://goo.gl/R9nWem>

### Journal Watch

‘A shift in scholarly publishing practices and the growing menace of predatory journals’ (p.17), in *The Medical Journal of Australia*.

### Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – Accessed 20 August 2018 – ‘**Education, training, and mentorship of caregivers of Canadians experiencing a life-limiting illness.**’ This study involved a rapid literature review that addressed caregiver experiences, needs and issues as they related to health, quality of life and well-being. The author outlines the resources required for a suitable education, training, and mentorship of caregivers of Canadians experiencing a life-limiting illness. **Full text:** <https://goo.gl/RqXuVu>
- *PALLIATIVE MEDICINE* | Online – 21 August 2018 – ‘**Psychological morbidity and general health among family caregivers during end-of-life cancer care: A retrospective census survey.**’ Family carers provide vital support for patients towards the end-of-life... Levels of psychological morbidity among these family carers are far higher than indicated by previous research, indicating a substantial public health problem. Consistent assessment and support for carers to prevent breakdown in caregiving may produce cost savings in long term. **Full text:** <https://goo.gl/2hMZPK>

## Quality improvement initiatives to reduce mortality: An opportunity to engage palliative care and improve advance care planning

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 20 August 2018 – Despite substantial efforts to integrate palliative care (PC) and improve advance care planning (ACP), both are underutilized. Quality improvement initiatives focused on reducing mortality may offer an opportunity for facilitating engagement with PC and ACP. Clinicians who participated in an initiative to reduce acute myocardial infarction mortality highlighted the challenges associated with decision-making regarding interventions, systems for documenting patient goals-of-care, and broader engagement with PC. Primary PC training is needed to improve discussions about patient and family goals-of-care near the end of life. **Abstract:** <https://goo.gl/WXU3dK>

## Specialized palliative and hospice care and the importance of mourning our nation's veterans

*AMERICAN MEDICAL ASSOCIATION JOURNAL OF ETHICS*, 2018;20(8):E787-792. One aspect of palliative medicine that has been underexplored is the perspective of veterans either facing critical life-limiting illness or at the end of life (EoL). The needs of veterans differ not only because military culture affects how veterans cope with their illness but also because exposure-related factors (combat and environmental) differ between military branches. The authors describe two cases involving EoL care for veterans with combat trauma and describe individualized approaches to their care. Of the estimated 20 million veterans in the U.S., just under half are currently enrolled in the Veterans Affairs (VA) system. What can be extrapolated from these data is that, while a significant portion of veterans die within the VA health care system, a significant number die in the community where their veteran status might be unknown or the influence of their military experience not fully appreciated. This circumstance limits effective delivery of veteran-specific outpatient palliative services over the course of a life-limiting illness by failing to ensure that caregivers of veterans at the EoL are sensitive to military culture and aware of post-traumatic stress disorder and its effects. The most immediate implication of limited veteran-specific outpatient palliative care is the inability of veterans with life-limiting illness to achieve a reasonable quality of life. A more far-reaching implication is the long-term impact on families throughout the course of the disease as well as family distress during the period of active dying, which could cause protracted or complicated grief. Assessing patients at the EoL for military-related factors can greatly improve the care of veterans and members of their support network. **Full text:** <https://goo.gl/9WUrQq>

### **A comprehensive approach to eliciting, documenting, and honoring patient wishes for care near the end of life: The Veterans Health Administration's Life-Sustaining Treatment Decisions Initiative**

*THE JOINT COMMISSION JOURNAL ON QUALITY & PATIENT SAFETY* | Online – 17 August 2018 – There is an emerging consensus that clinicians should initiate a proactive “goals-of-care conversation” (GoCC) with patients whose serious illness is likely to involve decisions about life-sustaining treatments (LSTs) such as artificial nutrition, ventilator support, or cardiopulmonary resuscitation. This conversation is intended to elicit the patient's values, goals, and preferences as a basis for shared decisions about treatment planning. LST decisions are often postponed until the patient is within days or even hours of death and no longer able to make his or her goals and preferences known. Decisions then fall to surrogates who may be uncertain about what the patient would have wanted. The Veterans Health Administration's Life-Sustaining Treatment Decisions Initiative (LSTDI) was designed to ensure that patients' goals, values, and preferences for LSTs are elicited, documented, and honored across the continuum of care. The LSTDI includes a coordinated set of evidence-based strategies that consists of enterprise-wide practice standards for conducting, documenting, and supporting high-quality GoCCs; staff training to enhance proficiency in conducting, documenting, and supporting GoCCs; standardized, durable electronic health record tools for documenting GoCCs; monitoring and information technology tools to support implementation and improvement; a two-year multi-facility demonstration project conducted to test and refine strategies and tools and to identify strong practices; and a program of study to evaluate the LSTDI and identify strategies critical to improving care for patients with serious illness. **Abstract (w. link to references):** <https://goo.gl/tFNZvZ>

Cont.

