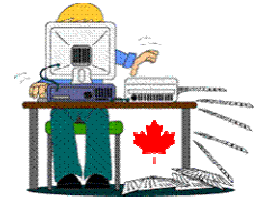


## Media Watch...

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

The transition to “permanent care”: Scroll down to [Specialist Publications](#) and ‘Would reframing aged care facilities as a “hospice” instead of a “home” enable older people to get the care they need? (p.14), in *Collegian*.

## Canada

### Bill C-277 passes into law

#### Canadian parliament makes plans for end-of-life care

*THE NATIONAL OBSERVER* | Online – 11 December 2017 – Canada has moved one step closer to creating national guidelines for palliative care (PC) following the Senate’s passage of a private member’s bill [C-277]. The legislation was adopted more than a year after it was first introduced in the House of Commons... ‘An Act providing for the development of a framework on PC in Canada,’ is expected to receive royal assent...<sup>1</sup> The legislation incorporates recommendations made by an all-party committee report...<sup>2</sup> The legislation requires the government to come up with a PC framework. The final framework is also expected to promote research and evaluate whether to re-establish a secretariat on PC and end-of-life care (EoLC).<sup>3</sup> Health care falls primarily under provincial and territorial government jurisdiction, and the federal government has expressed a commitment to working with them to improve PC access. EoLC can include acute, hospice, home, and crisis care, as well as counselling. These options, however, are particularly difficult to access in rural, remote and northern areas... <https://goo.gl/fuVuDZ>



Source: ‘Right to Care: Palliative care for all Canadians,’ Canadian Cancer Society, December 2015. [Noted in the 18 January 2016 issue of Media Watch (#445, p.1)] **Download/view at:** <http://goo.gl/f3iFEB>

Cont.

1. Bill C-277 received Royal Assent 12 December 2017. **Download/view at:** <https://goo.gl/LWW6kT>
2. 'Not to be Forgotten: Care of Vulnerable Canadians,' Parliamentary Committee on Palliative & Compassionate Care. [Noted in the 21 November 2011 issue of Media Watch (#228, p.1)] **Download/view at:** <https://goo.gl/hkXmxE>
3. Liberal Senator Sharon Carstairs was appointed Canada's first Minister with Special Responsibility for Palliative Care in March 2001 and in June of the same year the Secretariat on Palliative & End-of-Life Care was established, a first step, working with the provincial and territorial governments, in Health Canada's plan to coordinate the development of a national strategy on palliative and end-of-life care. In March 2007, however, under the Conservative government of the time, the Secretariat was disbanded and the work was stopped on the national strategy.

### Specialist Publications

**'Does access to end-of-life homecare nursing differ by province and community size?: A population-based cohort study of cancer decedents across Canada'** (p.15), in *Health Policy*.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC ('The Current') | Online – 11 December 2017 – **'Doctors frustrated with lack of clarity for medically assisted dying practices in Canada.'** It has been a year and a half since medical assistance in dying (MAiD) became legal in Canada. Since then, at least 2,000 Canadians have died with their doctors' help. Many physicians who have been involved in the procedure say they're seeing benefits for their patients in their lives as well as their deaths. "When someone is given the permission to go ahead and have an assisted death ... it's very clear to me that their life is no longer about dying," says Dr. Stefanie Green, co-founder and president of the Canadian Association of MAiD Assessors & Providers. Access to assisted dying isn't consistent across the country, leaving the onus on some doctors to travel widely to perform the procedure. <https://goo.gl/X22PUA>

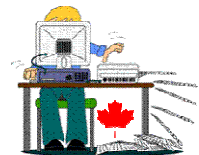
### Specialist Publications

**'Medical assistance in dying and mental health: A legal, ethical, and clinical analysis'** (p.20), in *Canadian Journal of Psychiatry*.

**'The right to die: Legalizing medical assistance in dying in Canada: A provincial/territorial health reform analysis'** (p.20), in *Health Reform Observer*.

### 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>



## U.S.A.

### ***Living in an immigrant family in America: How fear and toxic stress are affecting daily life, well-being, and health***

KAISER HEALTH NEWS | Online – 13 December 2017 – The climate surrounding current immigration policies potentially affect 23 million non-citizens in the U.S., including both lawfully present and undocumented immigrants, many of whom came to the U.S. seeking safety and improved opportunities for their families. They also have implications for the over 12 million children who live with a non-citizen parent who are predominantly U.S-born citizen children. Immigrant families across different backgrounds and locations are feeling increased levels of fear and uncertainty amid the current climate; these feelings extend to those with lawful status. The findings [of this report] show that these fears are having broad effects on the daily lives and routines of some immigrant families. In addition, they point to long-term consequences for children in immigrant families, including poorer health outcomes over the lifespan, compromised growth and development, and increased challenges across social and environmental factors that influence health. **Download/view Kaiser Family Foundation report at:** <https://goo.gl/61xEDk>

Noted in Media Watch 13 February 2017 (#499, p.10):

- *JAMA INTERNAL MEDICINE* | Online – 6 February 2017 – **‘Hospice access for undocumented immigrants.’** The 11.2 million undocumented immigrants living in the U.S. are not covered by the Medicare Hospice Benefit, and most are uninsured. Aging of undocumented patients owing to increasing lengths of residence in the U.S. is likely to increase hospice demand, and undocumented immigrants are the largest demographic group explicitly excluded from Affordable Care Act provisions. Clinicians have reported challenges in obtaining hospice for undocumented immigrants; however, little is known about hospice access in this population. **Abstract:** <https://goo.gl/rb4ocl>

**N.B.** Additional articles on undocumented immigrants in the U.S. in the context of palliative and end-of-life care are noted in this issue of Media Watch.

### **Wisconsin ranked 7th best state in the nation for family caregivers**

WISCONSIN | *The Wisconsin Gazette* (Milwaukee) – 13 December 2017 – With an estimated 34 million Americans taking on the role of unpaid caregiver to an aging loved one, the senior care website Caring.com released a list of the best and worst states in the U.S. for family caregivers of older adults.<sup>1</sup> To gather this list, the website weighed proprietary data on the availability of highly rated senior care options in each state. It also compared state-by-state rankings on caregiver supports from the Long-Term Services Scorecard, a joint report released earlier this year by the American Association for Retired Persons, The Commonwealth Fund, and the SCAN Foundation.<sup>2</sup> <https://goo.gl/zVBC1r>

1. ‘2017’s best and worst states for family caregivers,’ Caring.com, San Mateo, California, December 2017. **Download/view at:** <https://goo.gl/aVSsdJ>
2. ‘Long-Term Services Scorecard,’ American Association for Retired Persons, June 2017. [Noted in the 19 June 2017 issue of Media Watch (#517, p.3)] **Download/view at:** <https://goo.gl/ewWZLc>

#### **Related**

- HAWAII | *The New York Times* – 15 December 2017 – **‘Easing the burden on caregivers.’** A new program in Hawaii, the Kupuna Caregivers Act, is designed to help lift some of the burden on people caring for an elderly family member at home by paying them stipends of up to \$70 a day. The word Kupuna means elder in Hawaiian. The program ... is limited to those who work at least 30 hours per week. The money can be used for caregiving supplies, to supplement lost wages or to hire help. The legislation recognizes that many Hawaiian families prefer to have their parents and grandparents age at home, rather than in a nursing home or assisted living facility. <https://goo.gl/hXQ2FY>

## This is what LGBTQ people should look for when choosing hospice care

CALIFORNIA | *LGBTQ Nation* (San Francisco) – 12 December 2017 – Discrimination against lesbian, gay, bisexual, transgender, gender non-conforming, queer, and/or questioning (LGBTQ) people is unacceptable in any instance but it is particularly unforgivable when encountered in a hospice or palliative care (PC) environment. When an LGBTQ person has a serious or life-limiting illness and seeks PC or hospice care, they run the risk of isolation and marginalization at the precise time when they most need support. LGBTQ family members of straight patients seeking hospice care are also vulnerable. A 2016 survey<sup>1</sup> ... “found that the respondents were frequently mistreated by care center staff, including cases of verbal and physical harassment, as well as refusal of basic services. Some respondents reported being prayed for and warned they might ‘go to hell’ for their sexual orientation or gender identity.” Stripped of any sense of comfort, security or safety because of discrimination or poor quality care provided by well-intentioned healthcare providers, an LGBTQ person facing a serious illness may find their situation all the more excruciating. <https://goo.gl/849A9C>

1. ‘LGBT seniors are being pushed back into the closet,’ *The Atlantic*, 25 August 2016. <https://goo.gl/mN3F3a>

Noted in Media Watch 29 May 2017 (#514, p.9):

- *JOURNAL OF GAY & LESBIAN SOCIAL SERVICES* | Online – 19 May 2017 – ‘**Exploring the utilization of end-of-life documentation among an online sample of sexual- and gender-minority individuals in the U.S.**’ Lesbian, gay, bisexual, transgender, and queer (LGBTQ) persons often receive end-of-life care incongruent with wishes. Little is known about the knowledge, attitudes, and willingness regarding utilization of these documents among LGBTQ persons. Approximately one-third of survey respondents believed documents would be enforced more for heterosexual persons than themselves. **Abstract:** <https://goo.gl/XIz8n>

**N.B.** Additional articles on palliative and end-of-life care for LGBTQ communities are noted in the 22 May 2017 issue of Media Watch (#513, pp.18-19).

