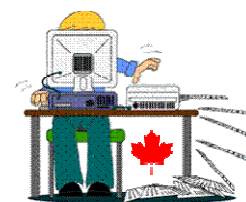


## Media Watch...

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

**'Mind the gap: Is the Canadian long-term care workforce ready for a palliative care mandate?' (p.5), in *Ageing & Society*.**

## Canada

### Improve care and quality of life for dementia patients, expert panel urges

CBC NEWS | Online – 16 January 2019 – An expert panel has released a report outlining the best ways to tackle the growing incidence of Alzheimer's and other forms of dementia among Canadians as a basis for the federal government's long-promised national strategy on the progressive brain diseases. The report by the Canadian Academy of Health Sciences panel<sup>1</sup> ... is aimed at helping the Public Health Agency of Canada create and implement a national dementia strategy, which is expected to be unveiled toward the end of this year. More than half a million Canadians are living with dementia. By 2031, that number is expected to nearly double... Panel members say quality of life for Canadians living with dementia and their caregivers, as well as access to health and social care, can be improved across all stages of the disease process, which in some people can last for years, even decades. Basing its overall findings on evidence from individual provinces and national and international policies and best practices in dementia care and support, the report

recommends that the development of a national strategy consider seven priorities. By 2031, that figure is expected to increase by 60%, to almost \$17 billion. <https://goo.gl/6dkHTR>

#### Extract from Canadian Academy of Health Sciences report (p.27)

##### **Inappropriate end-of-life care**

Although dementia is considered a life-limiting chronic condition, many families and health and social care providers often still do not view it as a terminal disease ... and as a result, they fail to implement a palliative approach with comfort as the primary goal of care. In many jurisdictions of Canada, palliative care does not yet embrace persons with dementia. The absence of a palliative approach with clear guidelines, along with divergent opinions amongst families and health and social care professionals, can result in poor management of symptoms, especially pain, towards the end of life, causing considerable distress to both the person with dementia and their caregivers...

1. 'Improving the quality of life and care of persons living with dementia and their caregivers,' Canadian Academy of Health Sciences, January 2019. **Download/view at:** <https://goo.gl/KKfCiK>

**N.B.** Selected articles, reports, etc., on palliative and end-of-life care for people living with Alzheimer's and other forms of dementia noted in several past issues of Media Watch, for example, 7 January 2019 (#596, pp.9=10); and, 10 and 31 December 2018 (respectively, #593, p.7 and #595, p.16).

## Canadian Foundation for Healthcare Improvement expanding access to innovative palliative approach that will improve end-of-life care

CANADIAN FOUNDATION FOR HEALTHCARE IMPROVEMENT | Online – 15 January 2019 – The Foundation, a not-for-profit organization funded by Health Canada, announced that it is working with seven organizations across five provinces and one territory to spread Embedding Palliative Approaches to Care (EPAC). EPAC is a innovation that helps staff in long term care identify residents who could benefit from a palliative approach to care, have conversations with them and their families about what they want, and develop and implement comprehensive care plans. EPAC was developed by a team at Vancouver Coastal Health in British Columbia and implemented in 48 long term care homes. From April 2014-March 2018 the program resulted in a 56% decrease in emergency department transfers, and a 45 percent reduction in number of days residents spent in acute care in the last 3 months of their life. Using a train-the-trainer approach, this model will then be spread throughout regions where participating organizations have regional responsibilities. <https://goo.gl/D8SJWj>



**N.B.** 'The Daisy Project: A Framework for Embedding a Palliative Care Approach in a Residential Setting,' Vancouver Coastal Health, January 2015. **Download/view at:** <https://goo.gl/SXCCcT>

Noted in Media Watch 11 September 2017 (#529, p.4):

- *ADVANCES IN NURSING SCIENCE*, 2017;40(3):263-279. '**Embedding a palliative approach in nursing care delivery: An integrated knowledge synthesis.**' A palliative approach involves adapting and integrating principles and values from palliative care into the care of persons who have life-limiting conditions throughout their illness trajectories. The aim of this research was to determine what approaches to nursing care delivery support the integration of a palliative approach in hospital, residential, and home care settings. The findings substantiate the importance of embedding the values and tenets of a palliative approach into nursing care delivery, the roles that nurses have in working with interdisciplinary teams to integrate a palliative approach, and the need for practice supports to facilitate that embedding and integration. **Full text:** <https://goo.gl/Rg5dT3>

## U.S.A.

### Updated pediatric standards

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online – 10 January 2019 – A new edition of the 'Standards of Practice for Pediatric Palliative Care' is available as an addendum to the updated, 2018 Standards of Practice for Hospice Programs and are organized around ten component areas. They are intended as a guide for both hospice and palliative care organizations providing care to infants, children, adolescents, and their families, regardless of whether care is delivered in the home, hospital, a long-term care setting or a respite facility. The resource defines programmatic elements and standards which, if uniformly implemented, would ensure that programs for children with life-threatening conditions and their families provide the best care available. **Download/view at:** <https://goo.gl/vhCdsQ>

### Specialist Publications

'National survey of oncologists at National Cancer Institute-designated comprehensive cancer centers: Attitudes, knowledge, and practice behaviors about LGBTQ patients with cancer' (p.8), in *Journal of Clinical Oncology*.

'Overcoming the Balkanization of state advance directive laws' (p.8), in *Journal of Law, Medicine & Ethics*.

'Impact of immigrant status on aggressive medical care counter to patients' values near death among advanced cancer patients' (p.10), in *Journal of Palliative Medicine*.

'Electronic medical orders for life-sustaining treatment in New York State: Length of stay, direct costs in an ICU setting' (p.9), in *Palliative & Supportive Care*.