Noted in Media Watch 18 December 2017 (#543, p.5):

- U.S. (California) | *California Healthline* (Oakland) – 11 December 2017 – ‘**Reverberations from war complicate Vietnam veterans’ end-of-life care.**’ For some veterans, the stoicism honed on the battlefield often returns full-force as they confront a new battlefield in the hospital, making them less willing to admit they are afraid or in pain, and less willing to accept treatment. Other vets, with post-traumatic stress disorder, are even more reluctant to take pain-relieving opioids because the drugs can actually make their symptoms worse, triggering frightening flashbacks. <https://goo.gl/uYpZHB>

Noted in Media Watch 2 October 2017 (#532, p.10):

- *HOME HEALTHCARE NOW*, 2017;35(9):485-493. ‘**End-of-life care for World War II, Korea, and Vietnam-era veterans.**’ Highlighted in this article are a variety of ways in which home care and hospice clinicians and agencies can honor and respect veterans. Listening to a patient reminisce and observing for potential complications can facilitate the clinician in seeking the right care or support for the patient, their families, and their caregivers. Asking the patient, their families, and caregivers what their wishes are is important to providing patient-centered care. **Full text:** <https://goo.gl/FKEL2b>

**N.B.** Selected articles on the treatment of post-traumatic stress disorder at the end of life noted in the 26 February 2018 issue of Media Watch (#552, pp.5-6).

### Editorial

#### **Social media in palliative medicine research: Jump into the cool water**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 1 September 2018 – Social media (SM) are now part of our everyday lives. But some areas have been more hesitant to engage and palliative care (PC) research, which potentially could benefit hugely from the data that SM generate on a daily basis, stands to lose out. In my time as an associate editor at *BMJ Supportive & Palliative Care*, I have often struggled to get SM research and education pieces peer reviewed. There is still a lack of researchers who are willing or perhaps able to critique articles that have used metrics involving SM, for instance, sentiment analysis. Perhaps this highlights the fact that this is an emerging field and that perhaps medicine has been slow to adapt, and that there is a lack of a firm knowledge base. In my conversations with researchers who wish to analyse SM trends in medicine, there is often mention of ethics and research committees baffled by SM proposals and how such research should be properly conducted. It is worth exploring the many potential uses. When I speak to prospective researchers, I am often asked how they might use SM to inform research. As a starting point, I generally tell them that the first part to a dissertation or any other research project is to define the exact research question from the outset. If they struggle to define that question, or if they fear it has already been asked elsewhere, and comprehensively answered, then SM can be a great pointer... **Introductory paragraphs:** <https://goo.gl/br42hz>

#### **From the archives**

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 28 January 2016 – ‘**Palliative care research centre’s move into social media: Constructing a framework for ethical research, a consensus paper**’ The primary themes that emerged from consensus meetings include: 1) Social media (SM) as a public or private space; 2) The status of open and closed groups; 3) The use of historical data; 4) Recruiting participants and obtaining informed consent; and, 5) Problems of anonymity associated with dissemination. Using SM in palliative research creates complex challenges that require extensive consideration. The authors detail the discussions taken at their research centre. These culminated in a set of guidelines that the authors are looking to pilot and further develop. In practice, these will take some steps towards ensuring that SM research within their centre is conducted in an agreed and ethically acceptable way. **Full text:** <https://goo.gl/BxoRvg>

## Performing sit down medicine in a stand-up place: Is it time for palliative care in the emergency department?

*EMERGENCY MEDICINE JOURNAL* | Online – 20 August 2018 – Heart failure (HF) remains among the most common reasons for hospitalisations with the majority of these admissions occurring through the emergency department (ED). Patients with advanced disease make up a disproportionately large share of hospitalised patients with HF and are particularly symptomatic with arguably the worst quality of life among chronically ill patients; hence, it is not a surprise that they end up in the ED frequently. It seems evident that palliative care (PC) ... would provide significant benefit to those with advanced HF. Evidence suggests that PC specialists can improve quality of life and resource use among patients with HF. More recently, the Palliative Care in Heart Failure trial demonstrated improvements in physical, psychosocial and quality-of-life domains through a systemic approach to outpatient PC, involving a single nurse practitioner and PC specialist, in a high-risk HF population. Hence, it is no surprise that guidelines recommend PC for patients with advanced HF. Most studies suggest that it is vastly underused in this patient population. The intriguing manuscript by Lipinski *et al* further supports these previous studies. **Introductory paragraphs:** <https://goo.gl/SYLCKg>

1. 'Heart failure and palliative care in the emergency department,' *Emergency Medicine Journal*, published online 24 July 2018. [Noted in the 30 July issue of Media Watch (#574, p.6)] **Abstract:** <https://goo.gl/rUKK56>

**N.B.** Additional articles on palliative care in emergency medicine noted in the 30 July 2018 issue of Media Watch (#574, p.6).

## Palliative care in neurology: Integrating a palliative approach to amyotrophic lateral sclerosis care

*EUROPEAN MEDICAL JOURNAL: NEUROLOGY*, 2018;6(1):68-76. This narrative review examines connections between neurology, specialist palliative care (PC), and an integrated palliative approach to care for people living with neurodegenerative conditions. To illustrate the complexities of including PC in the management of neurodegenerative conditions, amyotrophic lateral sclerosis (ALS) is used as a case study. ALS care and smooth care transitions between multiple services and healthcare professionals are discussed, including the timing of PC delivery in ALS; the education and training needs of healthcare professionals; and, misperceptions of PC held by healthcare professionals, patients, and families. The benefits of adopting an integrated palliative approach to care for patients, families, and healthcare professionals are clarified. To enhance this, a family perspective is given on experiences of ALS neurology and palliative services, the challenges they faced, and aspects of care that facilitated the patient's preferences for the time they had left. This review concludes that a palliative approach integrated into the care plan of people with ALS from the time of diagnosis can optimise quality of life by relieving symptoms; providing emotional, psychological, and spiritual support pre-bereavement; minimising barriers to a comfortable end of life; and, supporting the family post-bereavement. These outcomes can only be achieved if PC knowledge and expertise are extended beyond the domain of specialist PC services to include the full scope of health and community-based care. These challenges and potential actions are common for several neurodegenerative pathologies, and recommendations are made for enhancing the training of neurology health professionals within the wider community. **Full text:** <https://goo.gl/NnPabM>