## Native Americans feel invisible in U.S. health care system

NATIONAL PUBLIC RADIO | Online – 12 December 2017 – The life expectancy of Native Americans in some states is 20 years shorter than the national average. There are many reasons why. Among them, health programs for American Indians are chronically underfunded by Congress. And, about a quarter of Native Americans reported experiencing discrimination when going to a doctor or health clinic, according to findings of a poll by National Public Radio (NPR), the Robert Wood Johnson Foundation and Harvard T.H. Chan School of Public Health. In the NPR poll, Native Americans who live in areas where they are in the majority reported experiencing prejudice at rates far higher than in areas where they constituted a minority. Health care systems outside the Indian Health Service generally see very few Native American patients, because it’s so hard for American Indians to access care in the private sector. A lot of that has to do with high poverty and uninsured rates among American Indians, who also often live in rural areas with few health care providers. A persistent myth inside and outside Indian Country is that Native Americans get free health care from the federal government. <https://goo.gl/H1bKvM>

Noted in Media Watch 31 July 2017 (#523, p.11):

- *JOURNAL OF TRANSCULTURAL NURSING* | Online – 22 July 2017 – ‘**Culturally relevant palliative and end-of-life care for U.S. indigenous populations: An integrative review.**’ American Indians/Alaska Natives (AIs/ANs) have higher rates of chronic illness and lack access to palliative/end-of-life (EoL) care. Four themes emerged: 1) Communication; 2) Cultural awareness/sensitivity; 3) Community guidance for palliative/EoL care programs; 4) Barriers ...and, two sub-themes: 1) Trust/respect; and, 2) Mistrust. Limitations are lack of research funding, geographic isolation, and stringent government requirements. **Abstract:** <https://goo.gl/yegFi2>

**N.B.** Additional articles on palliative and end-of-life care for U.S. indigenous populations are noted in this issue of Media Watch.

## When a sibling has a serious, or even fatal, illness

*THE NEW YORK TIMES* | Online – 12 December 2017 – There is also little social support for bereaved siblings. A 2010 study ... of 109 major pediatric hospitals in the U.S. and Canada found that only 48% provided sibling support.<sup>1</sup> A 2014 study of young adults who lost siblings to cancer found that most were still grieving two to nine years later.<sup>2</sup> Beyond the lifestyle changes and the terror of the unknown, the healthy sibling's role in the family shifts.<sup>3</sup> Parents are in triage mode, and by default, the well child must take a back seat: Their needs simply aren't as important, or so the thinking has gone. Not surprisingly, research has found that pre-teens who had lost a sibling had higher anxiety and depression levels than those who did not.<sup>4</sup> They also had more attention problems, likely a result of their disrupted routines. Adults who lost siblings as kids also recall feeling as if their own emotions don't matter, what the family therapist Pauline Boss calls "ambiguous loss," or loss without closure. Others have labeled it "hidden

grief." Another issue, she found, is that healthy siblings are not necessarily part of the discussion about their sibling's illness or treatment plan. This affects how the sibling copes with the loss; the less cohesive the family unit, the harder it is to grieve. <https://goo.gl/VUGAJ9>

CANADIAN  Portail CANADIEN EN SOINS  
**Virtual Hospice** **palliatifs**

Supporting Grieving or Bereaved Children  
<http://goo.gl/ydHfq9>

**[Specialist Publications](#)**

**'Decision-making on therapeutic futility in Mexican adolescents with cancer: A qualitative study'**  
(p.12), in *BMC Medical Ethics*.

1. 'Providing support to siblings of hospitalised children,' *Journal of Paediatrics & Child Health*, 2010; 46(3):72-75. **Abstract:** <https://goo.gl/Qj4dAz>
2. 'They still grieve: A nationwide follow-up of young adults 2-9 years after losing a sibling to cancer,' *Psycho-Oncology*, 2014;23(6):658-664. [Noted in the 23 December 2013 issue of Media Watch (#337, p.10)] **Abstract:** <https://goo.gl/QD211A>
3. 'A systematic review of the experiences of siblings of children with cancer,' *Cancer Nursing*, 2016; 39(3):E12-E21. **Full text:** <https://goo.gl/FEpxaX>
4. 'Comparing parent loss with sibling loss,' *Death Studies*, published online 11 November 2010. **Abstract:** <https://goo.gl/td6e75>

## Reverberations from war complicate Vietnam veterans' end-of-life care

CALIFORNIA | *California Healthline* (Oakland) – 11 December 2017 – For some veterans, the stoicism they honed on the battlefield often returns full-force as they confront a new battlefield in the hospital, making them less willing to admit they are afraid or in pain, and less willing to accept treatment. Other vets, with post-traumatic stress disorder (PTSD), are even more reluctant to take pain-relieving opioids because the drugs can actually make their symptoms worse, triggering frightening flashbacks. About 30% of Vietnam vets have had PTSD in their lifetime, the highest rate among veteran groups... Their rate is higher because of the unique combat conditions they faced and the negative reception many of them received when they returned home... Since the war, many vets have developed coping strategies to keep disturbing memories and other PTSD symptoms at bay. But facing a terminal illness – the severe pain of cancer, the nausea of chemotherapy, or the breathlessness of heart failure – can drain their energy so much that they're unable to maintain their mental defenses. Vets previously diagnosed with PTSD can slip out of remission, and some may experience it for the first time. <https://goo.gl/uYpZHb>

Cont.

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

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

**N.B.** There are 18.8 million veterans in the U.S., according to the most recent statistics from the U.S. Census. To put that in context, there are 323.1 million Americans. Health care facilities are made up of 1,065 outpatient sites and 170 Department of Veterans Medical Centers.

## How loneliness affects our health

*THE NEW YORK TIMES* | Online – 11 December 2017 – As research moves forward on these topics, scientists are gaining a more refined understanding of the effects of loneliness and isolation on health. They are also looking into factors such as who is likely to be most seriously affected, and what kinds of interventions may reduce the associated risks. There are some surprising findings. First, though equivalent in risk, loneliness and social isolation don’t necessarily go hand-in-hand, Julianne Holt-Lunstad and Timothy B. Smith, psychologist-researchers at Brigham Young University, have pointed out. “Social isolation denotes few social connections

or interactions, whereas loneliness involves the subjective perception of isolation – the discrepancy between one’s desired and actual level of social connection,” they wrote ... last year.<sup>1</sup> In other words, people can be socially isolated and not feel lonely; they simply prefer a more hermitic existence. <https://goo.gl/9HAQSv>

### **Specialist Publications**

“‘I’ve no fear of dying alone’: Exploring perspectives on living and dying alone’ (p.17), in *Mortality*.