## First patient treated under right-to-try law

*REGULATORY FOCUS* | Online – 9 January 2019 – A patient diagnosed with an aggressive form of brain cancer became the first person in the U.S. to access an experimental treatment under the Right to Try Law of 2017. The law has been touted as a new way to help people with terminal illnesses and few other therapeutic options, although until now, no patients had ever used the law. ERC-USA and the University of California (Irvine) initiated treatment with the company's investigational compound ERC-1671, also known as Gliovac in Europe, and which is in Phase 2 clinical trials in the U.S. The patient's treatment began at the university in late November 2018. The patient resorted to "right-to-try" after failing to qualify for enrollment in the ongoing trial. But rather than work around the agency that may eventually approve the experimental treatment, the company said in August that it informed the U.S. Food & Drug Administration (FDA) that it intended to make the experimental treatment available to this one patient. FDA acknowledged acceptance of the company's notification on... As far as why the company used "right-to-try" rather than FDA's expanded access, ERC told *Focus* time was of the essence and "right-to-try" had a lower paperwork requirement and likely faster implementation. The law has proven to be a thorn in the side of FDA, which has said it will work to implement it in a manner consistent with congressional intent and with FDA's public health mission, but the agency still has its own process for helping terminally ill patients receive experimental treatments, known as expanded access. FDA grants about 99% of the expanded access requests it receives. <https://goo.gl/47E9KM>



**N.B.** Selected articles on the issue of "right-to-try" new experimental or investigational drugs noted 3 December 2018 issue of Media Watch (#592, p.2).

## International

### Hospice bosses earn almost £500,000 despite charity's financial strain

U.K. (England & Wales) | *Daily Gazette/Essex County Standard* (Colchester) – 17 January 2019 – A charity which is closing an in-demand day therapy centre to save money amid financial difficulties paid its seven highest earners a combined £500,000, it has been revealed. Last year St. Helena Hospice paid thousands of pounds more to its management staff than it did in year ending March 2017. Accounts published by the Charity Commission show in the year to March 2015, the chief executive of the hospice and a group of key directors earned £371,240, excluding pensions. By 2017, the hospice began including pension costs in its annual financial reports, which show the chief executive and seven directors received a total of £527,861 in the year ending March 2016. By March 2018, the latest financial records available, the chief executive and six directors – one fewer staff member – were earning a total of £486,528, including pensions and national insurance contributions. This is a £4,929 increase on average on the year leading up to March 2017. The increase comes as the hospice moves forward with plans

to close its Tendring Centre and sell the building as part of a bid to "protect core hospice services." <https://goo.gl/PbYUSC>

### Specialist Publications

'Prevalence and correlates of advance care directives among older Australians accessing health and residential aged care services: Multicentre audit study' (p.6), in *BMJ Open*.

'Palliative care in the cardiac setting: A consensus document of the Italian Society of Cardiology/Italian Society of Palliative Care' (p.7), in *Giornale Italiano di Cardiologia*.

'Will palliative care and voluntary assisted dying clash – or collaborate?' (p.12), in *newsGP*.

'Trust nurse shortages impacting on end-of-life care, Care Quality Commission finds' (p.12), in *Nursing Times*.

Cont.

## From the archives

- U.K. | *The Times* (London) – 11 September 2015 – ‘**Hospices rely on volunteers while paying their bosses up to £160,000.**’ Charities that rely on hundreds of volunteers to provide end-of-life care are paying staff up to £160,000 a year. An investigation by *The Times* has found 240 hospice bosses and senior consultants are earning more than £60,000/year with at least 25 earning six-figure sums. Medical charities have come under pressure recently over executives’ large salaries. <https://goo.gl/xs75Be>

**N.B.** Hospice UK response to *The Times* article: <https://goo.gl/dts775>

## Palliative care in Senegal

SENEGAL | Human Rights Watch – 15 January 2019 – Senegal is a regional leader in palliative care (PC), which focuses on pain treatment and quality of life. A 2012 study found 16 of 22 countries in Francophone Africa have no healthcare providers specializing in PC.<sup>1</sup> However, since 2014, the Senegalese government has taken steps to improve access to PC. It has revised its national estimate for morphine in order to increase the quantity, to address need, and it has expanded the types of morphine formulations available, buying morphine tablets for public hospitals. It changed regulations limiting the prescription of morphine to seven days at a time – forcing patients at the end of life to travel long distances to get a new prescription – to 28 days. Despite this progress, there is still some work that remains to be done in expanding PC services to incurable patients and areas of the country beyond the capital.

1. ‘Global Atlas of Palliative Care at the End of Life,’ World Health Organisation and Worldwide Palliative Care Alliance, January 2014. [Noted in 3 February 2014 issue of Media Watch (#343, p.5)] **Download/view at:** <https://goo.gl/3Qh7oa>

**N.B.** Extract from ‘Submission by Human Rights Watch to the Committee on Economic, Social & Cultural Rights on Senegal,’ Human Rights Watch, January 2019. **Download/view at:** <https://goo.gl/DAEUTR>

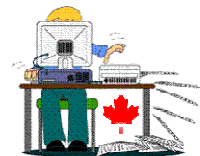
## The importance of holistic nursing

RWANDA | *The New Times* (Kigali) – 13 January 2019 – The Ministry of Health has integrated holistic nursing for patients under palliative care (PC) in 42 district hospitals across the country to help patients with incurable diseases. Holistic nursing focuses on promoting wellness by removing physical suffering and healing the whole person. Diane Mukasahaha, the national coordinator of PC at Rwanda Biomedical Center, says this kind of approach has seen a number of patients who were bedridden become liberated, and some even still work to provide for their families. She says that research shows that when there is no holistic care for a patient, at least three people in the family are affected. <https://goo.gl/BV8EVG>

Noted in Media Watch 7 November 2016 (#486, p.6):

- *CURRENT OBSTETRICS & GYNECOLOGY REPORTS* | Online – 29 October 2016 – ‘**Addressing end-of-life care in cancer patients through “ubuntu”:** Lessons learned from Rwanda in global health perspective of humanity.’ Multi-disciplinary palliative care (PC) is rarely integrated into the public health care system at all levels in Africa. This article describes PC in Rwanda and to address end-of-life care issues in a post-genocide society. **Abstract (w. list of references):** <https://goo.gl/dyx6tZ>