Noted in Media Watch 2 July 2018 (#570, p.12):

- *NEUROLOGY* | Online – 27 June 2018 – '**Palliative care needs are everywhere. Where do we begin?**' The concept of palliative care (PC) in neurology continues to evolve; yet, the stigma about PC remains. Some may view offering PC to patients with serious neurologic conditions as a medical failure. Until recently, most clinicians have associated PC with end-of-life care (EoLC) for patients with malignancy. Fortunately, many have increasingly recognized that EoLC is an important aspect of care for patients with neurologic conditions. Neuro-PC has begun to emerge as a specialty to address these important needs of our patients and their families. **Abstract:** <https://goo.gl/1nHaig>

**N.B.** Additional articles on palliative care in neurology noted in this issue of Media Watch.



## Advance directives and dementia

*THE HASTINGS REPORT*, 2018;48(4):2. A competent person can avoid the onset of dementia by refusing life-sustaining medical care and by voluntarily stopping eating and drinking, bringing life to an end well before any health crisis. A competent person can also try to limit the duration of dementia by drafting an advance directive (AD) that sets bounds on the life-sustaining care, including artificial nutrition and hydration, that medical caregivers can provide when the person no longer has the capacity to make her own medical decisions. But between these two strategies there can lie a significant gap. A person could live with moderate to severe dementia for a considerable time, no longer able to voluntarily stop eating and drinking yet also not yet requiring the life-sustaining care forbidden by an AD. Several years ago ... Paul Menzel and M. Colette Chandler-Cramer argued for what they described as a moderate correction to the dominant view that food and water should always be offered to a patient with dementia if the patient expresses a desire to eat and drink.<sup>1</sup> The problem is taken up again by the legal scholar Norman L. Cantor, and Cantor, too, tries to find a moderate alternative.<sup>2</sup> **Abstract:** <https://goo.gl/DZ5kAJ>

1. 'Advance directives, dementia, and withholding food and water by mouth,' *The Hastings Report*, 2014; 44(3):23-37. [Noted in the 19 May issue of *Media Watch* (#358, p.6)] **Abstract:** <https://goo.gl/WPbe8R>
2. 'On avoiding deep dementia,' *The Hastings Report*, 2018;48(4):15-24. **Abstract:** <https://goo.gl/VFwcxt>

### Related

- *THE HASTINGS REPORT*, 2018;48(4):24-25. '**When voluntary stopping of eating and drinking in advanced dementia is no longer voluntary.**' Respect for autonomy is one of the most fundamental principles of bioethics, and it requires that we allow patients with capacity to refuse life-sustaining treatment, even when that treatment is something as seemingly innocuous as nutrition and hydration. If a capacitated person uses an advance directive to prospectively refuse artificial nutrition or hydration, then that treatment must be withheld if the person develops dementia and loses the ability or willingness to eat. **Abstract:** <https://goo.gl/89SYnu>
- *THE HASTINGS REPORT*, 2018;48(4):26-27. '**Advance directives and discrimination against people with dementia.**' Where the author of 'On avoiding dementia' and I part ways is over the degree of control that advance directives should exert over the care of persons with moderate dementia. I believe that people with the condition should be represented in the debate over treatment standards. It's not surprising that many, perhaps most, people unaffected by dementia think that their preferences should control the care they would receive as dementia patients. **Abstract:** <https://goo.gl/uakkxg>

Noted in *Media Watch* 9 April 2018 (#558, p.9):

- *AGING & MENTAL HEALTH* | Online – 2 April 2018 – '**Exploring provider-surrogate communication during Physician Orders for Life-Sustaining Treatment discussions for individuals with advanced dementia.**' Study participants demonstrated emotional support by valuing what the surrogate said, acknowledging the surrogate's emotions, listening carefully, understanding the patient as a person, and eliciting questions. However, care providers rarely conveyed comprehensive information about the patient's current condition and end-of-life treatment options. **Abstract:** <https://goo.gl/e733Xt>

Noted in *Media Watch* 26 February 2018 (#552, p.12):

- *BMC MEDICAL ETHICS* | Online – 20 February 2018 – '**Advance directives as a tool to respect patients' values and preferences: Discussion on the case of Alzheimer's disease.**' Few and not conclusive data exist on the potential positive impact of advanced directives on the treatment of patients with severe cognitive impairment or dementia. This requires concrete policies and actions to make directives known and effective, particularly in a context of increased possibility of early diagnosis of Alzheimer's disease paired with lack of effective treatments. **Full text:** <https://goo.gl/iUAV3j>

## End-of-life care in Japan

### **Factors related to parent-child communication about end-of-life care: A survey of adult children with an elderly parent**