1. ‘Loneliness and social isolation as risk factors for CVD: Implications for evidence-based patient care and scientific inquiry,’ *Heart*, 2016;102(13):987-989. **Full text:** <https://goo.gl/9UQ5gT>

## Waiting too long to use hospice care can make suffering at end-of-life worse

*THE WASHINGTON POST* | Online – 10 December 2017 – Many people who are near the end of life wait too long to enter hospice care, according to a recent study...<sup>1</sup> In hospice care, attempts to cure a disease are usually replaced with treatments solely for pain and suffering, delivered by a specialized team. It usually includes medical and nursing care, counseling and social services, and it can be given at home, in a nursing home or in a hospital facility. People who put off hospice care might spend months in and out of hospitals, with their families struggling to attend to them. “At some point, patients and their families and doctors realize that hospice is appropriate, but that happens perhaps later than it should,” says study author Thomas Michael Gill, a professor of medicine, epidemiology and investigative medicine, and the Humana Foundation professor of geriatric medicine at Yale University. “When folks are referred to hospice only in the last days of their life, it’s difficult to have a meaningful benefit.” For nearly 16 years, Gill and a team of researchers followed 754 people, all age 70 and older when the study began. More than 40% of the 562 people who died during the study entered hospice care during the last year of their lives, but the median time spent in hospice was less than two weeks. <https://goo.gl/LLbyqM>

1. ‘Distressing symptoms, disability, and hospice services at the end of life: Prospective cohort study,’ *Journal of the American Geriatrics Society* (first published online 12 September 2017). [Noted in the 18 September 2017 issue of Media Watch (#530, p.4)] **Full text:** <https://goo.gl/g83Ekq>

## International

### Elder care in the U.K.

#### **Care homes are struggling. Blame the odd structure of the market**

U.K. | *The Economist* – 14 December 2017 – In the past decade profitability in the industry has plunged. That has limited investment in the care homes of tomorrow – which are sorely needed, since the population is ageing. Since 2015 the number of beds has in fact fallen slightly... That puts pressure on other services. The number of hospital beds occupied by people who are well enough to be discharged but who have no care home to go to has risen by 75% since 2011. What has gone wrong? In the 1970s the provision and the purchasing of care were both done mainly by government. Since then, much has changed. Local councils pay some or all of the care-home fees of those with assets of less than £23,250 (\$31,000), while those with more must pay their own way. In all, the state foots about half the bill. <https://goo.gl/YffGDr>

### Specialist Publications

'European Society for Medical Oncology position paper on supportive and palliative care' (p.10), in *Annals of Oncology*.

'Singapore takes six steps forward in 'The Quality of Death Index' rankings' (p.10), in *Asia-Pacific Journal of Oncology Nursing*.

'Impact of place of residence on place of death in Wales: An observational study' (p.12), in *BMC Palliative Care*.

#### **Results of the second part of a survey of U.K. adults, on behalf of Hospice UK**

U.K. | ComRes – 13 December 2017 – Two in five (40%) adults in the U.K. express concern that they will not be able to die in the place of their choice, while more than two thirds (68%) say they are concerned about funding pressure on the National Health Service (NHS), meaning their loved ones or the may not be able to get the hospice care they need in the future. Three quarters (75%) of adults in the U.K. say that NHS and hospice partnerships improve quality of care in hospitals, however two in five (41%) say they don't know if the NHS makes the most of hospice services. <https://goo.gl/N5CgmR>



### 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 p.22.

**IPCRC.NET**  
International Palliative  
Care Resource Center

Back Issues of Media Watch

<http://goo.gl/frPgZ5>

## End-of-life care in Ireland

### Many don't know of end-of-life aid available for their final months

IRELAND | *The Irish Examiner* (Blackpool, Cork) – Online – 12 December 2017 – The Irish Longitudinal Study on Ageing (Tilda), published by Trinity College Dublin in collaboration with an inter-disciplinary panel of scientific researchers, has published its latest report, which focuses on the end-of-life (EoL) experience of older adults in Ireland.<sup>1</sup> It also found that people can enjoy a better quality of life in their final months if some risks are avoided and treatable conditions are screened and tended to accordingly. More than 8,500 people over the age of 50 initially took part in Tilda, and its latest findings are based on interviews with the family members and friends of 375 participants who have died since the study began. The Tilda EoL findings also revealed that “a high proportion of people who needed home, community, and allied health services were unable to access them.” However, researchers

found that this access was not due to disability, their socioeconomic background, or where they lived. The report’s authors said: “It is perhaps surprising that socioeconomic and geographic factors are not presenting particular barriers but reasons for failure to access services suggests that substantial numbers of people are unaware of services and/or reluctant to apply, which should be of immediate relevance and interest to policy-makers.” <https://goo.gl/m9wdyi>

#### Specialist Publications

‘The commodification of care: A critical exploration of the marketing mix for domiciliary care at the end of life’ (p.15), in *Dublin Business School Review*.

1. ‘The end of life experience of older adults in Ireland,’ Irish Longitudinal Study on Ageing, October 2017. **Full text (Click on ‘The full report is available here’ at foot of page):** <https://goo.gl/LgzdEe>

#### Related

- IRELAND | *The Independent* (Dublin) – 15 December 2017 – ‘**Families forced to say goodbye to dying relatives in crowded communal rooms, report finds.**’ An unannounced inspection of the Highfield Hospital ... found “residents’ deaths were not always handled with dignity and propriety as residents were not always offered a single room to receive end-of-life care,” a new report reveals.<sup>1</sup> The hospital, which provides nursing home and mental health facilities to 110 patients with dementia, was found to be non-compliant in regulations concerning care of the dying. <https://goo.gl/uq5KB5>

1. ‘Approved Centre Inspection Reports,’ Mental Health Commission, December 2017 (Scroll down to Highfield Hospital). **Download/view at:** <https://goo.gl/mBkCVV>

**N.B.** Additional articles on palliative and end-of-life care in Ireland are noted in the 17 July 2017 issue of Media Watch (#521, p.14). See also ‘Palliative Care Services Three-Year Development Framework (2017-2019),’ Health Service Executive, November 2017 noted in the 20 November 2017 issue of Media Watch (#539, p.6). **Download/view at:** <https://goo.gl/CGRdog>

### Scotland’s Care Inspectorate call for improvements despite positive end-of-life care report

U.K. (Scotland) | *The Evening Express* (Aberdeen) – 12 December 2017 – Overall the Care Inspectorate found that more than half of the 145 homes it examined were “performing at a good or better level in terms of meeting people’s needs, rights and expectations.” But chief executive Karen Reid said: “There remain improvements to be made in ensuring that quality of life for people is not limited due to lack of expectations of what it means to be an older person living with dementia in a care home.” When it comes to providing end-of-life care that respects an individual’s wishes, inspectors said the performance of 42.1% of homes was adequate or lower. Two fifths (40%) of homes received this grading when it came to ensuring residents have the right to be as independent as possible and to be included in the community. The report was based on studies of 145 care homes across Scotland between June 2016 and March 2017. <https://goo.gl/fegQHz>

**N.B.** Additional articles on palliative and end-of-life care in Scotland are noted in the 20 November 2017 issue of Media Watch (#539, p.6).



## End-of-life care in Australia

### **No, most people aren't in severe pain when they die**

AUSTRALIA | The Conversation – 10 December 2017 – Many people fear death partly because of the perception they might suffer increasing pain and other awful symptoms the nearer it gets. There's often the belief palliative care (PC) may not alleviate such pain, leaving many people to die excruciating deaths. But an excruciating death is extremely rare. The evidence about PC is that pain and other symptoms, such as fatigue, insomnia and breathing issues, actually improve as people move closer to death.<sup>1</sup> More than 85% of PC patients have no severe symptoms by the time they die. Evidence from the Australian Palliative Care Outcomes Collaboration (PCOC) shows that there has been a statistically significant improvement over the last decade in pain and other end-of-life (EoL) symptoms.<sup>2,3</sup> Several factors linked to more effective PC are responsible. These include more thorough assessments of patient needs, better medications and improved multidisciplinary care

(not just doctors and nurses, but also allied health workers such as therapists, counsellors and spiritual support).



But not everyone receives the same standard of clinical care at the EoL. Each year in Australia, about 160,000 people die and we estimate 100,000 of these deaths are predictable. Yet, the PCOC estimates only about 40,000 people receive specialist PC per year. <https://goo.gl/4c6mhB>

#### [Specialist Publications](#)

**'Place of death in the Snowy Monaro region of New South Wales: A study of residents who died of a condition amenable to palliative care'** (p.11), in *Australian Journal of Rural Health*.