**N.B.** Ubuntu is a Nguni Bantu term loosely translating to “human kindness.”



### [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>

## Specialist Publications

### **Mind the gap: Is the Canadian long-term care workforce ready for a palliative care mandate?**

*AGEING & SOCIETY* | Online – 15 January 2019 – The average expected lifespan in Canadian long-term care (LTC) homes is now less than two years post-admission, making LTC a palliative care (PC) setting. As little is known about the readiness of LTC staff in Canada to embrace a PC mandate, the main objective of this study was to assess qualities relevant to PC, including personal emotional wellbeing, PC self-efficacy and person-centred practices (e.g., knowing the person, comfort care). A convenience sample of 228 professional and non-professional staff (e.g., nurses and nursing assistants) across four Canadian LTC homes participated in a survey. Tests showed that non-professional staff reported relatively higher levels of burnout, while professional staff reported greater job satisfaction and self-efficacy. There was no difference in secondary traumatic stress

or person-centred care. Overall, these results suggest that the emotional wellbeing of the Canadian LTC workforce is unlikely to impede effective PC. However, PC self-efficacy and person-centred care can be further cultivated in this context. **Abstract (w. list of references):** <https://goo.gl/6xe2DE>

#### Publishing Matters

**'Declaration on transparent editorial policies for academic journals'** (p.15), posting on the Institute for Science in Society website.

**'Who is pirating medical literature? A bibliometric review of 28 million Sci-Hub downloads'** (p.15), in *The Lancet Global Health*.

Noted in Media Watch 14 January 2019 (#597, p.7):

- *BMC PALLIATIVE CARE* | Online – 8 January 2019 – **'Are care staff equipped for end-of-life communication? A cross-sectional study in long-term care facilities to identify determinants of self-efficacy.'** As higher self-efficacy is associated with an increased likelihood of performing a certain procedure, nursing education programs should pay more attention to palliative care and end-of-life (EoL) conversations in their curriculum and use more experiential/bedside learning methods to promote successful experience with this in an early stage of working life. **Full text:** <https://goo.gl/CqraC4>
- *CANADIAN JOURNAL ON AGING*, 2019;11(1):1-13. **“That just breaks my heart”: Moral concerns of direct care workers providing palliative care in long-term care homes.** This research examined the moral concerns of personal support workers who provide direct care to residents. Two main moral dilemmas were ensuring that residents don't die alone, and providing the appropriate care based on residents' wishes. Their organizational constraints coalesced around policies, hierarchy, time, and balancing residents' needs. **Abstract (via PubMed):** <https://goo.gl/41Ggzi>

### **American College of Physicians Ethics Manual: Seventh Edition**

*ANNALS OF INTERNAL MEDICINE* | Online – 15 January 2019 – The seventh edition of the covers emerging issues in medical ethics and revisits older ones that are still very pertinent [see sidebar]. It reflects on many of the ethical tensions in medicine and attempts to shed light on how existing principles extend to emerging concerns. In addition, by reiterating ethical principles that have provided guidance in resolving past ethical problems, the manual may help physicians avert problems. The manual is not a substitute for the experience and integrity of individual physicians, but it may serve as a reminder of the shared duties of the medical profession. **Full text:** <https://goo.gl/EfaKT7>

#### **Care of patients near the end of life**

Palliative care  
Making decisions near the end of life  
Advance care planning  
Withdrawing or withholding treatment  
Artificial nutrition and hydration  
Do-not-resuscitate orders  
Futile treatments  
Determination of death  
Physician-assisted suicide and euthanasia



## **Integrated respiratory and palliative care leads to high levels of satisfaction: A survey of patients and carers**

*BMC PALLIATIVE CARE* | Online – 19 January 2019 – Integrated respiratory and palliative care (PC) provided by the Advanced Lung Disease Service [a multidisciplinary, single point-of-access, integrated respiratory and PC service, based within a major Australian teaching hospital] is associated with very high levels of patient and carer satisfaction. Continuity of care, high quality communication and feeling cared for were greatly valued and highlight simple but important aspects of care. Therefore core components of new integrated respiratory and 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, as well as further studies to understand patients' and carers' perspectives regarding these new models of care. **Full text:** <https://goo.gl/nRJcK6>

## **Prevalence and correlates of advance care directives among older Australians accessing health and residential aged care services: Multicentre audit study**

*BMJ OPEN* | Online – 15 January 2019 – This study provides one of the most detailed and comprehensive estimates to date on advance care directives (ACD) prevalence in Australian general practices, hospitals and residential aged care facilities, as well as one of the largest multisite data sets regarding ACD prevalence among older people internationally. Overall, approximately 30% of older Australians had at least one ACD documented in their health record, and the majority of these were non-statutory documents. The correlates of ACD completion were greater functional impairment and being in an aged care facility or hospital compared with attending general practice. Further work is required to increase the uptake of advance care planning (ACP) and documentation of preferences in ACDs. This might include greater promotion of ACP, particularly among high-risk populations, public and health professional education campaigns supporting the use of statutory ACDs, and efforts to standardise documentation within and between Australian jurisdictions. Using standardised measurement of ACD prevalence will facilitate evaluation of implementation efforts and support meaningful comparisons within Australia and internationally. **Full text:** <https://goo.gl/DAeYyZ>

**BMJ Open**

### **Correction**

'How do palliative care doctors recognise imminently dying patients? A judgement analysis.' <https://goo.gl/pesF77>

**N.B.** Noted in 3 December 2018 issue of Media Watch (#592, p.9).

### **Related**

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 17 January 2019 – '**Advance care planning in the nursing home setting: A practice improvement evaluation.**' This study evaluated a practice improvement initiative conducted over a 6 month period in 15 Canadian nursing homes. The initiative entailed two cycles of learning sessions followed by implementation of advance care planning (ACP) practice improvement projects in the facilities using a plan-to-study-act (PDSA) approach by participating clinicians... The initiative established routine data collection of outcomes to inform practice change, and successfully engaged physicians and non-physician clinicians to work together to improve ACP practices. Results suggest recurrent PDSA cycles that engage a "critical mass" of clinicians may be warranted to reinforce the standardization of ACP in practice. **Abstract:** <https://goo.gl/8GXXuF>



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## Unique palliative care needs of patients with advanced chronic kidney disease: The scope of the problem and several solutions

*CLINICAL MEDICINE*, 2019;19(1):26-29. Patients with advanced chronic kidney disease (CKD), including end-stage renal disease (ESRD), have a life-threatening illness complicated by high morbidity and mortality and, therefore, should be suitable candidates for early intervention by palliative care (PC) specialists. However, the average patient with CKD does not have an advanced care plan, has multiple debilitating symptoms, and does not utilise hospice care at the end of life. In this review, the authors outline the scope of the problem of unmet PC needs for patients with advanced CKD and ESRD, barriers to improving PC for patients with renal failure, and possible future directions for palliative nephrology. **Abstract:** <https://goo.gl/9Dgpa9>

**N.B.** Selected articles on palliative and end-of-life care for people living with chronic kidney disease noted in 13 August 2018 issue of Media Watch (#576, p.15).

