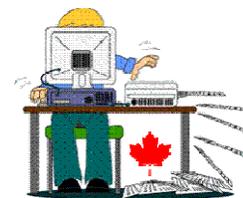


## Media Watch...

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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Compilation of Media Watch 2008-2018 ©

Compiled & Annotated by Barry R. Ashpole

**'Palliative care in adolescents and young adults with cancer: Why do adolescents need special attention?' (p.10), in *The Cancer Journal*.**

## Canada

### **Most Scarborough palliative patients die in hospital, not a hospice**

ONTARIO | Toronto.com – 29 November 2018 – Where should people stay as they're dying? It's a harder question to ask in Scarborough, because one option, a residential hospice, is missing. There are 49 hospices across Ontario, in small towns and large cities, but Scarborough's never had one. When patients in hospital reach a palliative stage, one where treatment no longer helps, most want to go home. In Scarborough ... about 70% don't get the chance, says data released by the Central East Local Health Integration Network (LHIN). Around 66.1% of palliative in-patients in Scarborough North, which includes Scarborough Health Network's Birchmount site in Agincourt, died in hospital during the first three months of this year. While palliative, they stayed in Birchmount for 13 days on average, and 11.7% of their stay counted as Alternative Level of Care (ALC), days when it was medically unnecessary for them to remain. The LHIN, provincial overseer of the area's healthcare, places the rest of Scarborough into Scarborough South, including network's Centenary and General sites. Figures were worse there. There, 72.4% of palliative patients died in hospital, stays while palliative were 14 days, and ALC percentage was 15.1. The combined Scarborough figure for palliative patients dying in hospital was 70.7%. Ontario-wide, the percentage in early 2017 was 51.92. Many people opting for palliative care can't be cared for at home, but daily cost of hospice is one-third that of beds in acute care hospitals, says Rick Firth, of Hospice Palliative Care Ontario, the provincial agency which manages hospice accreditation. <https://goo.gl/AZ1ceW>

### **National leadership in palliative care demanded**

QUEBEC | *The Sun* (Montreal) – 21 November 2018 – Fifty speakers at the first forum on palliative and end-of-life (EoL) care are calling for the rapid establishment of a national palliative care (PC) directorate in Quebec. For the president of Quebec Palliative Care Association (QPCA), rapid access to this care "should not be optional, but a right for all." Representatives from some 25 Quebec organizations met on the same day *The Sun* reported the suspension of the Quebec City's Hôtel-Dieu's PC services.<sup>1</sup> A situation attributable to the lack of medical staff, was explained in an internal note of the Centre hospitalier universitaire de Québec... According to these stakeholders at the initiative of the QPCA, access to quality

Cont.

PC everywhere in Quebec requires the rapid establishment of a government directorate in PC, which would solve “many problems, especially in training, and in recruitment” [of] caregivers. For the QPCA President, Dr. Louise La Fontaine, “all too often, accessible and well-established PC is based on the volunteer commitment of a small group of caregivers.” In a statement to the *The Sun*, Dr. La Fontaine laments the fact that too many patients seek PC late, at the EoL, and that “all too often palliative medicine is considered optional rather than essential. We are ready to work closely with government bodies to make high-quality PC accessible to all, and to ensure that professional and voluntary training is accessible and of high quality for all these caregivers, regardless of the type of care they provide, place of care or the Quebec region,” says Dr. La Fontaine. This is not the first time that the QPCA and the Quebec Society of Palliative Care Doctors are concerned about the lack of access to quality PC in Quebec. They have already alerted the Commission on EoL care in this regard, deploring the lack of efforts and resources deployed to ensure equity in access to these services. <https://goo.gl/d3YvSw>

1. ‘Doctor shortage at Quebec City hospital means patients lose access to outpatient palliative care,’ CBC News, broadcast 23 November 2018. [Noted in 26 November 2018 issue of Media Watch (#591, p.1)] <https://goo.gl/TwGv7h>

**N.B.** French language version of the *The Sun* article at: <https://goo.gl/LqXr6A>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | *The Delta Optimist* (Ladner) – 27 November 2018 – ‘**Delta Hospice reaffirms position on MAiD, still at odds with Fraser Health.**’ The society has been at odds with the health region over its policy to provide medical assistance in dying (MAiD), which is now legal in Canada, in hospices. Delta Hospice does not want the service offered at its Irene Thomas Hospice in Ladner, and although the health region hasn’t gone so far as to threaten it, at least publicly, the society could be stripped of its operating funding if MAiD isn’t provided. The society recently put an ad in the *Optimist* stating its board of directors completed an engagement with Delta residents, hospice staff and volunteers, and its membership. It also conducted a professional telephone survey across the community. “We found that opinions on MAiD varied widely across the spectrum of all groups engaged. This was also reflected in the discussion at the hospice boardroom table, and no clear consensus was reached,” the society stated. The society has decided not to recommend changing its bylaws and will continue to provide “compassionate and skilled” transfers from the local hospice facility for patients requiring any medical procedure, including MAiD. <https://goo.gl/QaR3yk>

## U.S.A.

### “Right-to-try” marks new era in the treatment of terminally ill patients

*THE REGULATORY REVIEW* (University of Pennsylvania Law School) | Online – 28 November 2018 – The recently enacted [federal] right-to-try law marks a new day for the process of approving medicines that sick and dying Americans desperately need. The law ... provides that patients have the right to seek medicines that have received basic safety approval by the U.S. Food & Drug Administration (FDA), but have not yet been fully approved for sale. A forthcoming journal article<sup>1</sup> ... addresses patient safety and treatment access in the context of the right-to-try movement, but it is important to point out some of the shortcomings of the forthcoming article. The authors base their forthcoming article on faulty understandings of the text of the right-to-try law and the reality of the FDA process for accessing investigational treatments before the movement to adopt right-to-try laws. Perhaps most importantly, they disregard the important patient protections built into the Right-to-Try Act. **Full text:** <https://goo.gl/VkYbzb>

1. ‘Regenerative medicine and the right-to-try,’ *Journal of Business & Intellectual Property Law* (Inprint), accessed 28 November 2018. **Abstract:** <https://goo.gl/8bGRWv>

**N.B.** Selected articles on the issue of “right-to-try” new experimental or investigational drugs noted in 20 August 2018 issue of Media Watch (#577, p.10).

## We're living longer ... but a medical journal sees many causes for alarm

FLORIDA | Floria Health News – 27 November 2018 – There's a worrying slowdown in progress against medical conditions that disable, sicken or kill. That's the message in an editorial in a recent issue of *The Lancet*. The editorial accompanies reports from a massive research project, which counts cases of disability, illness and death around the world.<sup>1</sup> In sobering words, the editorial warns that mortality rates from various conditions are no longer decreasing, new epidemics (think opioids and dengue) are occurring, and we shouldn't be complacent. The studies themselves show an increase in obesity and a stall in life expectancy increases in countries such as the U.S. and U.K. as well as in-

creasing rates of some conditions such as liver cancer and hypertensive heart disease. <https://goo.gl/LV51vr>

### Specialist Publications

**'A value-based payment model for palliative care: An analysis of savings and return on investment'** (p.12), in *Journal of Ambulatory Care Management*.