1. 'Physical symptoms at the time of dying was diagnosed: A consecutive cohort study to describe the prevalence and intensity of problems experienced by imminently dying palliative care patients by diagnosis and place of care,' *Journal of Palliative Medicine*, 2016;19(12):1288-1295 (first published online 7 September 2016). **Abstract:** <https://goo.gl/MoSDHt>
2. Palliative Care Outcomes Collaboration, University of Wollongong, Wollongong, New South Wales, Australia. **Website:** <https://goo.gl/q1TPJv>
3. 'Trends in patient outcomes: Palliative care in Australia 2009-2016,' Palliative Care Outcomes Collaboration, University of Wollongong, New South Wales. **Download/view on 'State & National Reports' webpage at:** <https://goo.gl/CQtdfB>

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

Representative sample of recent news media coverage:

- ITALY | Associated Press – 14 December 2017 – **'Italy OKs living wills amid long-running euthanasia debate'** Italy's Senate gave final approval [in a 180-71 vote] to a law allowing Italians to write living wills and refuse artificial nutrition and hydration, the latest step in nation's long-running and agonizing debate over euthanasia and end-of-life issues. <https://goo.gl/eozKNm>
- NEW ZEALAND | Radio New Zealand (Wellington) – 13 December 2017 – **'Euthanasia bill passes first reading.'** The vote on sending the 'End Of Life Choice Bill' to the Justice select committee was 76 in favour, 44 against. The vote was a conscience vote, meaning MPs did not have to follow a party line. <https://goo.gl/RfFBdp>



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

## Specialist Publications

### European Society for Medical Oncology position paper on supportive and palliative care

*ANNALS OF ONCOLOGY* | Online – 14 December 2017 – Oncology has come a long way in addressing patients' quality of life, together with developing surgical, radio-oncological and medical anticancer therapies. However, the multiple and varying needs of patients are still not being met adequately as part of routine cancer care. Supportive and palliative care (PC) interventions should be integrated, dynamic, personalised and based on best evidence. They should start at the time of diagnosis and continue through to end-of-life or survivorship. The society is committed to excellence in all aspects of oncological care during the continuum of the cancer experience. Following the 2003 Society's stand on supportive and PC, this position paper highlights the evolving and growing gap between the needs of cancer patients and the actual provision of care.<sup>1</sup> The concept of patient-centred cancer care is presented along with key requisites and areas for further work. **Abstract:** <https://goo.gl/g3R7PF>

1. 'European Society for Medical Oncology takes a stand on supportive and palliative care, *Annals of Oncology*, 2003;14(9):1335-1337. **Full text:** <https://goo.gl/QqYYQK>

### Singapore takes six steps forward in 'The Quality of Death Index' rankings

*ASIA-PACIFIC JOURNAL OF ONCOLOGY NURSING* | Online – 6 December 2017 – In the latest 2015 Quality of Death Index, Singapore managed to move six steps forward from 18th to the 12th position.<sup>1</sup> This advancement has been hard-won, with victories to improve the level of palliative care (PC) such as creating awareness of palliative service, improving coordinated care, and growing an adequate capacity to meet the demand of care in our fast-growing ageing population. Despite being a first world country, Asian societies like Singapore have inherited taboos regarding public dialogue about death and dying. Such dialogue is traditionally avoided. However, through years of continual effort in improving the standard of PC delivery, redesigning education module, creating public awareness, and improving funding system, Singapore's PC providers have improved the lives of those with life-limiting illnesses. **Abstract:** <https://goo.gl/1h1Stc>

1. '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit (London, U.K.), October 2015. Commissioned by the Lien Foundation of Singapore [Noted in the 12 October 2015 issue of Media Watch (#431, p.6)] **Download/review at:** <https://goo.gl/zXrniA>

### Journal Watch

'Survey on open peer review: Attitudes and experience amongst editors, authors and reviewers' (p.21), in *Plos One*.

'New feature aims to draw journals into post-publication comments on PubPeer' (p.21), in *Retraction Watch*.

'When authors get caught in the predatory (illegitimate publishing) net' (p.21), in *The Scholarly Kitchen*.

## Palliative Care Network

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

## Place of death in the Snowy Monaro region of New South Wales: A study of residents who died of a condition amenable to palliative care

*AUSTRALIAN JOURNAL OF RURAL HEALTH* | Online – 11 December 2017 – Participants in this cross-sectional quantitative study were residents, with advanced frailty or one of 10 conditions amenable to palliative care (PC), who died between 1 February 2015 and 31 May 2016. Of 224 deaths in this period, 138 were considered amenable to PC. Twelve per cent of these deaths occurred in a private residence, 38% in the usual place of residence, and 91% within the region. Most rural residents with conditions amenable to PC died in the region. Further qualitative work is needed to determine PC patients' and family caregivers' preferences for, and the importance placed on, place of death. While there may be a need to support an increase in home deaths, local rural hospitals and residential aged-care facilities must not be overlooked as a substitute for inpatient hospices. **Abstract:** <https://goo.gl/N176ou>

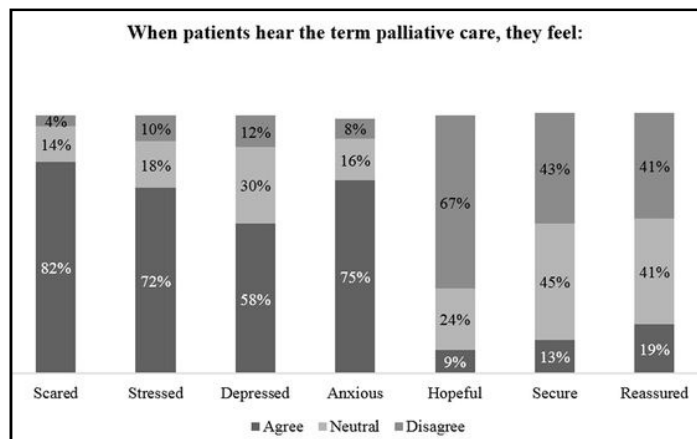
Noted in Media Watch 11 July 2016 (#470, pp.9-10):

- *AUSTRALIAN JOURNAL OF RURAL HEALTH* | Online – 5 July 2016 – 'Are rural and remote patients, families and caregivers needs in life-limiting illness different from those of urban dwellers? A narrative synthesis of the evidence.' Rural differences include: 1) People are more accepting of death and less likely to intervene to delay death; and, 2) Caregivers tend to be younger and include friends as well as family and local support networks are important. Rural and remote end-of-life needs are shaped by reduced access and availability of services, which has a negative influence on outcomes. This is counterbalanced by an acceptance of death and local support networks. **Abstract:** <http://goo.gl/QS1e7w>

### Palliative care in the U.S.

#### What do transplant physicians think about palliative care? A national survey study

*BLOOD* | Online – 7 December 2017 – The authors conducted a survey of transplant physicians who care for patients with hematologic diseases... Participants were recruited from the American Society for Blood & Marrow Transplantation membership list. The authors examined transplant physicians' 1) Access to palliative care (PC) services; 2) Perceptions and attitudes about PC; and, 3) Perceptions of the unmet PC needs of hematopoietic stem cell transplantation (HSCT) patients and their caregivers. Most physicians felt that they should coordinate the care of their patients across all stages of disease including at the end of life. The majority stated that they trust PC clinicians to care for their patients, but 40% agreed that PC clinicians do not have enough understanding to counsel their HSCT patients regarding their treatment. Most expressed concerns about how patients perceive PC. For example, 82% of physicians reported that when patients hear the term PC, they feel scared. In addition, 65% reported that if a PC referral is suggested, patients might think nothing more can be done for their disease. The majority reported that the service name "palliative care" is a barrier to PC utilization. However, most physicians recognized substantial unmet PC needs in their population including 1) Physical symptoms; 2) Graft-versus-host disease symptoms; 3) Emotional and psychological needs; 4) Spiritual needs; 5) Preparing for future medical care; and, 6) Supporting family and friends. **Abstract:** <https://goo.gl/nZKE5o>



The majority stated that they trust PC clinicians to care for their patients, but 40% agreed that PC clinicians do not have enough understanding to counsel their HSCT patients regarding their treatment. Most expressed concerns about how patients perceive PC. For example, 82% of physicians reported that when patients hear the term PC, they feel scared. In addition, 65% reported that if a PC referral is suggested, patients might think nothing more can be done for their disease. The majority reported that the service name "palliative care" is a barrier to PC utilization. However, most physicians recognized substantial unmet PC needs in their population including 1) Physical symptoms; 2) Graft-versus-host disease symptoms; 3) Emotional and psychological needs; 4) Spiritual needs; 5) Preparing for future medical care; and, 6) Supporting family and friends. **Abstract:** <https://goo.gl/nZKE5o>

**N.B.** Additional articles on organ transplantation in the context of palliative and end-of-life care are noted in the 9 October 2017 issue of Media Watch (#533, p.9).