## Palliative care in the cardiac setting: A consensus document of the Italian Society of Cardiology/Italian Society of Palliative Care

*GIORNALE ITALIANO DI CARDIOLOGIA*, 2019;20(1):46-61. Recently, there is increasing interest in the potential role of palliative care (PC) in refractory, advanced heart failure (HF) treated with optimal, maximized therapy. Fifty percent of patients with advanced HF die within 1 year of diagnosis and 50% of the remainder within 5 years. The trajectory of HF is often unpredictable and approximately 30% to 50% of patients die suddenly. Patients with HF suffer from numerous symptoms, often resistant to conventional treatments, frequently under-recognized and under-treated. Symptom assessment and control improve quality of life (QoL) in patients with advanced HF; this can be managed at best by collaboration between specialistic teams. Although HF is a life-shortening condition, therapeutic and technological advances ... can help healthcare professionals in the management of patients with advanced HF, improving global condition and reducing the risk of sudden death. On the other hand, it has to be acknowledged that management of cardiovascular implanted electronic devices towards end of life (EoL) requires awareness of legal, ethical, religious principles regarding potential withdrawal of life-sustaining therapies. Adequate communication with patients regarding adverse events, EoL, benefits vs burdens of therapies and interventions, treatment preferences, and decision-making should be an issue in early stages of disease. The process of advanced care planning (ACP) should be clearly documented and regularly reviewed. Barriers to the provision of PC in HF include clinical issues, prognostic uncertainty, failure in identification of patients who need PC and timing of referral to specialist services, but also misconceptions of patients, families and sanitary staff regarding the role of PC, organization problems, and finally educational and time issues. The authors focus on the need of further, coordinated research and work-out on: 1) Identification of HF patients eligible for PC, in terms of clinical and social-psychological issues; 2) Identification of trigger events and timing of referral; 3) Identification of adequate performance indicators/scales for measurement, assessment and follow-up of symptoms and QoL in end-stage HF, including patient-reported outcome measures; 4) Treatment, care and organization strategies and models for advanced/end-stage HF; and, 5) implementation of knowledge and education of healthcare professionals in the fields of communication, ethics, and ACP in heart failure. **Abstract:** <https://goo.gl/L8nVxM>



**N.B.** Italian language article. Additional articles on PC for HF patients noted in 17 December 2018 issue of Media Watch (#5594, pp.7-8).



### 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.16.

## **National survey of oncologists at National Cancer Institute-designated comprehensive cancer centers: Attitudes, knowledge, and practice behaviors about LGBTQ patients with cancer**

*JOURNAL OF CLINICAL ONCOLOGY* | Online – 16 January 2019 – This was the first nationwide study, to the authors' knowledge, of oncologists assessing attitudes, knowledge, and institutional practices of lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ) patients with cancer. Overall, there was limited knowledge about LGBTQ health and cancer needs, but a high interest in receiving education regarding this community. Of the 149 respondents, there was high agreement (65.8%) regarding the importance of knowing the gender identity of patients, which was contrasted by low agreement (39.6%) regarding the importance of knowing sexual orientation. There was high interest in receiving education regarding the unique health needs of LGBTQ patients (70.4%), and knowledge questions yielded high percentages of "neutral" and "do not know or prefer not to answer" responses. Stratified analyses revealed some but limited influence on attitudes and knowledge by having LGBTQ friends and/or family members, political affiliation, oncology specialty, years since graduation, and respondents' region of the country.

**Abstract:** <https://goo.gl/RdvGSF>

Noted in Media Watch 7 January 2019 (#596, p.4):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 1 January 2019 – '**Teaching healthcare providers to query patients with cancer about sexual and gender minority status and sexual health.**' End of life (EoL) is difficult for all patients but sexual and gender minorities (SGM) are prone to isolation and loneliness, especially if their SGM status is unknown or unaccepted. In oncology clinics, where goals-of-care discussions about EoL are integral and frequent, querying patients about their SGM status and sexual health is of particular importance. The American Society of Clinical Oncology's position statement calls for greater focus on SGM populations with the goal of reducing and eventually eliminating disparities in cancer care within this group.<sup>1</sup> **Abstract:** <https://goo.gl/Uc3FsW>

1. 'Reducing disparities in cancer care for sexual and gender minority individuals,' Policy Issue Brief, American Society of Clinical Oncology, May 2018. **Download/view at:** <https://goo.gl/JsXyN8>

Noted in Media Watch 1 January 2018 (#544, p.20):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 December 2017 – '**Current best practices for sexual and gender minorities in hospice and palliative care settings.**' Although several publications document the healthcare disparities experienced by sexual and gender minorities (SGMs), including lesbian, gay, bisexual, and transgender (LGBT) individuals, less is known about the experiences and outcomes for SGM families and individuals in hospice and palliative care (HPC) settings. This overview of issues pertaining to SGMs in HPC settings highlights gaps in knowledge and research. Current and best practices for SGM individuals and their families in HPC settings are described, as are recommendations for improving quality of such care. **Abstract:** <https://goo.gl/P8dsWG>