*JAPANESE JOURNAL OF GERIATRICS*, 2018;55(3):378-385. In Japan, because adult children are expected to perform a key role in decision-making on end-of-life care (EoLC) for older adults, conversing with parents on their wished-for EoLC can help these children to become prepared for this filial responsibility. The aim in this study was to explore how likely Japanese adult children were to discuss EoLC with their parents as well as correlates of such discussions. The authors conducted an online survey using a sample of 1,590 adult children with at least one living parent aged 65 or older. They analyzed data from 1,010 children who responded during three consecutive days in October, 2015. A small portion of participants (22.8%) had discussed EoLC with their parents. Occurrence of such discussions was associated with having older parents, parental experience of severe diseases, parent-child co-residing, and a higher level of perceived necessity for and a lower level of emotional avoidance of end-of-life communication. Generally, adult children rarely discuss EoLC with their aging parents, suggesting the need to promote such familial communication while considering both children's and parents' circumstances. **Abstract:** <https://goo.gl/rPZDhx>

**N.B.** Japanese language article.

### **Race, ethnicity, and end-of-life care in dialysis patients in the U.S.**

*JOURNAL OF THE AMERICAN SOCIETY OF NEPHROLOGY* | Online – 9 August 2018 – There appear to be substantial race- and ethnicity-based disparities in end-of-life practices for U.S. patients receiving dialysis. Among 1,098,384 patients on dialysis dying between 2000 and 2014, the primary outcome (i.e., a composite of discontinuation of dialysis and death in a non-hospital or hospice setting) was less likely in patients from any minority group compared with the non-Hispanic white population... The authors also observed similar significant disparities between any minority group and non-Hispanic whites for dialysis discontinuation, as well as hospice and non-hospital death. Individual minority groups (non-Hispanic Asian, non-Hispanic black, non-Hispanic Native American, and Hispanic) were significantly less likely than non-Hispanic whites to experience the primary outcome. This disparity was especially pronounced for non-Hispanic Native American and Hispanic subgroups. **Abstract:** <https://goo.gl/NngQrF>

**N.B.** Additional articles on racial disparities in the provision and delivery of end-of-life care in the U.S. noted in the 16 July 2018 issue of *Media Watch* (#572, p.5).

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

### **Patient, caregiver and taxpayer knowledge of palliative care and views on a model of community-based palliative care**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 24 August 2018 – Across 10 interviews and 4 focus groups ... there was varying knowledge of palliative care (PC). Gaps in interview and focus group participants' knowledge related to knowing the services available in PC, how PC is paid for, how to initiate PC, and how PC affects the patient's relationship with existing providers. Regarding the model, negative feedback from interview participants included not having PC explained adequately and PC providers seen as consultants, not full-time providers. Focus group participants indicated the model sounded promising, but noted the likely difficulty in enacting it in our current healthcare system. Positive feedback from interview participants included the perception that clinicians spent more time and provided more support for patients and families, and the developing ability of PC services to provide care more broadly than at the very end of life. Focus group participants had similar observations related to perceived attention to care and broader application of PC. Perceptions of time-constrained care delivery and suboptimal provider-patient communication persist for some patients getting PC services. **Abstract (w. link to list of references):** <https://goo.gl/oQRrmy>

Cont.

Noted in Media Watch 1 January 2018 (#544, p.19):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2018; 21(S1):S30-S36. ‘**The impact of public health awareness campaigns on the awareness and quality of palliative care.**’ A comprehensive public awareness campaign about palliative care should be based on clear and shared terminology, use well piloted materials, and the full range of mass media to suit different ages, cultures and religious/spiritual perspectives. There is evidence about key factors for success: targeting, networking, and use of specific, measurable, achievable, realistic time-bound objectives; continuous evaluation; and complementary to national and international policy. Campaigns should be located within the framework of public health promotion and the synergy between short national mass media campaigns and longer term local community action initiatives carefully considered. **Abstract:** <https://goo.gl/MfzCmX>

**N.B.** Additional articles on awareness/perceptions of palliative care and terminology used in the context of end-of-life care noted in the 20 August 2018 issue of Media Watch (#577, pp.14-15).

### **Hospice underutilization in the U.S.: The misalignment of regulatory policy and clinical reality**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 22 August 2018 – After three and a half decades of experience with the Medicare Hospice Benefit in the U.S., despite excellent quality outcomes in symptom management, patient and family satisfaction, and reduction in healthcare costs, only 12-15% of beneficiaries’ days during the last year of life are spent being cared for within the highly cost-effective interdisciplinary coordinated advanced illness care model known as hospice. Although there are many reasons for this, including difficulties in acknowledging mortality among patients, their families, and physicians, a significant cause of low overall hospice utilization and intractably low median lengths of stay, reflective of late admissions, can be attributed to increasingly difficult and highly variable prognostic determinations for most of the leading causes of death among Medicare beneficiaries. In addition to prognostic uncertainty constituting a barrier to timely hospice referral, the Centers for Medicare & Medicaid Services and its payer contractors have developed a robust and expensive retrospective review process that penalizes hospices when patients outlive their expected prognosis. The administratively burdensome and financially punitive review practices further delay or limit access to care for eligible patients as certifying physicians and agencies, fearful of the financial and legal repercussions of reviews and audits, are hesitant to take patients under care unless they are clearly in the dying process. The authors review pertinent history and address the core problem of access to a healthcare benefit built upon a policy that requires far greater prognostic certainty than any clinician can reasonably ascertain and fails to take into consideration

the favorable impact hospice care has on terminally ill patients in improving prognosis. This clinical conundrum that limits access of seriously ill people to high value quality care is of profound importance to the U.S. Medicare population, and also one with potential relevance to all complex and regulated health systems and to other models of care whose eligibility criteria is based on prognostication. **Abstract (w. link to references):** <https://goo.gl/KscyJt>