## Decision-making on therapeutic futility in Mexican adolescents with cancer: A qualitative study

*BMC MEDICAL ETHICS* | Online – 11 December 2017 – The objective of the current study was to explore in-depth and to explain the decision-making process from the perspective of Mexican oncologists, parents, and affected adolescents [i.e., study participants] and to identify the ethical principles that guide such decision-making. The oncologists stated that they broach the subject of palliative management when they have determined that curative treatment has failed. Respect for autonomy was understood as the assent of the parent/adolescent to what the oncologist determined to be in the best interest of the adolescent. The oncologists thought that the adolescent should be involved in the decision-making. They also identified the ability to count on a palliative care (PC) clinic or service as an urgent need. For the parents, it was essential that the oncologist be truly interested in their adolescent child. They did not consider it necessary to inform the child about impending death. The adolescents stated that the honesty

of their oncologists was important; however, several of them opted for a passive role in the decision-making process. The findings of this study evidence that to achieve good medical practice in low-middle income countries, like Mexico, it is urgent to begin effective implementation of PC, together with appropriate training and continuing education in the ethics of clinical practice. **Full text:** <https://goo.gl/SgfoZm>



## Impact of place of residence on place of death in Wales: An observational study

*BMC PALLIATIVE CARE* | Online – 12 December 2017 – For the first time, this study allows us to look into socio-economic deprivation and access to healthcare prevailing in Wales and their ability to influence end-of-life care (EoLC) and place of death in the region. It highlights the organization of dying in different areas across Wales and shows that large differences exist in the proportion of deaths and place of death among residents of different deprivation quintiles and that these differences are accounted for in part by provision of access to health care services and resources, and in part by the level of deprivation of the geographical regions in which they are living. It also shows a broad difference between the actual and preferred place of death among the Welsh population. Despite all unfavourable health indicators for deprived regions in Wales, home deaths was high. Further investigation is required to understand the reason for the contradictory findings. It is also recommended that further research is carried out to find out the quality and cost of care in all locations that provide EoLC in Wales, because currently there is little evidence on the quality of care experienced by the patient and the family and costs for both the patient and healthcare providers in each of the six locations. **Full text:** <https://goo.gl/hnxJoi>

Noted in Media Watch 20 November 2017 (#539, p.5):

- U.K. (Wales) | Click on Wales (Cardiff) – 16 November 2017 – **‘We urgently need to tackle inequalities in end-of-life care in Wales.’** Research shows that across the U.K. more than 100,000 people with terminal and life-limiting conditions are not able to access the expert care they need at the end of life, including hospice care.<sup>1</sup> In Wales the national picture of the level of current unmet need is not yet clear – largely due to a lack of comprehensive data. This lack of data about unmet need is, in itself, a barrier to improving access, as highlighted in a recent report.<sup>2</sup> <https://goo.gl/PZYUBT>

1. ‘Briefing: Open up hospice care,’ Hospice UK, July 2017. **Download/view at:** <https://goo.gl/V9UuUM>

2. ‘Hospice Care in Wales, 2017,’ Hospice UK, October 2017. **Download/view at:** <https://goo.gl/3iaxLS>

**N.B.** See ‘End-of-Life Care Delivery Plan, 2017-2020,’ National Health Service Wales, March 2017. [Noted in the 14 August 2017 issue of Media Watch (#525, p.4)] **Download/view at:** <https://goo.gl/r7rGZk>

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

### **“Worried to death”: The assessment and management of anxiety in patients with advanced life-limiting disease, a national survey of palliative medicine physicians**

*BMC PALLIATIVE CARE* | Online – 11 December 2017 – To the authors’ knowledge this is the first national survey [of members of the Association of Palliative Medicine (of Great Britain & Ireland)] exploring how palliative medicine (PM) physicians assess and manage anxiety in their patients. It highlights the infrequent use of screening tools, substantial variation in prescribing practice, potentially inappropriate use of benzodiazepines in patients with a prognosis of months, training gaps and poor access to psychological and psychiatric services in the U.K. This suggests that PM physicians should receive formal training in the management of anxiety and develop local referral networks with mental health services. **Full text:** <https://goo.gl/GMNxDq>

### **Ideology and palliative care: Moral hazards at the bedside**

*CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS*, 2018;27(1):137-144. Palliative care (PC) has had a long-standing commitment to teaching medical students and other medical professionals about pain management, communication, supporting patients in their decisions, and providing compassionate end-of-life care. PC programs also have a critical role in helping patients understand medical conditions, and in supporting them in dealing with pain, fear of dying, and the experiences of the terminal phase of their lives. The authors applaud these efforts to provide that critical training and fully support their continued important work in meeting the needs of patients and families. Although they appreciate the contributions of PC services, the authors have noted a problem involving some PC professionals’ attitudes, methods of decision making, and use of language. **Abstract:** <https://goo.gl/SnMKye>

### **Do end-of-life care pathways improve outcomes in caring for the dying?**

*CLINICAL NURSE SPECIALIST*, 2018;32(1):19-20. Internationally, it is reported that most deaths occur in institutional settings, mainly hospitals and nursing homes. In these facilities, nurses are the professionals who predominantly coordinate and provide care for people in the terminal phase. In the past, dying patients in hospitals received inadequate end-of-life care (EoLC), specifically symptom control and basic nursing cares. It was identified that improvements must be made and a holistic approach to EoLC was required to ensure dying people’s comfort and dignity. Integrated pathways are used in many healthcare settings to guide and standardize care for patients with a specific clinical problem. The Liverpool Care Pathway (LCP) is an integrated care pathway, specifically for the provision of terminal care.<sup>1</sup> The pathway focuses on the physical, psychosocial, spiritual, and religious elements of EoLC as provided in the hospice setting. Nineteen essential goals are outlined in regard to caring for the dying patients and their family or carer after death. Other pathways also exist to guide care of the dying people based on these principles, however, the LCP is

arguably the most widely used. Internationally, EoLC pathways are widely used; however, the use of such pathways is controversial. There have been serious concerns raised regarding the safety of implementing EoLC pathways, particularly in the U.K. **Review first page at:** <https://goo.gl/uAWdq6>

#### **Liverpool Care Pathway (LCP): The research**

LCP Italian Cluster Trial Study Group:

‘LCP for patients with cancer in hospital: A cluster randomised trial,’ *The Lancet*, 2014;383(9913):226-237 (first published online 14 October 2013). [Noted in the 21 October 2013 issue of Media Watch (#328, pp.7-8)] **Abstract:** <https://goo.gl/bvN37J>

Flinders University, South Australia & Duke Clinical Research Institute, North Carolina:

‘Lessons from the LCP – Evidence is key,’ *The Lancet*, 2014;383(9913):192-193 (first published online 14 October 2013). [Noted in the 21 October 2013 issue of Media Watch (#328, pp.7-8)] **Summary:** <https://goo.gl/DXozk4>

1. ‘Review of Liverpool Care Pathway for Dying Patients,’ Department of Health, July 2013. [Noted in the 22 July 2013 issue of Media Watch (#315, p.6)] **Download/review at:** <https://goo.gl/ujDKOT>

## Would reframing aged care facilities as a “hospice” instead of a “home” enable older people to get the care they need?