## **Overcoming the Balkanization of state advance directive laws**

*JOURNAL OF LAW, MEDICINE & ETHICS* | Online – 10 January 2019 – State law requirements for healthcare advance directive (AD) documents were reviewed in every state and the District of Columbia to determine whether they are consistent and/or flexible enough to permit the utilization by the public of "universal" AD forms, specifically a healthcare power of attorney, that would be valid under every state's AD statutes. Such documents would have to overcome the wide variability of state legal formalities for validity. If this could be accomplished, the public would benefit from having a variety of multi-state or truly universal forms available that could be used with confidence in their validity. The review found that a basic, multi-state healthcare power of attorney appears to be feasible in 41 States and the District of Columbia, compared to 36 states and the District in 2005. Only nine states prevent recognition of a truly universal form. Some barriers were surmountable, including differing agent and witness requirements, execution requirements, and effectiveness triggers. Other barriers were insurmountable, including mandatory forms, mandatory disclosures, and decision-specific language requirements. The strategies identified for overcoming some barriers can be used by lawyers in drafting true multi-state directives. More importantly, states should simplify state AD laws to facilitate a more meaningful communication model of advance care planning. **Abstract:** <https://goo.gl/kGWNy7>

Cont.



## Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 17 January 2019 – ‘**Inpatient goals-of-care conversations reduce intensive care unit transfers in high-risk patients.**’ At the authors’ medical center, they noticed a very high rate of floor-to-intensive care unit (ICU) transfers for patients with life-limiting illness and poor prognosis. They initiated a quality assessment and improvement project aimed at increasing goals-of-care conversations for high-risk patients early in their hospital stays. Outcomes showed a significant increase in overall goals-of-care discussions and a significant reduction in floor-to-ICU transfers during initial admission. There was no change in mortality at 1 year, but there was a trend toward more in-home deaths for those patients who died within the year. **Abstract:** <https://goo.gl/fwjnrT>
- *FAMILY PRACTICE* | Online – 14 January 2019 – ‘**Barriers to GPs identifying patients at the end-of-life and discussions about their care: A qualitative study.**’ Identification of patients at the end-of-life (EoL) is the first step in care planning and many general practices [in the U.K.] have Palliative Care Registers. There is evidence that these largely comprise patients with cancer diagnoses, but little is known about the identification process. GPs reported identifying non-malignant patients at the EoL as challenging and were reluctant to include frail or elderly patients due to resource implications. GPs described rarely using prognostication tools to identify patients and conveyed that poor communication between secondary and primary care made prognostication difficult. GPs also detailed challenges around talking to patients about EoL care. **Abstract:** <https://goo.gl/L7XNc4>
- *JOURNAL OF LAW, MEDICINE & ETHICS* | Online – 10 January 2019 – ‘**Universal advance directives necessary but not sufficient.**’ Over the past several decades, clinicians, estate planners and policymakers have taken steps to increase patient involvement in medical decisions. The old model of the doctor-patient relationship – which emphasized physician knowledge and authority – has been replaced by a construct that prioritizes patient autonomy and consent. Informing patients, weighing options, and making medical decisions together is now favored because it promotes individualized, respectful, patient-centred care. But what happens when a patient lacks the capacity to choose? How do we respect such patients’ individuality and personhood, or more concretely, their autonomy and right to self-determination? Are written advance directives sufficient? **First page view:** <https://goo.gl/YVrQVY>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 14 January 2019 – ‘**Electronic medical orders for life-sustaining treatment in New York State: Length of stay, direct costs in an ICU setting.**’ Electronic Medical Orders for Life-Sustaining Treatment (eMOLST) is a standardized documentation process used in New York State to convey patients’ wishes regarding cardiopulmonary resuscitation and other life-sustaining treatments. No study to date has looked at the effect of eMOLST as an advance care planning tool on ICU and hospital costs using estimates of direct costs. A retrospective chart review was conducted between July 2016 and July 2017. Completing an eMOLST form did not have any effect on reducing total direct cost, ICU cost, total length of hospital stay, and total hours spent in the ICU. **Abstract (w. references):** <https://goo.gl/rihB9Z>

## Top ten tips palliative care clinicians should know about medical cannabis

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 14 January 2019 – The use of medical cannabis is increasing significantly throughout the U.S. in spite of limited and sometimes contradictory data about its effectiveness. Palliative care providers are being asked to consider cannabis as part of symptom-directed treatment regimens although many providers have limited experience recommending medical cannabis and were trained before it was commercially available. This article seeks to dispel myths about medical cannabis and provides a balanced view of the benefits and burdens of this therapeutic option, providing evidence where it exists and offering practicing clinicians guidance on conditions in which medical cannabis is likely to be helpful or burdensome. **Abstract:** <https://goo.gl/jq1Smp>

Cont. next page



Would this article be of interest to a colleague?

Noted in Media Watch 8 October 2018 (#584, p.12):

- *JOURNAL OF CACHEXIA, SARCOPENIA & MUSCLE*, 2018;9(2):220-234. ‘**Systematic review and meta-analysis of cannabinoids in palliative medicine.**’ Following the Grading of Recommendations Assessment, Development & Evaluation methodology, no recommendations can be made for the use of cannabinoids in palliative care (PC) treatment for cancer, HIV-AIDS, or dementia. In view of this finding, further research is urgently needed to identify the efficacy and safety of cannabinoids as adjunctive or complementary therapies and to provide evidence-based recommendations on their clinical utility in PC. **Full text:** <https://goo.gl/hQHd1u>

**N.B.** Additional articles on cannabinoids in palliative medicine noted in this issue of Media Watch.

### **Impact of immigrant status on aggressive medical care counter to patients’ values near death among advanced cancer patients**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 11 January 2019 – Findings from this study indicate that immigrants are more likely to receive aggressive care inconsistent with their own preferences and values for comfort-focused end of life (EoL) care. These findings are critically pertinent to the delivery of high-quality cancer care for advanced cancer patients in a healthcare setting that is increasingly utilized by immigrants. Specifically, this study indicates that immigrant advanced cancer patients are not only receiving more futile aggressive care at the EoL, but are also likely receiving the care that is counter to their own preferences for EoL care. It is critical to further investigate ways to better communicate EoL care options to immigrants and ensure they receive top-quality EoL care consistent with their own values and preferences. With a growing threat to both legal and undocumented immigrants’ healthcare in the U.S. and the multitude of unique factors contributing to health disparities faced by immigrants, it is critical for healthcare providers to ensure that immigrants receive the highest quality EoL care. **Full text (free access through 31 January 2019):** <https://goo.gl/Y8pHUK>