**'Factors associated with hospices' non-participation in Medicare's Hospice Compare Public Reporting Program'** (p.13), in *Medical Care*.

1. 'Global burden of disease,' *The Lancet*, November 2018. **Download/view at:** <https://goo.gl/PBXQMk>

## How California is changing palliative care

*FORBES* | Online – 27 November 2018 – In January, California became the first state to mandate home-based palliative care (PC) ... to those in its Medicaid program. In California, that program is called Medi-Cal. Although other Medicaid programs may pay for components of PC – such as advance care planning – “California is truly leading in this regard,” says Stacie Sinclair, senior policy manager for the Center to Advance Palliative Care, a national organization. Hawaii and Washington are also looking at adding home-based PC to their Medicaid benefits. Most of the Medi-Cal population is enrolled in managed care plans which in turn contract with agencies to deliver home-based PC. Many of the patients face not only serious illness but a host of other challenges, including homelessness, food insecurity, mental illness or substance abuse. The Medi-Cal PC benefit was inspired by another California program, established in 2006, to provide pediatric PC through a waiver from the federal Centers for Medicare & Medicaid Services. “The waiver enabled seriously ill kids to get hospice and curative treatment simultaneously,” explains Judy Thomas, CEO of Coalition for Compassionate Care of California in Sacramento. “The state had a good experience and track record with pediatric PC, and research showed it was cost-effective.” In 2014, a law passed mandating PC services be offered to Medi-Cal patients in their homes. The benefit is given only to people who have functional impairment from one or more of four conditions: congestive heart failure, chronic obstructive pulmonary disease, end-stage liver disease and stage three or four cancer. It took until 2018 for the program to be implemented. <https://goo.gl/cDn2Uw>

## Advanced cancer patients can live longer with palliative care, Tulane study says

LOUISIANA | Tulane University (New Orleans) – 27 November 2018 – Outpatient palliative (PC) care can improve survival duration as well as quality of life (QoL) in advanced cancer patients, according to a Tulane University study.<sup>1</sup> A team of researchers led by Michael Hoerger, assistant professor of psychology, psychiatry and oncology at Tulane, sampled 2,092 patients with advanced cancers, most commonly lung and gastrointestinal cancers. They used a statistical method called meta-analysis to combine the results of eight randomized clinical trials that examined the impact of outpatient PC on patients' survival and QoL. 56% of patients who were randomized to receive outpatient PC were alive after one year as opposed to 42% who received typical care. The numbers translate into PC patients living more than four months longer than their counterparts who did not receive PC. <https://goo.gl/Mj5mi8>

1. 'Impact of interdisciplinary outpatient specialty palliative care on survival and quality of life in adults with advanced cancer: A meta-analysis of randomized controlled trials,' *Annals of Behavioral Medicine*, published online 28 September 2018. **Abstract:** <https://goo.gl/LNrB5J>

## More Oregonians take control of their deaths with POLST forms

OREGON | Jefferson Public Radio – 27 November 2018 – Oregonians are taking more control of their deaths, according to a new study in the *Journal of Palliative Medicine*.<sup>1</sup> Back in 1993, Oregon was the first state in the nation to introduce the Physician Orders for Life-Sustaining Treatment (POLST) form. It tells your doctor what medical interventions you want at the end of life. For example, many people don't want to be put on a feeding tube or intubated when they're dying. They just want pain medication. Researchers at Oregon Health & Science University have found that about 45% of Oregonians now fill out a POLST form before they die. That's up from about 30% eight years ago. While the oldest Oregonians increased their POLST usage the most, there was also a rise in POLST use by middle-aged people. The total number of people aged 95 years and older who used POLST forms before death increased 8% between 2010-2011 and 2015-2016, while those aged 45 to 64 used the forms about 19% more during the same time. The data also indicate more Oregonians want extensive medical care when they die. For example, about 13% of POLST forms between 2015-2016 requested CPR, compared with about 8% in 2010-2011. And about 11% in 2015-2016 requested full medical treatment, compared with about 6% in 2010-2011. About 65% of Oregonians die at home. That exceeds the American average for deaths at home. About 60% of Americans die in hospice or in a hospital. <https://goo.gl/RWDKbj>

1. A link to the full text of the *Journal of Palliative Medicine* article, 'Changes over time in the Oregon Physician Orders for Life-Sustaining Treatment Registry: A study of two decedent cohort,' published online 21 November 2018, is embedded in the Jefferson Public Radio report. Click on "new study" in the first sentence.

## How end-of-life care in New Jersey could be greatly improved

NEW JERSEY | NJ Spotlight (Montclair) – 26 November 2018 – A long-awaited report on what New Jersey should be considering when it comes to end-of-life care (EoLC) had no shortage of recommendations — 26 of them, in fact.<sup>1</sup> They include the creation of a state-wide stakeholder coalition to oversee improvements in EoLC; education and training programs for providers, and culturally appropriate public awareness campaigns for state residents; better systems to document final wishes; and, allowing intensive-care paramedics to treat chronically ill patients at home in an effort to avoid a trip to the hospital. Some findings echo research by other policy groups that have also highlighted the need to focus more on how the medical system treats patients in their final days. Many agree the issue requires urgent attention. Medical treatments are "often misaligned with a patient's preference and wishes" for how they want to die,

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

REUTERS | Online – 26 November 2018 – People entrusted with decision-making for incapacitated loved ones tend to believe they know what their loved ones would choose – but the vast majority of surrogate decision-makers in a recent study were wrong about loved ones' wishes.<sup>1,2</sup> "Patients and their loved ones actually tend to overestimate how well they've talked to each other and how well the loved ones understand what the patient would want under circumstances of advanced illness and making decisions about those illnesses," said the study's lead author, Dr. Terri Fried, a professor of medicine at the Yale School of Medicine... "The thing that's particularly disturbing in this study is we asked how confident they were and their confidence level was high." The problem is many assume they've made their wishes clear when they haven't, Fried said. <https://goo.gl/eMjTjS>

1. 'Assessment of surrogates' knowledge of patients' treatment goals and confidence in their ability to make surrogate treatment decisions,' *JAMA Internal Medicine*, **Abstract:** <https://goo.gl/vFkfsf>
2. 'Preparing surrogates for complex decision making: The often neglected piece of the advance care planning equation,' *JAMA Internal Medicine*. **Abstract** <https://goo.gl/WyUQs6>