*COLLEGIAN* | Online – Accessed 10 December 2017 – “Home” is a concept that is central to our sense of self. It is about belonging and having an environment that is uniquely one’s own, reflecting one’s personality and provides security. In hospice and/or palliative care (PC), the concept of “home” is important to many people in terms of where their care is provided and, for some, also where they actually die. Most people indicate that institutional care beyond an acute illness is a less preferable place of care and that they ideally want to spend as many days as possible at home. Whilst spending as many days at home is desirable, it is not always possible, especially in the context of advanced age, dementia and/or fragility. With the current policy emphasis on supporting people to remain at home, the transition to permanent care typically occurs once all possible options have been exhausted. This policy reform has markedly decreased the average length of residential care stay in the last two decades. If we acknowledge that aged care “is a place of rest for a traveller on an arduous journey,” then we could stop pretending that these permanent care facilities are residents’ homes, and rename, and staff and fund them as hospices. Instigating this level of reform would enable the aged care sector to be reconfigured to provide the type of care that our most vulnerable elders need, that is aged-PC services. Referring to aged care facilities as hospices would also send a clear message to the public as to the role of these facilities and address expectations about the level and type of care they can expect and demand. **Full text:** <https://goo.gl/483CAX>

### Palliative care, end-of-life care, and advance care planning in neuro-oncology

*CONTINUUM*, 2017;23(6):1709-1726. This article provides an overview of the role of palliative care (PC) in neuro-oncology. Management recommendations are made for neurologic symptoms in patients with advanced brain tumors, including headaches, nausea, and fatigue. Special attention is given to how and when to involve subspecialty PC and hospice services to improve symptom management during active tumor treatment and in the end-of-life (EoL) phase of patients with brain tumors. Advance care planning and EoL goals should be addressed early in the disease trajectory; this article provides a road map for these discussions. **Abstract:** <https://goo.gl/PTLiNG>

**N.B.** Additional articles in palliative and end-of-life care in neuro-oncology are noted in the 7 August 2017 issue of *Media Watch* (#524, p.13).

#### Related

- *BMC MEDICAL INFORMATICS & DECISION MAKING* | Online – 6 December 2017 – ‘**Recognizing difficult trade-offs: Values and treatment preferences for end-of-life care in a multi-site survey of adult patients in family practices.**’ Patients need assistance to recognize possible trade-offs among their values and to understand the relationship between their values and their treatment preferences. The results of this study demonstrate a need to improve the processes and tools to support advance care planning. **Full text:** <https://goo.gl/nTwqVK>

### Palliative care in gynecologic oncology

*CURRENT OPINION IN OBSTETRICS & GYNECOLOGY* | Online – 8 December 2017 – Patients with gynecologic malignancies face many difficult issues in the course of their diseases, ranging from physical symptoms to advance care planning in light of a poor prognosis. This review examines the evidence supporting integration of palliative care early in the course of disease and symptom management, and provides a framework for difficult conversations. **Abstract:** <https://goo.gl/MAAHwV>

**N.B.** Additional articles on palliative care in gynecologic oncology are noted in the 14 August 2017 issue of *Media Watch* (#525, p.13).

## **The commodification of care: A critical exploration of the marketing mix for domiciliary care at the end-of-life**

*DUBLIN BUSINESS SCHOOL REVIEW* | Online – Accessed 15 December 2017 – The home care industry has grown exponentially around the world. Within palliative care (PC), the delivery of home care has been promoted as the ideal type of formal care; offering cost savings to local authorities and “choice” for patients and their families. However, there is a dark side to the commodification of home care that is rarely discussed in the marketing literature. The commodification of care obscures the tensions between providing good quality care and making a profit. It also obscures the affective inequalities for patients and care providers. In the discourses of the market we do not see any suffering or vulnerability. One of the problems associated with importing choice into PC services can be explained by the fact that a logic of choice emanates from an economic system of thought which differs from a logic of care... Patients in home care are normally vulnerable people who are “buying” into a service that they desperately need, but not necessarily want. On the other hand, carers are doing a job that they might enjoy to an extent, but that they would not necessarily choose. When these vulnerable groups meet under market conditions there is a tension between “care” and “profit.” Health care policies seem to have not considered the simplistic nature of the language of choice, when using it for home care services. The logic of the market excludes patient’s vulnerability, lack of knowledge, the asymmetric relationship, the dependency and the need for care, as well as his or her varying abilities to make choices... It fails to take account of prior inequalities in power relations, economic and affective resources and differences in cultural values... The logic of the market also seems to have overestimated patients’ willingness to opt for choice in end-of-life care and carers’ possibility to provide good care under market conditions. **Full text (click on pdf icon):** <https://goo.gl/kRirPv>

## **Does access to end-of-life homecare nursing differ by province and community size?: A population-based cohort study of cancer decedents across Canada**

*HEALTH POLICY* | Online – 13 December 2017 – Studies have demonstrated the strong association between increased end-of-life (EoL) homecare nursing use and reduced acute care utilization. However, little research has described the utilization patterns of EoL homecare nursing and how this differs by region and community size. This study examined EoL homecare nursing provision in multiple provinces [i.e., Ontario, British Columbia, and Nova Scotia] across Canada. Results show that differences in the proportion of patients using EoL homecare nursing are much larger between provinces than between community sizes. This suggests that higher-level regional policies and structure are more influential on EoL care delivery than are intra-province differences by community size. In future research, there is great potential for jurisdictions to learn from one another, both in understanding how health care structure may affect care, and in addressing the capacity of communities of different size to provide high-quality EoL care. Full text: <https://goo.gl/TKbkZc>

## **Is social work prepared for diversity in hospice and palliative care?**

*HEALTH & SOCIAL WORK* | Online – 13 December 2017 – The purpose of this article is to assess current and future trends in hospice and palliative care with the objective of informing culturally appropriate best practice for social work. Concern for the intersectionality of racial, ethnic, social, and other differences in end-of-life care (EoLC) is imperative given the ever growing range of diversity characteristics among the increasing aging populations in the U.S. A review of literature from the current decade that is pertinent to the profession contributes to the ability of social work to consider evidence and build agreement germane to end-of-life practice settings. Administrative reports, government data, academic literature, professional standards, and assessment tools contribute to the profession’s ability to work toward cultural competence and develop practice strategies for EoLC. The varied roles held by social workers across health care arenas provide a unique opportunity to promote cultural competence and advance best practice on all levels of work. **Abstract:** <https://goo.gl/ecHzPd>

Cont.

Noted in Media Watch 1 August 2016 (#473, p.14):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2016;12(3):185-194. '**A time and place: The role of social workers in improving end-of-life care.**' With the release of a second Institute of Medicine report devoted to what it means to die in America in the 21st century,<sup>1</sup> momentum and opportunity for change may increase. If this is to happen, social workers will need to deliver the range of bio-psychosocial care that patients and families so desperately need. However, holistic care of the individual will only improve, if the nation also addresses ongoing systemic problems in financing, policy, and service delivery in end-of-life care. **Abstract:** <http://goo.gl/2hrcbo>

1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in 22 September 2014 issue of Media Watch (#376, p.4)] **Download/view at:** <http://goo.gl/mm4o6W>

### **The need for culturally-based palliative care programs for African American patients at end-of-life**

*JOURNAL OF FAMILY STRENGTHS*, 2017;17(1):Article 14. Patients facing life-threatening illness often experience unnecessary and preventable suffering including extreme and prolonged pain, psychological distress, as well as unsatisfactory communication with doctors, all of which result in enormous strain on patients and caregivers... It is common for needs in the physical, psychosocial and spiritual domains to be unmet... As a result, the last few weeks and months of life, and that of their loved ones, may be additionally burdened with physical, emotional and spiritual suffering. Palliative care (PC) programs, interdisciplinary care focused on relief of pain and other symptoms in support of best possible quality of life for patients with serious illness and their families, or consultations with PC experts where such team programs are not available, have been shown to reduce symptoms, alleviate suffering, improve doctor-patient communication and satisfaction with care, improve family satisfaction, and enhance the efficiency and effectiveness of hospital services..., as well as to be associated with hospital cost savings... PC consultations for inpatients have successfully identified unrecognized symptoms and unmet problems..., and have been associated with lower use of ICUs..., lower likelihood of dying in ICU..., lower costs of care..., and improvement in care processes, including medication prescribing and documenting patient goals for care... **Abstract:** <https://goo.gl/HLbi6r>

#### **Related**

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 12 December 2017 – '**Making sense of loss through spirituality: Perspectives of African American family members who have experienced the death of a close family member to cancer.**' Participants [in this study] made sense of the death of their loved one using five themes: 1) Ready for life after death; 2) I was there; 3) I live to honor their memory; 4) God's wisdom is infinite; and, 5) God prepares you and brings you through. These themes are grounded in conceptualizations of spirituality as connectedness to God, self, and others. The authors' findings support the results that even during bereavement, spirituality is important in the lives of African Americans. African American family members might struggle with issues related to life after death, their ability to be physically present during end-of-life care, and disentangling beliefs around God's control over the beginning and ending of life. **Abstract:** <https://goo.gl/L7VT6P>

### **Handling stereotypes of religious professionals: Strategies hospice chaplains use when interacting with patients and families**

*JOURNAL OF PASTORAL CARE & COUNSELING* | Online – 10 December 2017 – Stereotypes of religious professionals can create barriers for those who provide spiritual/pastoral care. Through interviews and journal entries, hospice chaplains identified the following stereotypes that affected their work: chaplains as people whom others try to impress, who only talk about spiritual and religious topics, who are male, and who try to convert others. Participants [in this study] reported using a variety of communication strategies to counteract stereotypes and make meaningful connections with the people they serve. **Abstract:** <https://goo.gl/9nnBgB>

**N.B.** Additional articles on the role of chaplains in palliative and end-of-life care are noted in the 30 October 2017 issue of Media Watch (#536, p.12).