Noted in Media Watch 9 October 2017 (#533, p.12):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 2 October 2017 – ‘**End-of-life care among immigrants: Disparities or differences in preferences?**’ Although describing a “good death” is an existentially challenging exercise, most people, if asked to do so, would note the importance of the presence of friends and family, relief from distressing symptoms, time at home, completing life goals, and other values. Although these goals are likely shared quite widely, how they are prioritized, and how they relate to other goals, may vary among individuals and across cultures. **Full text:** <https://goo.gl/unQG1K>

**N.B.** Selected articles on undocumented immigrants in the U.S., in the context of palliative and end-of-life care, noted in 7 January 2019 issue of Media Watch (#596, p.4).

### **Don’t forget to assess the family caregiver of your older adult patient**

*MD MAGAZINE* | Online – 18 January 2019 – Healthcare providers are trained extensively in the assessment of patients who present to the healthcare system. In many instances when older adults present for care, a family member or friend accompanies the older adult. However, busy schedules and multiple responsibilities compete with healthcare providers’ time during an assessment. Unlike assessments of pediatric patients, healthcare providers do not routinely include the family members or friends in the assessment of older adults. This omission should be of concern as the number of “baby boomers” advancing into older age increases and their need for caregiving assistance also increases. Family caregivers can be an invaluable source of information for healthcare providers as they plan care for the older adult. Therefore, family caregivers’ well-being should also be assessed by healthcare providers during the older adult healthcare visit to ensure family caregivers are able to sustain their caregiving role. **Full text:** <https://goo.gl/wnt9Bn>

## Reducing the role of the courts in treatment withdrawal

*MEDICAL LAW REVIEW* | Online – 15 January 2019 – In *A National Health Service Trust and others v Y and another*, the Supreme Court [in the U.K.] concludes that a court declaration is not a mandatory requirement before clinically assisted nutrition and hydration (CANH) is withdrawn from a person with prolonged disorder of consciousness (PDOC). The decision recognises the practical challenges for the courts, hospitals, and medical staff of involving over-worked courts in perceived non-controversial clinical judgments. It also recognises that judicial involvement can cause unnecessary anguish for the family and may merely delay the inevitable. It is an understandable decision and in most cases it is likely to be unproblematic. However, the judgment does not adequately recognise the vital role played by a court application in ensuring that the voice of the incapacitated patient is heard and explicitly considered by a neutral person. The withdrawal of CANH from persons in PDOC raises unique ethical concerns because it leads to the death of a vulnerable person not able to express his or her own opinion on whether life should now cease and it does so by withdrawing the most basic of medical treatment. It brings to an end the state's positive steps to preserve the life of the patient and thus requires very careful scrutiny in order to ensure compatibility with Article 2. It is regrettable, therefore, that the Supreme Court in *Y* has removed a valuable safeguard for both the right to life and the autonomy of incapacitated patients. **Full text:** <https://goo.gl/mj8CjF>

## Inequalities in access to health and social care among adults with multiple sclerosis: A scoping review of the literature

*MULTIPLE SCLEROSIS & RELATED DISORDERS*, 2019;28(1):290-304. Variations in access to health care are known to contribute to differences in life expectancy, morbidity and health-related quality-of-life across population sub-groups. 4,959 unique abstracts yielded 36 papers which met the authors' eligibility criteria. Only 3 studies were cohort studies and only 4 were population-based... There were 6 studies on access to multiple sclerosis focused care... There were 3 studies on access to prevention/lifestyle programmes and none on access to welfare services or information support. There were no papers examining inequalities in access for "vulnerable" groups, such as, those with learning disability. In the available studies, 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. In the studies 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:** <https://goo.gl/t7Vfkt>

### Patient and caregiver involvement in formulation of guideline questions: Findings from the European Academy of Neurology Guideline on Palliative Care of People with Severe Multiple Sclerosis

*EUROPEAN JOURNAL OF NEUROLOGY* | Online – 23 July 2018 – Patient and public involvement in clinical practice guideline development is recommended to increase guideline trustworthiness and relevance. Of 1,199 participants, 79% completed an online survey; 934 from seven countries were analyzed. 80% of respondents were multiple sclerosis (MS) patients and 183 caregivers. Participants agreed/strongly agreed on inclusion of the 9 pre-specified topics (from 89% for "advance care planning" to 98% for "multidisciplinary rehabilitation")... There were 569 free comments: 32% on pre-specified topics, 40% on additional topics (16 guideline-pertinent), and 160 (28%) on outcomes. Five focus group meetings (three of MS patients, two of caregivers, overall 35 participants) corroborated the survey findings. In addition, they allowed the explanation of the guideline production process, the exploration of patient-important outcomes and of taxing issues. MS patient and caregiver involvement was resource and time intensive, but rewarding. It was key for the formulation of the 10 guideline questions, and for the identification of patient-important outcomes. **Abstract:** <https://goo.gl/18J9hY>

**N.B.** This article first noted in the 30 July 2018 issue of *Media Watch* (#574, p.11). Additional articles on palliative care for people living with multiple sclerosis not in the 10 December 2018 issue of the weekly report (#593, p.13).