### Specialist Publications

'Older adults' preferences for discussing long-term life expectancy: Results from a national survey' (p.12), in *Annals of Family Medicine*

Cont.

according to the state report, in part because too few individuals discuss their wishes with loved ones and codify these requests in writing. In addition, the healthcare system is focused on saving lives and invests too little in hospice care and palliative treatment for those at the end of their lives, it found. The issue is particularly important in New Jersey, where only 30% of residents die at home, despite the fact that most wish to do so. And patients here are subjected to more medically intense EoLC than in any other state, consuming more healthcare resources, according to statistics cited in the report. <https://goo.gl/kA7Qxs>

1. 'New Jersey Governor's Advisory Council on End-of-Life Care: Report and Recommendations,' Department of Health, November 2018. **Download/view at:** <https://goo.gl/VztCQF>

**N.B.** See 'End-of-Life Care Strategic Plan for New Jersey,' New Jersey Health Care Quality Institute, 2018. [Noted in 18 June 2018 issue of Media Watch (#568, p.3)] **Download/view at:** <https://goo.gl/rEWRQh>. According to a Dartmouth Atlas of Health Care Report, New Jersey is ranked lower than any other state in the nation in the use of hospice and palliative care; see 'Tracking Improvement in the Care of Chronically Ill Patients: A Dartmouth Atlas Brief on Medicare Beneficiaries Near the End of Life,' June 2013. [Noted in 11 June 2013 issue of Media Watch (#310, p.4)] **Download/view at:** <http://goo.gl/aRxuH6>

### **Vermont's home health and hospice agencies face hit to federal funding**

VERMONT | Vermont Public Radio (Colchester) – 26 November 2018 – The non-profit agencies that provide home-based healthcare to thousands of residents across Vermont are bracing for a hit to the federal funds that account for the majority of their operating revenue. The Centers for Medicare & Medicaid Services issued new rules recently that will change the qualifying criteria for supplementary payments to "home health and hospice" agencies that provide care in rural settings. The changes affect seven of the 10 home health agencies in the state. The loss of the rural add-on follows a decade of incremental reductions in Medicare reimbursement rates for home health agencies in Vermont, according to Olson. And while those reimbursement rates are set to rise by 2% in 2019, Medicare rates for the home health providers are down by 14% since 2009. <https://goo.gl/QwfEtr>

### **Assisted (or facilitated) death**

Representative sample of recent news media coverage:

- CALIFORNIA | *The San Francisco Chronicle* – 27 November 2018 – '**California's right-to-die law upheld by state appeals court.**' A state appeals court rejected a challenge to California's right-to-die law for terminally ill patients, overturning a judge's ruling in May that had briefly blocked enforcement of the law. The statute, in effect since June 2016, allows a dying adult patient to take lethal drugs that a doctor has prescribed. Before that, two doctors must have determined that the patient would die within six months and was mentally competent to choose death. Riverside County Superior Court Judge Daniel Ottolia halted enforcement of the law in May, ruling that state lawmakers had illegally considered and passed the legislation during a special session devoted to healthcare. Allowing patients to take their own lives has no apparent connection to improving Californians' healthcare, Ottolia said. Bills passed in a special session require the same majority vote as in normal legislative sessions, but are generally reviewed more quickly and take effect sooner than in regular sessions. However, the right-to-die bill, which Governor Jerry Brown signed in October 2015, was drafted to take effect eight months later. <https://goo.gl/Z6iAdn>

### **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>



## International

### **In worrying trend, terminally ill people in Kerala choosing to end lives**

INDIA (Kerala) | *The New Indian Express* (Chennai) – 1 December 2018 – Kerala's health index is top in the country in terms of overall health performance. But a worrying trend is casting a shadow over the state, that reveals many people are ending lives unable to cope with the illnesses they suffer from. As per government data, 2,325 people have committed suicide between July 2016 and March 2018 after being diagnosed with various diseases, including cancer and AIDS. Union Government figures show in 2016 alone, 1,734 people ended lives, out of whom 836 committed suicide after becoming terminally ill (prolonged illness), followed by 761 owing to mental illness, 113 because of cancer, and 23 due to paralysis. Only one person ended life due to AIDS/HIV. No transgender has committed suicide due to any illness. When it comes to handling stress and mental trauma due to any illness, women fare better than men as the figures show only 479 females committed suicide, while the number of males was 1,255 in 2016. Though this trend has been giving worrying signs, no proper attempt has been made so far to estimate the scale of suicides related to illness. <https://goo.gl/8tVeBt>

### **Medicinal cannabis to be extended to all those in palliative care**

NEW ZEALAND | *New Zealand Herald* (Auckland) – 29 November 2018 – Health Minister David Clark has proposed changes to the medicinal cannabis legislation that will extend its use to all people needing palliative relief, rather than just those with a year or less to live. "This legislation will greatly increase availability of quality medicinal cannabis products, and will allow for their domestic manufacture. It will mean many New Zealanders living in pain will have another option to find relief," Clark said. Clark outlined the planned changes, made as a result of talks with coalition partners New Zealand First and the Green Party, during the second reading of the Misuse of Drugs (Medicinal Cannabis) Amendment Bill in Parliament... They will be introduced via an supplementary order paper during the bill's committee stage. <https://goo.gl/KTSozd>

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.**' The aim of this study is to evaluate the efficacy, tolerability, and safety of cannabinoids as an adjunct or complementary therapy 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.

### Specialist Publications

'**Solving the global crisis in access to pain relief: Lessons from country actions**' (p.11), in *American Journal of Public Health*.

'**Experiences with approaches to advance care planning with older people: A qualitative study among Dutch general practitioners**' (p.8), in *BMJ Open*.

'**Standards for the management of cancer-related pain across Europe. A position paper from the EFIC Task Force on Cancer Pain**' (p.10), *European Journal of Pain*.

'**Are we making progress on communication with people who are near the end of life in the Australian health system? A thematic analysis**' (p.11), in *Health Communication*.

'**Future of assisted dying reform in Australia**' (p.16), in *Australian Health Review*.

'**Informing the euthanasia debate: Perceptions of Australian politicians**' (p.16), in *UNSW Law Journal*.