## Medical futility and family obstinacy in intensive therapy. When to stop and when to keep going?

*MEDICINA*, 2017; 2017;77(6):491-496. There have been several recent publications related to therapeutic obstinacy and futility in the intensive care unit. However, little has been published about “the family obstinacy” in persisting with invasive measures in seriously ill patients, despite the appropriate information provided to them about the patient’s poor short-term prognosis. On certain occasions, these critical patients are unable to make decisions on the proposed treatments and, unfortunately, many of them have not previously indicated their preferences in terms of limits to invasive measures (advanced directives). Thus, the patient’s relatives are the ones who finally assume this arduous task and, in several occasions, they make decisions that do not correspond with the patient’s actual wishes. Palliative medicine is of invaluable help in the difficult goal of improving communication among doctors, patients and patients relatives. Limits to intervention can be difficult and vague, generating multiple problems in the decision-making process. On certain occasions and despite adequate information provided by therapists and palliative care doctors, patients’ relatives do not accept professional directives indicating to stop invasive interventions. Understanding futility justification may be relevant to the appropriate resolution of these disputes. **Full text:** <https://goo.gl/kZM1o2>



**N.B.** Spanish language article.

### Related

- *MEDICAL LAW REVIEW* | Online – 13 December 2017 – ‘**Awake and (only just) aware? A typology, taxonomy, and holistic framework for withdrawing clinically assisted nutrition and hydration in the minimally conscious state.**’ Using an analysis of statute, common law and academic commentary, the authors articulate a typology for the elements that tend to engage in these decisions. Next, they construct a taxonomy of overarching legal and ethical issues and then proceed to develop a novel framework for holistic decision-making. The authors validate this on the principle upon which it is grounded: coherent weighting of elements and theoretical proof of concept. The framework has potentially far-reaching benefits that include consistency and transparency of decision-making, thereby enabling a more uniform judicial approach. The authors suggest this as a foundational paradigm for decision-making in this context. **Abstract:** <https://goo.gl/iC1RxS>

## “I’ve no fear of dying alone”: Exploring perspectives on living and dying alone

*MORTALITY* | Online – 13 December 2017 – Dying alone is portrayed as undesirable in terms of policy, health and social care provision, the wishes of family and friends, and in popular culture. Despite this, people do often die alone, both in institutional and domestic settings. This paper reports findings from a study which explored ways of investigating individuals’ perspectives on dying alone at home. For the older people, the idea of dying alone was less problematic than the idea of needing care and support from others, and the perceived loss of independence that this would entail. Participants [in this study] reacted in differing ways to threats to their independence, but all utilised a form of relational reflexivity when considering the effect their actions might have on others. The nurses would prefer no one to die alone, but believed they had seen patients managing their own dying so that they could be alone at the moment of death. The paper suggests that dying alone may be a problem for survivors, rather than for the person who is dying. **Abstract:** <https://goo.gl/4CmtRU>

**N.B.** Additional articles on the potential detrimental effect on health of loneliness and isolation are noted in the 22 May 2017 issue of *Media Watch* (#513, pp.3-4). On a related subject, articles on decision-making for “unbefriended” or “unrepresented” patients are noted in the 18 September 2017 issue of *Media Watch* (#530, p.14).

## **Selling in a dying business: An analysis of trends during a period of major market transition in the [U.S.] funeral industry**

*OMEGA – JOURNAL OF DEATH & DYING* | Online – 13 December 2017 – As a result of recent economic changes in the U.S. and cultural changes among the population, the funeral industry has experienced a “legitimation crisis.” The objective of this research is to examine new advertising and marketing strategies engaged in by professionals in the funeral industry to respond to market and cultural changes that have affected both the funeral industry at large and the role of the funeral director as a participant in this industry. A meta-analysis of articles from issues of the industry trade journal *American Funeral Director* for the years 2008 through 2015 was conducted. Two major themes emerged. First, that funeral home owners should respond to market changes by using their assets for diverse reasons and second that forms of community engagement can create feelings of goodwill that will increase usage and loyalty from families. Within each of these major themes, a variety of sub-themes emerged from the data. **Abstract:** <https://goo.gl/TcMtHq>

## **How is palliative care understood in the context of dementia? Results from a massive open online course**

*PALLIATIVE MEDICINE* | Online – 13 December 2017 – A palliative approach to the care of people with dementia has been advocated, albeit from an emergent evidence base. The person-centred philosophy of palliative care (PC) resonates with the often lengthy trajectory and heavy symptom burden of this terminal condition. Participants [in this study] were found to have a general awareness of PC, but saw it primarily as terminal care, focused around the event of death and specialist in nature. Comfort was equated with pain management only. Respondents rarely overtly linked PC to dementia. A general lack of PC literacy, particularly with respect to dementia, was demonstrated by [study] participants. Implications for dementia care consumers seeking PC and support include recognition of the likely lack of awareness of the relevance of PC to dementia. **Abstract:** <https://goo.gl/aJZimJ>

### **Related**

- *PALLIATIVE MEDICINE* | Online – 13 December 2017 – ‘**Needs of people with advanced dementia in their final phase of life: A multi-perspective qualitative study in nursing homes.**’ Data analysis generated a total of 25 physical, psychosocial, and spiritual needs divided into 10 categories. Physical needs were classified as: “food intake,” “physical well-being,” and “physical activity and recovery.” Categories of psychosocial needs were classified as: “adaptation of stimuli,” “communication,” “personal attention,” “participation,” “familiarity and safety,” as well as “self-determination.” Spiritual needs addressed “religion.” The results reveal a multitude of key aspects for recognizing and meeting these needs, stressing the importance of personhood. **Abstract:** <https://goo.gl/Fcb5pj>

Noted in Media Watch 20 November 2017 (#539, p.3):

- U.S. (Minnesota) | *RAC Monitor* (St. Paul) – 16 November 2017 – “**Oh God, I have lost myself”: Palliative care and Alzheimer’s dementia.**’ Those stricken with Alzheimer’s dementia (AD) die twice. First, they experience the death of who they are. This death of self is more frightful than the death of their body. A terminal diagnosis of AD is fraught with obstacles for those who want to control the way they die or family members who want to intervene with palliative care. Dementia kills slowly, frequently over a span of years, and unlike many terminal medical processes, there isn’t a plug to pull – there is no life support to discontinue, no chemotherapy to stop, and no dialysis to terminate. **Full text:** <https://goo.gl/qMa9mh>

**N.B.** Additional articles on palliative and end-of-life care for people living with Alzheimer’s and other forms of dementia are noted in the 21 August 2017 issue of Media Watch (#526, p.15).

## **Dying persons' perspectives on, or experiences of, participating in research: An integrative review**

*PALLIATIVE MEDICINE* | Online – 13 December 2017 – Conducting research with dying persons can be controversial and challenging due to concerns for the vulnerability of the dying and the potential burden on those who participate with the possibility of little benefit. Analysis [of the literature] revealed four themes: 1) Value of research; 2) Desire to help; 3) Expression of self; and, 4) Participation preferences. Understanding dying persons' perspectives of research participation will enhance future care of dying persons. It is essential that researchers do not exclude dying persons from clinically relevant research due to their prognosis, fear or burden or perceived vulnerability. The dying should be afforded the opportunity to participate in research with the knowledge it may contribute to science and understanding and improve the care and treatment of others. **Abstract:** <https://goo.gl/BPTqJT>

**N.B.** Additional articles on research priorities in palliative and end-of-life care are noted in the 11 December 2017 issue of *Media Watch* (#542, p.12).