## Better words for better deaths

*NEW ENGLAND JOURNAL OF MEDICINE*, 2019;380(3):211-213. Words have a power that is deeper and stranger than their accepted definitions. When the end of life is inevitable and patients or their families consent, we may withdraw aggressive therapies or medications, or stop interventions, but we should never withdraw care. **Introductory paragraph:** <https://goo.gl/F92iWM>

## Will palliative care and voluntary assisted dying clash – or collaborate?

*NEWSGP* | Online – 14 January 2019 – From mid-June, suffering Victorians at the end of life who meet strict eligibility criteria will be able to seek voluntary assisted dying via a substance causing death. The move is not insignificant, as Victoria accounts for 25% of Australia's population. And such a shift in policy begs the question, will palliative care (PC) and voluntary assisted dying clash or collaborate? A new report commissioned by Palliative Care Australia (PCA) found that the PC sector had actually benefitted in overseas jurisdictions where assisted dying legislation had been passed.<sup>1</sup> “[There is] no evidence to suggest that the PC sectors were adversely impacted by the introduction of the legislation,” the report states. “If anything, in jurisdictions where assisted dying is available, the PC sector has further advanced.” The report is designed to help PCA review its position on euthanasia and assisted dying before the first Victorians can seek assistance dying. **Full text:** <https://goo.gl/yWftTT>



1. 'Experience internationally of the legalisation of assisted dying on the palliative care sector,' Palliative Care Australia, October 2018. **Download/view at:** <https://goo.gl/p17UKh>

Noted in Media Watch 17 December 2018 (#594, p.6):

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

## Trust nurse shortages impacting on end-of-life care, Care Quality Commission finds

*NURSING TIMES* | Online – 14 January 2019 – Nursing shortages mean dying patients at a London trust do not always get the best care, Care Quality Commission (CQC) inspectors have warned. They raised concerns about staffing problems at Lewisham & Greenwich National Health Service Trust following an inspection in September 2018. The CQC gave the trust an overall rating of “requires improvement” – unchanged since its last visit in March 2017. As part of the inspection, the watchdog assessed end-of-life (EoL) care at the trust’s two hospital sites – Queen Elizabeth Hospital and University Hospital Lewisham. Both hospitals were given a rating of “requires improvement” for their services for terminally ill patients. At University Hospital Lewisham, shortfalls in nursing staff were affecting patient care, the CQC found. “Some staff told CQC inspectors that shortages of nursing staff on certain wards sometimes affected good EoL patient care,” the CQC said in a report... It noted that at the time of the visit, only half of wards had an EoL care link nurse in place. Members of the specialist palliative care team (SPCT) told the CQC that general workforce problems meant it was “difficult” to get staff released to become link nurses. The report said: “The absence of link nurses reduced the day to day monitoring of standards and implementation of information distributed by the SPCT.” A pilot study showed that 43% of EoL patients at the hospital did not receive their pain relief medication on time and there was “no plan in place for how to improve upon this”, the watchdog highlighted. **Full text:** <https://goo.gl/31i7VN>



## **Brief psychosocial interventions improve quality of life of patients receiving palliative care: A systematic review and meta-analysis**

*PALLIATIVE MEDICINE* | Online – 16 January 2019 – Patients with a terminal disease report a high need for psychosocial and spiritual support. Previous literature reviews on psychosocial interventions in palliative care (PC) were restricted to certain sub-types of techniques, included a wide range of patients, conditions, and settings, or required a number of sessions unrealistic to be achieved in patients nearing the end of their lives. The aim of this study was to review and synthesize the evidence on brief psychosocial interventions (i.e. four sessions or less and less than 21 days) for patients receiving palliative treatment. In total, 15 studies met the eligibility criteria and reported the effects of 17 interventions and a total of 1,248 patients. The most frequently used techniques were life review techniques and music therapy. After exclusion of outliers, psychosocial interventions showed to be superior with regard to the improvement of quality of life, and the reduction of emotional and existential distress compared to the control groups. Brief psychosocial interventions can improve clinically relevant health outcomes and should therefore be made available for patients receiving PC. **Abstract:** <https://goo.gl/RBei7A>

## **Wishes to die at the end of life and subjective experience of four different typical dying trajectories. A qualitative interview study**

PLOS One | Online – 17 January 2019 – The motivations that lead to wishes to die (WTD) in palliative care (PC) patients with cancer are relatively well studied. But little is known about WTD in other pathologies and the relation between subjective understandings of dying trajectories and a WTD. In addition to personal motivations, the authors found that people [in their study population] dealing with similar trajectories were often confronted with similar questions and concerns due to similar challenges. For four trajectories the authors show typical patterns, similarities and differences that should be considered when talking with patients about their WTD. These illness-related considerations do not explain the WTD completely, but give important information on the challenges for particular patient groups that might experience a WTD. In all patient groups, there were clear moments that triggered a WTD: for neurological patients it was experiencing breathlessness, high-dependency care, or when considering tube feeding or respiratory support; for persons with organ failure it was an acute burdensome crisis; for patients with cancer after the initial diagnosis, it was the first relapse or the move into advanced PC; for elderly frail persons it was the move into care facilities, or the loss of important relationships or capabilities. The feeling of being a burden to others was reported in all patient groups. WTD can be triggered within disease trajectories by specific conditions and transitional points that affect agency and self-understanding. A better understanding of the concerns and challenges of a particular dying trajectory as well as its charac-

teristic trigger points can facilitate early and comprehensive communication about patients' WTD, and the underlying motivations and protective factors. **Full text:** <https://goo.gl/BA5i8>

**“This condition isn’t going to get any better so I can’t see why we’re prolonging it”: Risks and benefits of using empirical research to inform normative decisions concerning end-of-life care**

*JOURNAL OF DISABILITY & RELIGION* | Inprint – Accessed 15 January 2019 – Progressive neurological diseases are often complicated by declining cognitive function (leading to impaired decision-making capacity) in addition to the physical impairments which have significant emotional and social consequences. Options for managing the later stages vary from invasive medical procedures, palliative care, and (in some jurisdictions) assisted suicide or euthanasia. Decisions about the right approach to take may be influenced by facts about the likely effectiveness of treatment. However, moral questions, such as the right balance between preserving life and maximising quality of life, are an inherent part of the care-planning process. The authors take nutritional support as an example of one area of decision-making that needs to be addressed during care planning for people with progressive neurological disease. It describes research into the way in which the values of practitioners, members of the public and people with lived experience of progressive neurological disease may influence their decision-making about the right approach to maintaining nutritional intake during end-of-life care; and, discusses some of the challenges of incorporating such findings into normative frameworks. **Abstract:** <https://goo.gl/HhEHPb>

Cont.