## **A vision for population health: Towards a healthier future**

U.K. (England) | The King's Fund (London) – 27 November 2018 – Over the course of the 20th century, this country and many others made the “great escape”: life expectancy increased by more than 30 years in the 100 years to 2010. But today, we do not perform well on many health outcomes compared with similar countries, and health inequalities are persistent and widening. Increasing spending on the National Health Service and social care will not change this on its own. In this report, the authors have set out the case for a new approach, one that better reflects what determines our health as a population. This requires stronger national action, including new binding national goals and a national health inequalities strategy. It also requires concerted, systematic and coherent effort across the four pillars of a population health system: the wider determinants of health, our behaviours and lifestyles, an integrated health and care system, and the places and communities we live in and with. The authors have set out a framework to achieve that, a framework that places far more emphasis on the connections between the pillars, that is, what defines a population health system. They have argued for the need to focus on changes to funding, and clearer and stronger accountability for population health ... [and] ... emphasised the need for stronger system leadership at local, regional and national levels, including political leadership and engagement with places and communities themselves. **Download/view at:** <https://goo.gl/ZhD6HE>

**The King's Fund**

## **Royal Pharmaceutical Society (Wales) launches palliative care policy...**

U.K. (Wales) | *The Pharmaceutical Journal* (Cardiff) – 26 November 2018 – The Royal Pharmaceutical Society (Wales) in Wales ... policy's focus is on ensuring that patients who are approaching the end of their lives can access a full range of pharmacy services, helping to ensure that their death is “as peaceful and symptom-free as possible.”<sup>1</sup> Taking into account the Welsh government and National Health Service Wales's ‘Palliative and end-of-life (EoL) care delivery plan,’<sup>2</sup> the policy makes several recommendations, including: a call for pharmacists to be embedded in all multidisciplinary teams delivering palliative care (PC); the right for patients to die in a care setting of their choice without any compromise to the level of care they receive; and, for the health status of patients on a PC register to be automatically shared with the multidisciplinary team, including the sharing of advance care plans with the patient's community pharmacy. Around 32,000 people die each year in Wales and around 75% of these people require some form of PC. This includes around 100 children who could, the policy document says, benefit from specialised paediatric PC. The policy also recognises the needs of family, friends and the wider circle of people surrounding a patient nearing the EoL. <https://goo.gl/pZ6Jtx>

1. ‘Palliative & End-of-Life Care Pharmacy's contribution to improved patient care,’ Royal Pharmaceutical Society (Wales), November 2018. **Download/view at:** <https://goo.gl/1hG6fF>
2. ‘End-of-Life Care Delivery Plan, 2017-2020,’ National Health Service Wales, March 2017. [Noted in 14 August 2017 issue of Media Watch (#525, p.4)] **Download/view at:** <https://goo.gl/r7rGZk>

## **Rule on ending life-sustaining treatment to be more practical**

SOUTH KOREA | *The Korea Times* (Seoul) – 25 November 2018 – The regulation on ending life-sustaining treatment for terminally ill patients will be eased next year to become more practical, narrowing the scope of “family consent” required for approval of the cessation. According to the Ministry of Health & Welfare, the National Assembly recently passed the revision to the law to allow patients to end medical treatment after getting consent from their spouse, parents and children only. The new regulation will take effect on March 28 next year. Under the current law, the life-sustaining treatment of an unconscious patient can be halted when all of the patient's lineal family members consent to it, including spouse, parents, children and grandchildren. If one member of the family is not in reach, the patient has to continue “unnecessary medical treatment” against their will. <https://goo.gl/7RCQv3>



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## Hundreds of care home patients have died dehydrated or malnourished

U.K. (England & Wales) | *The Guardian* (London) – 25 November 2018 – More than 1,000 care home patients have died suffering from malnutrition, dehydration or bedsores, new figures reveal. At least one of the conditions was noted on the death certificates of as many as 1,463 vulnerable residents in National Health Service, local authority and privately-run care homes in England and Wales over the past five years. The figures have been obtained by *The Guardian* from the Office for National Statistics (ONS), which completed an analysis of death certificates at the newspaper's request. It follows a separate *Guardian* investigation that revealed some of the country's worst care homes were owned by companies that made a total profit of £113 million despite poor levels of care.<sup>1</sup> The ONS statistics showed where any of the three conditions were mentioned on patient death certificates as either the underlying cause or contributory factor. From 2013 to 2017, dehydration was noted in 398 cases; malnutrition recorded 226 times; and bedsores mentioned 839 times. The conditions affected women far more than men, with females accounting for 1,005 of the deaths and males, 458. The ONS cautioned that the data did "not provide enough information to link the deaths to poor care in the care home" but acknowledged that "it is possible that poor care may have been a factor in some of the deaths." <https://goo.gl/KC5Hpe>

1. 'Companies running "inadequate" U.K. care homes make £113 million profit,' *The Guardian*, 23 November 2018. [Noted in 26 November 2018 issue of Media Watch (#591, p.2)] <https://goo.gl/9xFTbd>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (England) | *The Guardian* (London) – 27 November 2018 – **'Supreme court rejects request for right-to-die case to be heard.'** The supreme court has dismissed an emergency application to hear a right-to-die case challenging the legal ban on assisted dying. The U.K.'s highest court turned down the request from lawyers for Noel Conway, a retired lecturer who is paralysed from the neck down by progressive motor neurone disease. The three supreme court justices ... acknowledged that the issue was of "transcendent public importance." But the justices decided there was little chance of success if Conway's claim were heard in full by the court. "Not without some reluctance, it has been concluded that in this case those prospects are not sufficient to justify giving permission to appeal," they said. The judges stressed any change to the law would have to be for parliament, although it would be within the supreme court's powers to make a declaration that U.K. law was incompatible with Conway's rights under the European convention on human rights. <https://goo.gl/4bzWjg>

## Specialist Publications

### Experiences with approaches to advance care planning with older people: A qualitative study among Dutch general practitioners

*BMJ OPEN* | Online – 25 November 2018 – Approaches to advance care planning (ACP) with older patients can be divided into two categories: systematic and *ad hoc*. Respondents had positive experiences with both approaches. With systematic approaches, respondents discussed a fixed combination of topics with systematically selected community-dwelling patients and patients living in residential care facilities. These meetings were aimed at providing information, encouraging patients to take further steps in ACP and at making agreements anticipating acute situations and situations in which patients would be unable to speak for themselves. Respondents invited these patients for group information meetings about ACP, or initiated ACP during intakes, periodic assessments or comprehensive geriatric assessments. Resuscitation and euthanasia seemed to be important topics, because respondents who approached ACP systematically always discussed them. *Ad hoc* approaches consisted of discussing one or two topics, which were often related to the near future and varied from treatment limitations to care, preferred place of liv-

Cont.

ing, and views on life, dying and death. Respondents reported these topics were discussed when patients took the initiative or seemed to be open to ACP, when a patient's situation deteriorated or if respondents felt the provided care was not appropriate. Different systematic and *ad hoc* approaches complemented each other in the ACP process; they could be used simultaneously or sequentially and were used for both initiating and following up on ACP. **Full text:** <https://goo.gl/URxgdB>