#### **End-of-life care, not end-of-life spending**

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2018;320(7):631-632. People in the U.S. spend a lot of money at the end of life (EoL). In fact, about one quarter of all Medicare spending goes toward care for people during their last year of life. Beyond this shockingly high number, we know that EoL care patterns and spending vary widely across hospitals and communities. The combination of high spending and variability in spending has convinced many policy makers that EoL care is an attractive target for health care savings, although many clinicians are skeptical. Emerging evidence suggests that saving money on EoL care is much easier said than done. Instead of focusing on spending, we should focus on improving the well-being of those who are terminally ill. One way to potentially save money is to reliably predict who will die and therefore would not benefit from receiving intensive care. But this turns out to be extremely hard to do. In addition, patients with high predicted mortality do not necessarily incur larger expenses. If it’s not possible to reliably predict which sick people are going to die, then reducing EoL spending becomes extremely difficult. **Full text:** <https://goo.gl/w54wNY>

Cont.

Noted in Media Watch 2 April 2018 (#557, p.3):

- NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online – 28 March 2018 – ‘**Facts & figures: Hospice care in America.**’ Hospice professionals continue to be concerned about the number of people who receive hospice care for a short period of time. The national organization’s report indicates that just over 40% of Medicare beneficiaries accessing hospice received care for 14 days or less in 2016, which is considered too short a period for patients to fully benefit from the person-centered care available from hospice. **Download/view at:** <https://goo.gl/Kg28nN>

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

#### **How we should assess the delivery of end-of-life care in general practice? A systematic review**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 21 August 2018 – The majority of end-of-life care (EoLC) care occurs in general practice. However, we still have little knowledge about how this care is delivered or how it can be assessed and supported. A total of 43 studies representing nine evaluation tools were included. A relatively restricted focus and lack of validation were common limitations. Key general practitioner (GP) activities assessed by the evaluation tools were summarized and the main issues in current GP EoLC practice were identified. The review of evaluation tools revealed that GPs are highly involved in management of patients at the end of life, but there are a range of issues relating to the delivery of care. An EoLC registration system integrated with electronic health records could provide an optimal approach to address the concerns about recall bias and time demands in retrospective analyses. Such a system should ideally capture the core GP activities and any major issues in care provision on a case-by-case basis. **Abstract:** <https://goo.gl/CbfjL7>

Noted in Media Watch 30 July 2018 (#574, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 25 July 2018 – ‘**General practice palliative care: patient and carer expectations, advance care plans and place of death: A systematic review.**’ Advance care planning and the involvement of GPs were important factors, which contributed to patients being cared for and dying in their preferred place. There was no reference to general practice nurses in any paper identified. Patients and carers prefer a holistic approach to care. Proactive identification of people approaching end of life (EoL) is likely to improve all aspects of care, including planning and communicating about EoL. **Abstract:** <https://goo.gl/kRSxTS>

#### **“One day I will find the right words, and they will be simple” – Rethinking DNACPR at a national level**

*JOURNAL OF PUBLIC HEALTH*, 2018;40(2):404-408. Evidence has shown a diversity of practices and terminology concerning the implementation and documentation of do not attempt cardiopulmonary resuscitation (DNACPR) notices across different hospital Trusts in England & Wales, and the Resuscitation Council (U.K.) has recently proposed a standard approach for how DNACPR notices can be better incorporated into overall care plans. However, the Council can only make recommendations for good practice. This discussion reviews current practices and suggests that the time has come for a national standardized approach to the process of initiating and documenting DNACPR, along with a dedicated programme to increase public understanding of what is involved. A national policy framework for DNACPR notices would avoid regional and institutional differences, bust current myths, and ensure communication with, and involvement of, the patient remains at the heart of medical practice and decision-making. Importantly, it would both ensure that the respective legal rights and obligations of patients and professionals are respected, as well as providing clear public health benefits. At the very least, a national conversation would help achieve common understandings and expectations. **Abstract:** <https://goo.gl/jVLK7g>



**Resuscitation Council (UK)**

Cont.