Noted in Media Watch 26 March 2018 (#556, p.9):

- *FRONTIERS IN PHARMACOLOGY* | Online – 14 March 2018 – ‘**Ethical challenges for an understanding of suffering: Voluntary stopping of eating and drinking and the wish to hasten death in advanced patients.**’ The authors analyze the data reported in some studies in relation to primary care patients who died as a result of voluntarily stopping eating and drinking (VSED) and examine their results in light of the qualitative findings of patients that expressed a wish to die. In their view, VSED can be understood as a response to physical/psychological/spiritual suffering, as an expression of a loss of self, a desire to live but not in this way, a way of ending suffering, and as a kind of control over one’s life. **Abstract:** <https://goo.gl/DgVY6q>

N.B. Additional articles on the wish to hasten death noted in this issue of Media Watch.

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *JOURNAL OF MEDICINE & PHILOSOPHY*, 2019;44(1):50-70. ‘**Continuous deep sedation and euthanasia in pediatrics: Does one really exclude the other for terminally ill patients?**’ Debates on morally acceptable and lawful end-of-life (EoL) practices in pediatrics were reignited by the recent amendment in Belgian law to allow euthanasia for minors of any age who meet the criteria for capacity. Euthanasia and its legalization in pediatrics are often opposed based on the availability of aggressive palliative sedation. For terminally ill patients, this type of sedation is often identified as continuous and deep sedation until death (CDS). The authors demonstrate that this reasoning is based on flawed assumptions: 1) CDS is a morally preferable alternative to euthanasia; 2) CDS can meet the same patient needs as euthanasia; 3) Children lack the capacity and experience to make EOL decisions; and, 4) Unlike euthanasia, CDS does not raise capacity issues. The authors’ aim is not to reject CDS as a valid option at the EOL, nor to offer a clear-cut defense of euthanasia for minors, but to emphasize the ethical issues with both practices. **Abstract:** <https://goo.gl/PRAKJQ>
- *THE MEDUCATOR*, 2019;(34):11-12. ‘**Ethics of paediatric medical assistance in dying.**’ When adult MAiD [medical assistance in dying] legislation was introduced in Canada, it received criticism for being overly vague —providing poor definitions of terminal illness and intractable pain. In a paediatric context, this establishes an environment of uncertainty for children and families in which the standard practices of care would vary drastically between healthcare providers and legal institutions within and between Canadian provinces. Current evidence presents clear obstacles to paediatric MAiD including difficulties in ascertaining informed consent, inadequate legal infrastructure to address the complex concerns around paediatric MAiD, and the availability of other end-of-life care options. **Access options at:** <https://goo.gl/qKamsU>

Noted in Media Watch 23 April 2018 (#560, p.14):

- *PAEDIATRICS & CHILD HEALTH*, 2018;23(2):125-130. ‘**Medical assistance in dying: A paediatric perspective.**’ This statement [of the Canadian Paediatric Society] describes the current Canadian legal and medical context of MAiD and articulates a paediatric perspective that has emerged from – and been informed by – the broad, structured consultation process unfolding in Canada and elsewhere. **Full text:** <https://goo.gl/FPQSTb>



Photo: Lori Waselchuk. Philadelphia, PA

Updated

### Prison Hospice: Backgrounder

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report can be downloaded/viewed on the Palliative Care Network website at: <https://goo.gl/TLSo27>

## Publishing Matters

### **Declaration on transparent editorial policies for academic journals**

INSTITUTE FOR SCIENCE IN SOCIETY | Online – Accessed 17 January 2019 – Peer review and post-publication discussions are important pillars of quality management in academic publishing. However, it is surprisingly hard to learn the details of research journals' peer review procedures and editorial policies from their websites and editorial instructions. Journal websites often do not contain information about reviewer selection, review criteria, blinding, the use of digital tools such as text similarity scanners, as well as policies on corrections and retractions. **Introductory paragraph:** <https://goo.gl/c8nGkR>

### **Who is pirating medical literature? A bibliometric review of 28 million Sci-Hub downloads**

*THE LANCET GLOBAL HEALTH*, 2019;7(1):e30-e31. Access to the medical literature is essential for both the practice of evidence-based medicine and meaningful contribution to medical sciences. Nonetheless, only 12% of newly published papers are freely accessible online, and, as of 2014, only 3 million of the 26.3 million articles indexed on PubMed were available on the site's repository of free materials, PubMed Central. Access to paywall-protected literature remains primarily through institutional subscriptions. Such subscriptions are costly and many struggle to afford access. The result is a disparity in access to the medical literature, particularly for those in low-income and middle-income countries (LMICs). In the early 2000s, the rapid expansion of online publication was recognised as an opportunity to iron out these inequities. The WHO-led Health InterNetwork Access to Research Initiative was developed to offer free access to medical journals for not-for-profit medical facilities and research institutions in some LMICs. Yet knowledge of the programme's existence remains poor, the platform is cumbersome, and there is evidence that access to the highest-impact-factor journals has been restricted. The use of illegal online "shadow libraries" such as Sci-Hub has also emerged as a means of accessing scientific literature. An analysis of requests to the site logged from September 2015 to January 2016 revealed that Sci-Hub had successfully satisfied 99.3% of queries. Due to copyright protections, such sharing remains illegal, and Elsevier, the largest academic publisher, has taken legal action against Sci-Hub, winning a \$15 million settlement in U.S. courts. **Full text:** <https://goo.gl/VhjrXv>

THE  
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**N.B.** Health InterNetwork Access to Research Initiative: <https://goo.gl/o2B5N6>

### **Media Watch: Editorial Practice**

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

### **Distribution**

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

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4. Access to a complete article, in some cases, may require a subscription or one-time charge.
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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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- 2017, Jan - Dec
- 2016, Jan - Dec
- 2015, Jan - Dec
- 2014, July - December
- 2014, January - June
- 2013, July - December
- 2013, January - June
- 2012, July - December
- 2012, January - June
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#### Asia

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

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

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## Canada



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

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## Europe



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