#### Related

- *BMC Family Practice* | Online -28 November 2018 – ‘**Advance care planning conversations with palliative patients: Looking through the GP's eyes.**’ Remarkably, GPs experienced difficulties with initiating advance care planning (ACP) when patients are being treated in the hospital. If GPs and medical specialists would work more closely together, this could help GPs in fulfilling their role in the timely initiation of ACP. Lack of this form of collaboration might prove disadvantageous. Future research could focus on a multidisciplinary approach, and the role of medical specialists in ACP. We recommend commencing with current issues, viz. staying close to the now. In doing so, a start can be made in addressing issues that may become important in the near future. Also, the tension between ACP's focus on the patients' own direction and an in medical ethics recognized right not to know can be difficult. **Full text:** <https://goo.gl/DfXAcC>
- *JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE* | Online – 2 November 2018 – ‘**Interventions guiding advance care planning conversations: A systematic review.**’ 82 articles reporting on 34 unique interventions met the inclusion criteria. Analysis of the conversation guides revealed a framework for advance care planning (ACP) conversations consisting of 4 phases: 1) Preparation; 2) Initiation; 3) Exploration; and, 4) Action. Exploration of patient's perspectives on illness, living well, end-of-life issues, and decision making formed the core part of the guides. Their design was often expert-based, without an underlying theoretical background. The studies showed varying effects on knowledge of ACP, decisional conflict, quality of communication, and preferences-concordant care. Qualitative research showed that participants appreciate the importance and benefits of ACP conversations, yet perceive them as difficult and emotional. **Abstract (inc. link to references):** <https://goo.gl/MwwFxr>

#### How do palliative care doctors recognise imminently dying patients? A judgement analysis

*BMJ OPEN* | Online – 25 November 2018 – The aim of this research was to understand how doctors, with a measured prognostic ability, recognise when a patient is imminently dying. The authors found that for hospice inpatients with end-stage malignancy, the Palliative Performance Score (PPS) was the most influential factor in doctors' decision making, followed by the presence of Cheyne-Stokes breathing, decline in overall condition, level of agitation or sedation, presence of noisy respiratory secretions and peripheral cyanosis. This insight into the decision making of top prognosticators could be used to develop teaching resources to help less experienced doctors to model their own judgement policies on those of the experts. Using the authors' results as a guide, novices could be taught to hone their clinical intuition by giving greater weight to certain factors (e.g., PPS and presence of Cheyne-Stokes breathing) over other less important factors (e.g., noisy respiratory secretions, peripheral cyanosis, urinary output). A similar approach to improving the decision-making abilities of novices by teaching them to model their judgement policies on those of experts has been shown to be successful in other (non-prognostic) situations and with other health and social care professionals. This research is important because, implicit in most clinical guidelines and policies about end-of-life care (EoLC), is the assumption that it is possible to recognise which patients are, or are not, imminently dying. The National Institute for Health & Care Excellence guideline on EoLC describes the recognition of imminent death as an essential first step towards improving care for dying patients.<sup>1</sup> However, the guideline does not clearly explain how doctors are expected to identify such patients, nor how novice doctors can be expected to learn or improve this clinical skill. **Full text:** <https://goo.gl/eJvni2>

1. 'Care of dying adults in the last days of life,' National Institute for Health & Care Excellence, December 2015. [Noted in 21 December 2015 issue of Media Watch (#441, p.7)] **Download/view at:** <https://goo.gl/uKRYjt>

**N.B.** Selected articles on awareness of imminent or impending death noted in 25 June 2018 issue of Media Watch (569, p.10).

## **Palliative care in adolescents and young adults with cancer: Why do adolescents need special attention?**

*THE CANCER JOURNAL*, 2018;24(6):336-341. Meeting shortfalls in the provision of care to adolescents and young adults with cancer has focused largely on improving outcomes and psychosocial support. A significant percentage of adolescents and young adults with cancer will die of disease because of initial poor prognosis conditions or disease relapse. In adults, progress has been made in the concept of an integrated cancer/palliative care (PC) service. In pediatric oncology, the application of this philosophy of care has lagged behind somewhat. In the case of adolescents, particularly those with advanced cancer, the PC needs, in a broader sense than only end-of-life care, are often not adequately met, irrespective of whether treatment is delivered in a pediatric or adult cancer service. There are a number of age-specific aspects to palliative and supportive care for adolescents. Complex interactions between clinicians, parents, and patients potentially limit the young person's ability to influence care planning. The wide variation in real or perceived competency at this age, the developmental challenges in relation to behavior, communication, and coping strategy all require particular professional expertise that is not always available.

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

Noted in Media Watch 24 September 2018 (#582, p.8):

- *CHILD & ADOLESCENT PSYCHIATRIC CLINICS OF NORTH AMERICA*, 2018;27(4):511-526. **“Will you remember me?”: Talking with adolescents about death and dying.** This article describes the preparation, rationale and benefits of talking with adolescents who have life-threatening or life-limiting illness about advance care planning (ACP) and end-of-life concerns... The authors outline how to assess patient and family readiness, including developmental, cultural, personal, and psychosocial considerations. Evidence-based techniques for respectfully and productively engaging adolescents in ACP conversations are discussed. **First page review:** <https://goo.gl/cpmEAG>

Noted in Media Watch 10 July 2017 (#520, p.11):

- *INTERNATIONAL JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2017;19(4):376-382. **‘End-of-life transitions and hospice utilization for adolescents: Does having a usual source of care matter?’** 10% of the study sample used hospice services. Having a usual source of primary care was associated with an increase in hospice enrollment, hospice length of stay, and end-of-life transitions. Adolescents with a cancer diagnosis were more likely to enroll in hospice services. This study is among the first to demonstrate a relationship between primary care and hospice use among this population. **Abstract:** <https://goo.gl/ZQy1Qo>

Noted in Media Watch 24 October 2016 (#484, p.9):

- *JAMA PEDIATRICS* | Online – 17 October 2016 – **‘Ethics, emotions, and the skills of talking about progressing disease with terminally ill adolescents: A review.’** The pediatrician's opportunities to engage in difficult conversations about poor prognosis may be rare, but such conversations can be crucial. These discussions affect how patients live at the end of their lives, how they die, and how their families go on. Improved understanding of basic principles of communication, as well as augmented understanding of patient, family, and clinician perspectives may better enable us to navigate these important conversations. **Abstract:** <https://goo.gl/v91oh0>

## **Standards for the management of cancer-related pain across Europe. A position paper from the EFIC Task Force on Cancer Pain**

*EUROPEAN JOURNAL OF PAIN* | Online – 27 November 2018 – The European Pain Federation established a Task Force in 2017 which convened a European group of experts, drawn from a diverse range of relevant clinical disciplines, to prepare a position paper on appropriate standards for management of cancer-related pain. The expert panel reviewed the available literature and made recommendations using the GRADE system to combine quality of evidence with strength of recommendation. The panel took into