Noted in Media Watch 20 August 2018 (#577, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 1 August 2018 – ‘**Cardio-pulmonary resuscitation decision-making conversations in the U.K.: An integrative review.**’ The findings from this integrative review of the literature on patients, family and caregivers’ experience of cardio-pulmonary resuscitation decision-making discussions are at odds with the current legal state in the U.K. and are potentially challenging for health professionals, who are required to discuss do not attempt cardio-pulmonary resuscitation decisions at the earliest opportunity. **Full text:** <https://goo.gl/u4zmjP>

Noted in Media Watch 30 July 2018 (#574, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 25 July 2018 – ‘**Tracey judgement and hospice do not attempt cardiopulmonary resuscitation orders: Steady as she goes or seismic change?**’ The 2014 Court of Appeals decision with respect to *Tracey vs Cambridge University Hospital* (i.e., “the Tracey judgement”) changed the requirements for discussing do not attempt cardiopulmonary resuscitation (DNACPR) decisions with patients. This study is a retrospective case note review aiming to identify any changes in practice around discussing DNACPR decisions in hospices following the judgement. **Abstract:** <https://goo.gl/xf9xWq>

### **Are docs giving patients the wrong idea about brain death?**

*MEDSCAPE* | Online – 21 August 2018 – When doctors discuss brain death with families, the doctors have to be very clear to use the term “dead” instead of “brain-dead.” If someone wants to know how [to be] sure that a relative, loved one, or child has died, you don’t start off with the concept of brain death, because they hear that differently. People confuse coma with brain death. They think the doctor said, “He might be permanently unconscious,” and they equate that with brain death because that may be something they have heard about or seen in the media. Everybody needs clarity. There’s only one condition between life and death. Death is the end of life, and how we get that is by pronouncing either cardiac death or brain death. If doctors believe someone to be dead, they should say that and then explain how they know. Don’t confuse patients by beginning with terms like “brain death,” because they’ll mishear you. **Full text:** <https://goo.gl/3Hdpuh>

**N.B.** Additional articles on defining “brain death” noted in the 20 August 2018 issue of Media Watch (#577, p.5).

### **Cultural and religious diversity in hospice and palliative care: A qualitative cross-country comparative analysis of the challenges of healthcare professionals**

*OMEGA – JOURNAL OF DEATH & DYING* | Online – 24 August 2018 – Research has abundantly demonstrated a strong relationship between culture, religion, and the experiences of death, dying, and bereavement. Consequently, cultural competence and a religiously sensitive practice have become highly relevant to social policies and professional practice. However, current knowledge of culturally competent and religiously sensitive end-of-life care is primarily context specific, with little space for generalizability. This article reports on findings from a qualitative comparative analysis of two nation-specific studies that examined religious literacy and cultural competency, respectively, among palliative care professionals, drawing on similarities and attempting to identify further applicability of nation-centered knowledge. The study recognized six practice-based approaches in palliative and hospice care, when responding to cultural and religious or non-religious identities of services users. These approaches intersect with each other via three organizational layers identified in the study: foundations, culture, and professionals. Each identified practice-based approach seems to be incomplete when working with individuals for whom religion, belief, and cultural identities are important. Change in practice is possible if all three organizational layers are considered simultaneously, while further research will shed more light about the benefits and challenges of each approach. **Abstract:** <https://goo.gl/XmihGd>

## Tools measuring quality of death, dying, and care, completed after death: Systematic review of psychometric properties

*THE PATIENT – PATIENT-CENTERED OUTCOMES RESEARCH* | Online – 24 August 2018 – Measuring the quality of care (QoC) at the end of life (EoL) and/or the quality of dying and death can be challenging. Some measurement tools seek to assess the QoC immediately prior to death; others retrospectively assess, following death, the quality of EoL care. The comparative evaluation of the properties and application of the various instruments has been limited. This systematic review has identified and critically appraised tools for assessing, following death, the QoC at the EoL and of dying and death. This evaluation demonstrates that a limited number of tools exists and that they show some promising psychometric properties but still need further investigation. Despite the abundance of tools available to assess the quality of dying and death and satisfaction with care at the EoL, many gaps remain in our understanding of the psychometric properties of these tools. Future research, rather than seeking to develop new tools, might more productively focus on improving and validating existing tools. **Full text:** <https://goo.gl/4Ah95f>

### Related

- *JOURNAL OF PATIENT-REPORTED OUTCOMES* | Online – 22 August 2018 – ‘**Design and introduction of a quality of life assessment and practice support system: perspectives from palliative care settings.**’ The process of designing, integrating and supporting sustained use of electronic quality of life assessment systems in palliative clinical practice is complex and requires intentional engagement with health care providers (administrators and clinicians) and recipients (patients and family caregivers) in their initial design and implementation. It is important to understand and respond to contextual considerations pertaining to the technology, use at the point of care, and health care organizational contexts as the basis for enhancing chances of successful integration and sustainability. **Full text:** <https://goo.gl/zbPcJf>

## Adaptation of the Ambulatory & Home Care Record for collecting palliative care service utilisation data from family carers in the U.K.: A pilot study

*PILOT & FEASIBILITY STUDIES* | Online – 18 August 2018 – Measuring service use and costs is an important aspect of service delivery evaluation. In end-of-life care, there is heavy reliance on care by family/friends (informal carers) and this should be reflected in the total cost of care alongside formal services. The Ambulatory & Home Care Record (AHCR), developed in Canada,<sup>1</sup> is both comprehensive in coverage and validated for collecting data on formal and informal caring. This study aimed to adapt and pilot the AHCR questionnaire for use in the U.K. within a study evaluating a new palliative care service. The objectives were to test if family carers could be recruited and assess acceptability and usability of data gathered. 194 carers were invited by mail to participate in the study, of which 23 (11.8%) completed at least one interview and 16 (8.2%) completed all possible interviews. Recruitment to the study was lower than anticipated, but most participants seemed to find the interviews acceptable. The modified questionnaire produced usable and relevant data for an economic evaluation of formal and informal caring costs. Modifications are needed to the process of recruitment as a postal recruitment strategy did not have a high response rate. The AHCR has proved a viable tool for use in the U.K. setting, with a few minor modifications, and will be used in a larger study comparing hospice models. **Full text:** <https://goo.gl/4f2CFq>