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account the desirable and undesirable effects of the management recommendation, including the cost and inconvenience of each when deciding the recommendation. The 10 standards presented are aimed to improve cancer pain management and reduce variation in practice across Europe. The task force believes that adoption of these standards by all 37 countries will promote the quality of care of patients with cancer related pain and reduce unnecessary suffering. **Abstract:** <https://goo.gl/Rv97wn>

#### Related

- *AMERICAN JOURNAL OF PUBLIC HEALTH* | Online – 29 November 2018 – ‘**Solving the global crisis in access to pain relief: Lessons from country actions.**’ Annually, more than 61 million people worldwide experience about 6 billion days of serious health-related suffering that could be alleviated with access to palliative care (PC) and pain relief. However, PC is limited or non-existent in most parts of the world. The access abyss is so stark that 50% of the world’s poorest populations live in countries that receive only 1% of the opioid analgesics distributed worldwide. By contrast, the richest 10% of the world’s population live in countries that receive nearly 90% of the opioid pain relief medications. The authors present the inequities in access to pain relief and highlight key points from country responses, drawing from and building on recommendations of the *Lancet* Commission report to close the access abyss in relief of pain and other types of serious health-related suffering.<sup>1</sup> **Abstract:** <https://goo.gl/kAvNRu>
  1. ‘Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage,’ *The Lancet*, published online 12 October 2017. [Noted in 16 October 2017 issue of Media Watch (#534, p.14)] **Full text:** <https://goo.gl/i7r9M1>
- *AMERICAN JOURNAL OF PUBLIC HEALTH* | Online – 29 November 2018 – ‘**Evidence-based pain management: Building on the foundations of Cochrane Systematic Reviews.**’ The authors discuss the history and current status of evidence-based medicine for the prevention and treatment of acute and chronic pain as it has developed in the Cochrane Collaboration’s Pain, Palliative & Supportive Care Review Group. To date, group has published 277 reviews and a further 11 reviews of systematic reviews summarizing the evidence for interventions. The Cochrane Library has readily available high-quality summaries of evidence of pharmacological interventions especially for postsurgical pain but also for chronic musculoskeletal and neuropathic pain. The library covers all forms of intervention, not only pharmacological. The world of evidence-based medicine is changing: most historical trials have been entered into reviews, but the evidence is still not well disseminated and needs to be better translated into decision support. **Abstract:** <https://goo.gl/FGFUPN>

#### **Are we making progress on communication with people who are near the end of life in the Australian health system? A thematic analysis**

*HEALTH COMMUNICATION* | Online – 26 November 2018 – Initiating end-of-life (EoL) discussions with patients is often delayed or avoided altogether by healthcare practitioners even in light of imminent death. This continues despite the availability of guidelines and conceptual frameworks on how to communicate prognoses at EoL. The authors surveyed healthcare practitioners to elicit their exposure to and confidence in EoL discussions and to better understand factors that enable or challenge the initiation of discussions in Australian healthcare settings. Thematic analysis identified that EoL discussions could be emotionally burdensome for healthcare practitioners, but were regarded as valuable. Effective communications were challenged by conflict with families and between healthcare practitioners as to appropriate care goal transition, and by prognostic uncertainty. Communication skills appeared to be developed more from experience, and beneficial strategies such as role play and mentoring particularly for younger nurses and doctors were identified. Specific training in EoL communications should target undergraduates and new healthcare practitioners. **Abstract:** <https://goo.gl/KcLdS8>

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## Related

- *ANNALS OF FAMILY MEDICINE*, 2018;16(6):530-537. **‘Older adults’ preferences for discussing long-term life expectancy: Results from a national survey.** Most participants did not wish to discuss life expectancy in a hypothetical scenario depicting a patient who had serious illnesses, but was not imminently dying. This result contrasts with those of previous studies involving smaller convenience samples, in which 55% to 66% of participants wanted to discuss life expectancy. Several reasons may contribute to the different finding in this study. **Full text:** <https://goo.gl/C1ypkC>.
- *JOURNAL OF PALLIATIVE CARE* | Online – 28 November 2018 – **‘Communication challenges at the crossroads of oncology and palliative care: Finding a way forward when clinicians differ on prognosis.’** In such situations, we may find a way forward by identifying common ground and exploring patients’ and clinicians’ values. Specifically, we can ask what constitutes a reasonable quality of life for our patients, and explore our colleagues’ hopes, worries, and values using familiar communication techniques. **Abstract:** <https://goo.gl/Te9Aqq>

Noted in Media Watch 26 November 2018 (#591, p.9):

- *JAMA INTERNAL MEDICINE* | Online – 19 November 2018 – **‘Softening our approach to discussing prognosis.’** We tend to cringe when we hear “So, how much time do I have, doc?” Yet prognostic discussions are a core skill of being a compassionate physician, preparing patients and families to live with serious illnesses, and enabling informed medical and personal decisions. The first challenge of prognostic communication is the inherent and unavoidable uncertainty, that the exact trajectory of health (or illness) is unknowable. **Introductory paragraph:** <https://goo.gl/LrtzxX>

## Palliative care in the U.S.

### **A value-based payment model for palliative care: An analysis of savings and return on investment**

*JOURNAL OF AMBULATORY CARE MANAGEMENT*, 2019;42(1):66-73. 5% of the U.S. population accounts for 50% of total health expenditures. This “5%” problem requires moderating Medicare cost trends. SPARK, a community-based palliative care (PC) program, focused on its costliest Medicare Advantage patients. This cohort's projected costs were 280% higher than average beneficiaries, based on Medicare's risk model. Despite significant losses during enrollees’ first year, a positive 5.1% ROI was found over the program’s 4 years when stop-loss insurance payments were included. SPARK demonstrates that a high-quality, community-based PC program can be financially self-sustaining using a value-based payment model with premium plus stop-loss income exceeding actual costs. **Abstract:** <https://goo.gl/odBRqW>

### **Meaning in life and self-esteem help hospice nurses withstand prolonged exposure to death**

*JOURNAL OF NURSING MANAGEMENT* | Online – 27 November 2018 – [In a survey of hospice nurses] the presence of meaning in life was associated with lower psychological distress, burnout, and negative affect, and higher levels of positive affect, whereas the search for meaning in life was only associated with higher negative affect. Self-esteem mediated the relationship between the presence of meaning in life and psychological distress, burnout, and negative affect. Although managers cannot directly instill meaning in life in hospice nurses, they may be able to help nurses find or maintain meaning by promoting policies that allow them to participate in meaningful personal, cultural, or religious activities. Additionally, managers of hospice nurses could connect them with resources (e.g., mentors, counselors, or chaplains) to cope with the existential demands of providing end-of-life care. **Abstract:** <https://goo.gl/9FDmKx>

## Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 27 November 2018 – **‘Honoring life after death: Mapping the spread of The Pause.’** The Pause is a contemplative intervention that has been deployed to foster honor and self-care... It is most widely learned about by the bedside in practice settings. Participants [in this study] believe it is malleable and has a powerful systemic effect in fostering a culture of support and honor. The Pause should continue to be taught in clinical scenarios to foster a broader humanistic ethos in healthcare. **Abstract:** <https://goo.gl/fAsfG2>

## End-of-life care in Australia

### **Where patients with cancer die: A population-based study, 1990 to 2012**

*JOURNAL OF PALLIATIVE CARE* | Online – 28 November 2018 – Using the South Australian Cancer Registry records of 86,257 patients with cancer, the proportion of deaths in hospital decreased from 63.4% to 50.9%, and in nursing homes increased from 8.2% to 22.5%. After the year 2000, the proportions in hospices and at home were both below 15%. Young patients with cancer were more likely to die in a hospice or at home, compared to elderly patients with cancer who were more likely to die in a nursing home; the likelihood of dying in a hospice increased with socio-economic status; patients with a short survival time or a hematological malignancy were more likely to die in a metropolitan hospital. Compared to most other countries, the proportion of cancer deaths at home was low, and many patients would not have died at their preferred place. The trend for more cancer deaths to occur in nursing homes is likely to continue, but nursing homes generally lack the resources and skilled staff to provide quality palliative care (PC). Models of PC delivery should take account of patient preferences, the growth of terminal cancer care in nursing homes, and apparent inequities. **Abstract:** <https://goo.gl/yHQVvp>

### **Compassion and mercy are not helpful in resolving intractable family-physician conflicts on end-of-life care**

*JOURNAL OF PERINATOLOGY* | Online – 24 November 2018 – “Compassion and mercy” are important values for humanizing medicine. There are limits, however, in their ability to help resolve disputes between physicians and families regarding appropriate end-of-life care. The recent cases of Charlie Gard and Alfie Evans in England highlight the issue. The English courts resolve such conflicts by an independent assessment of a court. The American judicial system does not share the centralized system of the English courts. In the U.S. Federal structure some 50 state legislatures and 50 state court systems go their separate ways. The result is differing, frequently conflicting, standards. The authors explore possible ways to avoid court involvement in the American context for resolving such disputes within the patient-physician relationship. **Abstract (w. list of references):** <https://goo.gl/v9Bi6P>

**N.B.** Selected articles on the Charlie Gard and the Alfie Evans cases noted in 28 May and 11 June 2018 issues of *Media Watch* (#565, p.3 and #567, p.10, respectively). The November 2017 issue of the *American Journal of Bioethics*, noted in 13 November 2017 issue of *Media Watch* (#538, p.8), focuses on the medical decision-making process in pediatrics. **Journal contents page:** <https://goo.gl/yQE2Lk>

### **The potential role of psychosocial rehabilitation in palliative care**

*JOURNAL OF THE ROYAL COLLEGE OF PHYSICIANS OF EDINBURGH*, 2018;48(4):311-317. The existence of psychopathology is common in patients undergoing palliative care (PC), and psychiatric comorbidities, such as depression and anxiety, are frequent and often under-diagnosed. This article constitutes a review of the literature and a reflection on the potential role of psychosocial rehabilitation in mental health in PC. Psychosocial rehabilitation may play a role in the mental health of patients undergoing PC, contributing to minimisation of symptoms, support in daily life activities, the improvement of quality of life and the preparation for death. **Abstract (via PubMed):** <https://goo.gl/xko67A>

**N.B.** Click on the link to the journal (on the PubMed page) to access full text.

### **Factors associated with hospices' non-participation in Medicare's Hospice Compare Public Reporting Program**

*MEDICAL CARE* | Online – 26 November 2018 – To enhance the quality of hospice care and to facilitate consumers' choices, the Centers for Medicare & Medicaid Services (CMS) began the Hospice Quality Reporting Program, in which CMS posted the quality measures of participating hospices on its reporting website, Hospice Compare. Little is known about the participation rate and the types of non-participating

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hospices. Among the 4,123 certified hospices subject to penalty from non-participation, 259 did not participate in Hospice Compare. California, New Mexico, Texas, and Wyoming had participation rates lower than 80%. Hospices that were for-profit, had no accreditation, had few nurses per patient day, provided no inpatient care, and were located in competitive markets were less likely to participate than other hospices. Hospice Compare successfully motivated hospice in participating in the quality report program in most of states. For-profit hospices, hospices with less quality, and hospices located in competitive markets were less likely to participate. Further research is warranted to examine the quality of these non-participants, especially in the 4 states with a lower participation rate. **Abstract:** <https://goo.gl/scNMka>

**N.B.** Hospice Compare website: <https://goo.gl/26QbHf>

## Are we getting it wrong? Perspectives on the future of palliative care in hospitals

*PALLIATIVE MEDICINE* | Online – 28 November 2018 – Hospitals have always occupied an ambiguous position within palliative care (PC). Their “sterile” nature provided the genesis for the modern hospice movement and contemporary PC policy positions hospitals as having little to offer.<sup>1</sup> However, rapidly rising demand for PC globally necessitates optimal utilisation of all facets of the health system, including hospitals. Clear direction is now needed in terms of a future research, policy and service development agenda: it is here that research published in *Palliative Medicine* can make a significant contribution. The first contribution is by way of confirming that hospitals do play an important role in the care of people with PC needs. For example, in the first nationwide study of its kind, Clark *et al* identified that almost 30% of a Scottish inpatient cohort died within 12 months of hospitalisation.<sup>2</sup> This confirms that people in their last year of life are high users of inpatient services. For policy makers this has raised the prospect that many of these admissions could be prevented, with a resultant significant cost saving. But is this really the case? Several papers published in *Palliative Medicine* make an important contribution to this debate. Two studies conducted in different countries and from different perspectives concluded that less than 8% of hospital deaths or hospital admissions among people in the last year of life are potentially inappropriate and could have been avoided.<sup>3,4</sup> This indicates a need for the research agenda to move to determining how hospitals can be optimised to better meet the needs of people with life-limiting illnesses and their families. There are a number of papers which help place the service user perspective at the centre of this discussion. **Full text:** <https://goo.gl/f7mHjs>



1. ‘The “problematization” of palliative care in hospital: An exploratory review of international palliative care policy in five countries,’ *BMC Palliative Care*, published online 26 July 2016. [Noted in 1 August 2016 issue of Media Watch (#473, p.10)] **Full text:** <http://goo.gl/bOnwZ3>

2. ‘Imminence of death among hospital inpatients: Prevalent cohort study,’ *Palliative Medicine*, published online 17 March 2014. [Noted in 24 March 2014 issue of Media Watch (#350, p.5)] **Abstract (w. list of references):** <https://goo.gl/qWAA2b>