1. ‘The Ambulatory and Home Care Record: A methodological framework for economic analyses in end-of-life care,’ *Journal of Aging Research*, March 2011. **Full text:** <https://goo.gl/7uPTze>

Noted in Media Watch 3 October 2016 (#482, p.15):

- *PALLIATIVE MEDICINE* | Online – 26 September 2016 – ‘**What cost components are relevant for economic evaluations of palliative care, and what approaches are used to measure these costs? A systematic review.**’ Research which captures the full economic cost should be prioritised in order to gain insight into the inter-relationships between different cost domains and different provider viewpoints and could build on the cost framework proposed here. Methodological developments are also required to generate novel approaches to data collection which provide more accurate cost estimates. **Full text (via PubMed):** <https://goo.gl/JdijHY>

## End-of-life care in New Zealand

### **Towards a bicultural psychotherapy: Decolonising psychotherapy in hospice care**

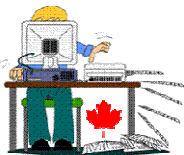
*PSYCHOTHERAPY & POLITICS INTERNATIONAL* | Online – 16 August 2018 – Discrepancies between hospice service usage and cancer rates in Māori – the indigenous peoples of Aotearoa [i.e., the Māori name for New Zealand] – raise several questions. There have been numerous studies into these discrepancies highlighting issues regarding the appropriateness of care in hospice services in Aotearoa for Māori. The authors explore these issues, accentuating some gaps in the literature – such as intergenerational trauma – as well as ways that Pākehā psychotherapists [i.e., New Zealander psychotherapists of European descent) can bi-culturally engage with Māori. The author encourages psychotherapists to become allies by embracing a Māori-centred approach to psychotherapy that brings both groups together as partners, while working through numerous post-colonial issues. **Abstract:** <https://goo.gl/BJQSyn>

**N.B.** Additional articles on Māori beliefs and practices in the context of and end-of-life care noted in the 7 May 2018 issue of Media Watch (#562, p.11).

### **Advocating for end-of-life choice at home: A survey of rural Australian nurses**

*RURAL & REMOTE HEALTH* | Online – 21 August 2018 – The willing and supported use of the autonomy available in the district nurse (DN) role to make time and become involved with people receiving end-of-life (EoL) care is needed to advocate for person-centred goal planning. Relational knowledge enables respectful understanding of the people and rural resources available for advocacy. Support from a variety of sources assists self-care to promote confidence in providing choice in emotionally and ethically demanding rural EoL care. Higher levels of emotional intelligence enable DNs to manage the moral dilemmas and responsibilities of person-centred EoL advocacy. DNs take advocacy action successfully for the EoL goals of rural Australians using respectful relationships that facilitate access to choice. Advocacy underpins the process of holistic assessment, communication and organisation of empowering, supportive care. This survey highlights factors enabling advocacy action in complex rural EoL relational care that may reduce the need for DNs to go beyond duty to provide effective care. The evidence-based understanding gained in this study can be used with confidence to inform a range of quality improvements and develop a practice model that can assist rural DN EoL advocacy care in line with community and palliative care policy. **Full text:** <https://goo.gl/7xifa7>

**N.B.** Additional articles on the provision and delivery of end-of-life care in rural and remote regions of Australia noted in the 27 November and 18 December 2017 issues of Media Watch (#540, pp.9-10 and #543, p.11, respectively).



#### **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>



#### **Closing the Gap Between Knowledge & Technology**

<http://goo.gl/OTpc8l>

## The last low whispers of our dead: When is it ethically justifiable to render a patient unconscious until death?

*THEORETICAL MEDICINE & BIOETHICS* | Online – 21 August 2018 – A number of practices at the end of life can causally contribute to diminished consciousness in dying patients. Despite overlapping meanings and a confusing plethora of names in the published literature, this article distinguishes three types of clinically and ethically distinct practices: 1) Double-effect sedation; 2) Parsimonious direct sedation; and, 3) Sedation to unconsciousness and death. After exploring the concept of suffering, the value of consciousness, the philosophy of therapy, the ethical importance of intention, and the rule of double effect, these three practices are defined clearly and evaluated ethically. It is concluded that, if one is opposed to euthanasia and assisted suicide, double-effect sedation can frequently be ethically justified, that parsimonious direct sedation can be ethically justified only in extremely rare circumstances in which symptoms have already completely consumed the patient's consciousness, and that sedation to unconsciousness and death is never justifiable. The special case of sedation for existential suffering is also considered and rejected. **Abstract (inc. list of references):** <https://goo.gl/VYnaZR>