3. ‘Appropriateness and avoidability of terminal hospital admissions: Results of a survey among family physicians,’ *Palliative Medicine*, published online 12 July 2016. [Noted in 18 July 2016 issue of Media Watch (#471, p.14)] **Abstract (w. list of references):** <http://goo.gl/D6DHCV>

4. ‘Economic impact of hospitalisations among patients in the last year of life: An observational study,’ *Palliative Medicine*, published online 23 December 2013. [Noted in 30 December 2013 issue of Media Watch (#338, p.12)] **Abstract (w. list of references):** <https://goo.gl/SHd2fy>



### 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.

## **Morbidity burden and community-based palliative care are associated with rates of hospital use by people with schizophrenia in the last year of life: A population-based matched cohort study**

*PLOS ONE* | Online – 29 November 2018 – The authors found evidence that people with schizophrenia who are dying with conditions amenable to palliative care (PC) were half as likely to receive specialist PC in the home compared to the matched cohort. This is similar to findings from New Zealand and Canada. Yet, they found that decedents with schizophrenia were just as likely to have accessed non-palliative community-based services in the last year of life as decedents without schizophrenia. Studies from countries with universal health care like Australia have also reported regular and increased access to GP services by people with schizophrenia. This suggests the barriers inhibiting receipt of PC for people with schizophrenia are at least partly health system driven rather than patient driven. Considering the vulnerability of people with schizophrenia to poorer general health outcomes and lower life expectancy, efforts to remedy this are essential. **Full text:** <https://goo.gl/XMP8ke>

Noted in Media Watch 15 October 2018 (#585, p.13):

- *JOURNAL OF PALLIATIVE CARE* | Online – 10 October 2018 – ‘**On the margins of death: A scoping review on palliative care and schizophrenia.**’ Four themes were identified: 1) Stigma affecting quality of care and access to care; 2) Issues related to consent and capacity for the patient’s end-of-life care (EoLC) decisions and to appoint substitute decision makers; 3) Best practices for psychosocial interventions, pharmacology, family and healthcare collaborations, goals of care, setting, and smoking; and, 4) Barriers to care, including setting, communication, provider education, and access to care. collaborative frameworks to enable the provision of quality EoLC for individuals with schizophrenia. **Abstract:** <https://goo.gl/SXxchu>

Noted in Media Watch 2 April 2018 (#557, p.9):

- *BMC PALLIATIVE CARE* | Online – 27 March 2017 – ‘**Palliative care for people with schizophrenia: A qualitative study of an under-serviced group in need.**’ Barriers to palliative care (PC) are outlined, but more importantly facilitators to PC are presented that identify key indicators needed to ensure good care. These include identifying a carer or nominating an advocate for the person, case conferencing in multidisciplinary and cross sector teams, and building capacity within the pre-existing workforce and care providers through education and advocacy. **Full text:** <https://goo.gl/HxhSVC>

## **The requirements of hospital-based spiritual care for cancer patients**

*SUPPORTIVE CARE IN CANCER* | Online – 24 November 2018 – This study revealed 3 themes and 8 sub-themes including fundamental requirements (changes in the attitudes and behaviors of the health-care team), structural requirements (inter-professional collaborations, a reference system), and functional requirements (religious-spiritual, pastoral, psycho-spiritual, and supportive-spiritual care). These findings add to the repertoire of knowledge about the spiritual needs of cancer patients. They indicated that it is essential to get acquainted with the spiritual care requirements in the hospital and enforce them through inter-professional collaboration. Accordingly, the spiritual care program should be designed, implemented, and evaluated. **Abstract (w. list of references):** <https://goo.gl/HrjwkK>

**N.B.** Selected articles on spirituality and spiritual care in the context of palliative and end-of-life care noted in 26 November 2018 issue of Media Watch (#591, p.13).



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



Closing the Gap Between Knowledge & Technology  
<http://goo.gl/OTpc8I>

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *AUSTRALIAN HEALTH REVIEW* | Online – 30 November 2018 – ‘**Documenting the process of developing the Victorian voluntary assisted dying legislation.**’ Many countries have legislated for their constituents to have control over their death. Commonalities and differences can be found in the regulations surrounding the shape and practices of voluntary assisted dying (VAD) and euthanasia, including an individual’s eligibility and access, role of health professions and the reporting. In Australia there have been perennial debates across the country to attempt legislative change in assisting a terminally ill person to control the ending of their life. In 2017, Victoria became the first state to successfully legislate for VAD. In describing the Victorian process that led to the passage of legislation for VAD, this article examines the social change process. The focus of this article is on the vital role played by a multidisciplinary ministerial advisory panel to develop recommendations for the successful legislation... **Abstract (w. list of references):** <https://goo.gl/WwDzht>
- *AUSTRALIAN HEALTH REVIEW* | Online – 23 November 2018 – ‘**Future of assisted dying reform in Australia.**’ The Voluntary Assisted Dying Act 2017 (Victoria) will come into force in June 2019, becoming the first law in Australia in 20 years to permit voluntary assisted dying (VAD). The authors consider how other Australian states and territories are likely to respond to this development. They analyse three key factors that suggest that law reform is likely to occur in other parts of Australia: 1) The growing international trend to permit VAD; 2) Social science evidence about how VAD regimes operate; and, 3) Changes to the local political environment. The authors argue that these three factors, coupled with the effect of Victoria changing its law, suggest that other VAD law reform is likely to occur in Australia. It also considers the different types of laws that may be adopted, including whether other states and territories will follow the very conservative Victorian approach or adopt more liberal models. **Abstract (w. list of references):** <https://goo.gl/GVNPbo>
- *UNSW LAW JOURNAL*, 2018;41(4):1367-1417. ‘**Informing the euthanasia debate: Perceptions of Australian politicians.**’ In the debate on euthanasia or assisted dying, many different arguments have been advanced either for or against legal reform in the academic literature, and much contemporary academic research seeks to engage with these arguments. However, very little research has been undertaken to track the arguments that are being advanced by politicians when Bills proposing reform are debated in Parliament. Politicians will ultimately decide whether legislative reform will proceed and, if so, in what form. It is therefore essential to know what arguments the politicians are advancing in support of or against legal reform so that these arguments can be assessed and scrutinised. This article seeks to fill this gap by collecting, synthesising and mapping the pro- and anti-euthanasia and assisted dying arguments advanced by Australian politicians, starting from the time the first ever euthanasia Bill was introduced. **Abstract:** <https://goo.gl/5DzsDz>

### 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.

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### [Links to Sources](#)

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5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

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

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INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/RoL82M>

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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']

#### **Canada**



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

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

[Scroll down to 'Additional Resources']

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

#### **Europe**

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

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

Cont.

South America



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

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