### Related

- *THEORETICAL MEDICINE & BIOETHICS* | Online – 22 August 2018 – '**Palliative sedation: Clinical context and ethical questions.**' Practitioners of palliative medicine frequently encounter patients suffering distress caused by uncontrolled pain or other symptoms. To relieve such distress, palliative medicine clinicians often use measures that result in sedation of the patient. Often such sedation is experienced as a loss by patients and their family members, but sometimes such sedation is sought as the desired outcome. Peace is wanted. Comfort is needed. Sedation appears to bring both. Yet to be sedated is to be cut off existentially from human experience, to be made incapable of engaging self-consciously in any human action. **Abstracts (inc. list of references):** <https://goo.gl/BJNGER>

**N.B.** Selected articles on palliative sedation noted in the 20 August 2018 issue of Media Watch (#577, p.16).

### Assisted (or facilitated) death

Representative sample of recent journal articles:

- *EUROPEAN PSYCHOLOGIST* | Online – 16 August 2018 – '**The psychology of euthanasia: Why there are no easy answers.**' Voluntary euthanasia has been legalized in several countries and associated with this development there has been much discussion concerning the relationship between the ethical principle of autonomy and the respect for human life. Psychological science should make a significant contribution to understanding how polarizing positions may be taken in such debates. However, little has been written concerning the implications of this research for the euthanasia debate and about the contributions of psychology. In the same way, very little is written about the psychologist's role in countries where voluntary euthanasia or assisted suicide is legalized. The authors take as a starting assumption that there are no solutions that will meet everyone's wishes or needs, but that an understanding of psychological ideas can assist in developing strategies that may help people with opposing views come to some agreement. In their view, it is fundamental to a fruitful analysis, to leave aside a polarized approach and to understand that an eventual answer to the question of how we approach voluntary euthanasia will only be achieved after the hard process of carefully considering the consequences of having either legalized voluntary euthanasia or its prohibition in the context of a psychological understanding. **Abstract (w. link to references):** <https://goo.gl/R5p8NM>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 23 August 2018 – '**Caregivers' experiences with medical aid-in-dying in Vermont: A qualitative study.**' Eight jurisdictions in the U.S. currently permit medical aid-in-dying (AID), yet little is known about the direct experience of caregivers in supporting a loved one through the process. In-depth interviews were conducted with caregivers of terminally ill patients who pursued AID under Vermont's 2013 'Patient Choice and Control at End of Life' Act. While AID is often presented as a simple matter of individual choice and autonomy, most patients who pursue it do so with tremendous support from caregivers, who are in turn deeply implicated, socially and morally, in the process. Including caregivers in education and planning, where warranted, can mitigate feelings of unpreparedness and ensure a smoother experience for everyone involved. **Abstract (w. link to references):** <https://goo.gl/3oHWZQ>



## Journal Watch

### **A shift in scholarly publishing practices and the growing menace of predatory journals**

*THE MEDICAL JOURNAL OF AUSTRALIA*, 2018;209(4):149-150. Although open access journals are freely available at no cost, there is still considerable expense in producing them. Copy-editing, electronic storage and other publishing expenditures are unavoidable and need to be



recovered from some source of revenue. One way of obtaining such funds in an open access model is to charge authors an article processing fee for publication, although this is not the only method currently used by open access journals. This has resulted in a recent shift whereby publishers are repositioning themselves in this market space. The old paradigm saw content being provided as a service to readers who covered publishing costs through their subscription fees, whereas the new paradigm is that publishers are now a service provider to authors; therefore, fundamentally changing the publisher–author relationship. This recent shift in academic publishing practices has also created a new phenomenon: the “predatory journal” – a dangerous and corrosive development. Predatory journals often charge publication fees to authors without meeting expected baseline scholarly standards or providing robust editorial and review services, which act as the cornerstone of legitimate traditional journals. The result has been that low quality research is now being published, threatening the integrity of the body of scientific literature as a whole. This acts as a disservice to the readers of these journals, and authors also suffer by not receiving the constructive feedback that occurs with a robust peer review system. As many commentators have stated, the advent of predatory journals is an unfortunate and unwelcomed corruption of the legitimate open access publishing business model. To add insult to injury, authors can be charged, in some cases, large sums of money to publish in these poor quality predatory journals. In other documented cases, predatory journals have chosen to charge relatively low publication fees as a way to increase their market share and popularity among authors worldwide. This issue is further exacerbated because authors often experience considerable professional pressure to publish and predatory journals provide a deceptively easy route to fulfil this goal. Inexperienced or naive authors often become entrapped by these publishers, who typically find their victims through cleverly worded broadcast emails to the scientific community. **Full text:** <https://goo.gl/Qa8G2N>

### Media Watch: Access on Online

#### **International**



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/kV9zaN>

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

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

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

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

#### **Asia**

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

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

#### **Australia**

PALLIATIVE CARE WESTERN AUSTRALIA: <https://goo.gl/fCzNTL>

[Scroll down to 'International Websites']

Cont.

## Canada

BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION: <https://goo.gl/qw5ti8>

[Click on 'National Resources,' scroll down to 'Palliative Care Network Community']



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

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

ONTARIO | Acclaim Health (Palliative Care Consultation): <https://goo.gl/wGi7BD>

[Scroll down to 'Additional Resources']

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

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

[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

SASKATCHEWAN | Saskatchewan Medical Association: <https://goo.gl/5cftPV>

[Scroll down to 'Palliative Care Network Community']

## Europe

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

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

## South America



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

## Media Watch: Editorial Practice

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

### Distribution

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### Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.

Cont.

6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

**Something Missed or Overlooked?**

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

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