## **How should we talk about palliative care, death and dying? A qualitative study exploring perspectives from caregivers of people with advanced cancer**

*PALLIATIVE MEDICINE* | Online – 13 December 2017 – This study is among the first to directly address caregiver perspectives of communication about death, dying and the introduction to palliative care (PC). The recommendations derived from caregiver perspectives build upon existing guidelines and offer health professionals some preliminary considerations around how to undertake these important communication tasks in future. Caregivers [i.e., study participants] reported wanting routinely available written resources about (PC), supplemented by conversations that are ideally staged overtime. Education about the tasks of PC should be separated from referral process, allowing time for gradual adjustment, and re-visiting discussion to enable patients and families to take some control in the process of transition. Once death is imminent, carers wanted health professionals to clarify how much they want to know about the dying process; provide spoken acknowledgement when death is close; include the words “death” and “dying”; use direct language, avoiding euphemisms; and communicate about death with patient present. **Abstract:** <https://goo.gl/QJXrFz>

### **Related**

- *PATIENT EDUCATION & COUNSELING* | Online – 11 December 2017 – ‘**Affective science and avoidant end-of-life communication: Can the science of emotion help physicians talk with their patients about the end of life?**’ Despite believing end-of-life (EoL) discussions with patients are important, doctors often do not have them. Multiple factors contribute to this shortfall, which interventions including reimbursement changes and communication skills training have not significantly improved to date. One commonly cited but under-researched reason for physician avoidance of EoL discussion is emotional difficulty. High occupational demand for frequent difficult discussions may overload physicians' normal emotional functioning, leading to avoidance or failure. The authors propose that cognitive, behavioral, and neuroscience evidence from affective science may offer helpful insights into this problem. **Abstract:** <https://goo.gl/YVNkAa>

## **Participation and interest in support services among family caregivers of older adults with cancer**

*PSYCHO-ONCOLOGY* | Online – 11 December 2017 – A large proportion of family caregivers (i.e., survey respondents), including those experiencing depression and anxiety symptoms and who were under-prepared, are not using formal support services. Being interested in support services was significantly associated with being a minority, shorter durations of caregiving, and with higher stress burden. Strategies to increase service use may include targeting distressed caregivers early in their caregiving experience. **Abstract:** <https://goo.gl/GsDLZz>

**N.B.** Additional articles on carer's support networks are noted in the 9 October 2017 issue of *Media Watch* (#533, p.12).

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS*, 2018;27(1):145-153. **'Fear of life, fear of death, and fear of causing death: How legislative changes on assisted dying are doomed to fail.'** Fear of life, fear of death, and fear of causing death form a combination that prevents reasoned changes in laws concerning end-of-life (EoL) situations. Prevalent fears are explicated and interpreted to see how their meanings differ depending on the chosen normative stance. When the meanings have been clarified, the impact of the fears on the motivations and justifications of potential legislative reforms are assessed. Two main normative stances are evoked. The first makes an appeal to individual self-determination, or autonomy, and the second to the traditional professional ethics of physicians. These views partly share qualifying elements, including incurability and irreversibility of the patient's medical condition, proximity of death, the unbearable nature of suffering, and issues of voluntariness further shade the matter. The conclusion is that although many motives to change EoL laws are admirable, they are partly contradictory, as are calls for autonomy and appeals to professional ethics; to a degree that good, principled legislative solutions remain improbable in the foreseeable future. **Abstract:** <https://goo.gl/y1efhN>
- *CANADIAN JOURNAL OF PSYCHIATRY* | Online – 7 December 2017 – **'Medical assistance in dying and mental health: A legal, ethical, and clinical analysis.'** Medical assistance in dying (MAiD) legislation is over a year old in Canada, and consideration is turning to whether MAiD should be extended to include serious mental illness as the sole qualifying condition for being eligible for MAiD. This article considers this question from ethical and clinical perspectives. It argues that extending the eligibility for MAiD to include those with a serious mental illness as the sole eligibility criterion is not ethical, necessary, or supported current psychiatric practice or opinion. **Abstract:** <https://goo.gl/KdNJBx>
- *HEALTH REFORM OBSERVER* | Online – 11 December 2017 – **'The right to die: Legalizing medical assistance in dying in Canada: A provincial/territorial health reform analysis.'** In June of 2016, the federal government passed legislation that amended the Criminal Code to permit eligible adults to request and receive medical assistance in dying (MAiD). The new legislation explicitly discusses the need for a pan-Canadian system to collect data, monitor trends, and deliver information on implementation of MAiD to the public. Furthermore, the law requires the federal Minister of Health to put any necessary regulations in place to establish systems for monitoring requests for and provision of MAiD. This process was initiated in the fall of 2016 through a forum discussion hosted by the Canadian Institute for Health Information. Regulations for the establishment of the federal monitoring system are currently underdevelopment, and are expected to come into force in 2018. However, significant work remains to be done. Developing these systems in a timely manner will be a pressing challenge for all governments moving forward. **Full text:** <https://goo.gl/FJzwXV>
- *JOURNAL OF BIOETHICAL INQUIRY* | Online – 11 December 2017 – **'Knowing, anticipating, even facilitating but still not intending: Another challenge to double effect reasoning.'** A recent administrative law decision in Victoria, Australia, applied double effect reasoning in a novel way. Double effect reasoning has hitherto been used to legitimate treatments which may shorten life but where the intent of treatment is pain relief. The situation reviewed by the Victorian tribunal went further, supporting actions where a doctor agrees to provide pentobarbitone (Nembutal) to a patient at some time in the future if the patient feels at that time that his pain is unbearable and he wants to end his life. The offer to provide the drug was described as a palliative treatment in that it gave reassurance and comfort to the patient. Double effect reasoning was extended in this instance to encompass potentially facilitating a patient's death. This extension further muddies the murky double effect reasoning waters and creates another challenge to this concept. **Abstract:** <https://goo.gl/EBkSdA>

## Journal Watch

### Survey on open peer review: Attitudes and experience amongst editors, authors and reviewers

*PLOS ONE* | Online – 13 December 2017 – Traditional peer review is generally: 1) Anonymous, with either the reviewer unknown to the author (single-blind review) or both author and reviewer unknown to each other (double-blind review); 2) Selective, with reviewers selected by editors; and, 3) Confidential, with neither the review process nor the reviews themselves made public. This model has long been recognized to have significant flaws, accused of being unreliable (by, e.g., failing to detect errors or demonstrating inconsistency between reviewer reports), taking too long (i.e., delaying times between submission and publication), being unaccountable and enabling social and publication biases, lacking in incentive for reviewers, and being wasteful of effort (as the same manuscript may be reviewed many times as it goes through cycles of submission and rejection). In response to these criticisms, a wide variety of changes to peer review have been suggested... Amongst these innovations, many have been labelled as “open peer review” (OPR) at one time or another. These innovations .... in fact encompass a wide variety of discrete ways in which peer review can be “opened up.” **Full text:** <https://goo.gl/Aoj2yg>

#### Related

- *JOURNAL OF RESEARCH PRACTICE*, 2017;13(2):V2. ‘**Doing peer review: Reflections from an international group of postdoctoral fellows.**’ The authors offer their reflections on how to get the most out of doing peer reviews as a trainee researcher. They touch upon the variety and complexity of peer reviews, the debates concerning the nature and validity of peer reviews, the issue of conflict of interest, the menace of predatory journals, but also the potential gain from doing peer reviews. **Full text:** <https://goo.gl/7pMkFN>

### New feature aims to draw journals into post-publication comments on PubPeer

RETRACTION WATCH | Online – 12 December 2017 – When a paper is challenged on PubPeer, is a journal paying attention? A new feature recently unveiled by the site makes it easier to find out. The Journal Dashboards allow journals to see what people are saying about the papers they published, and allows readers to know which journals are particularly responsive to community feedback. <https://goo.gl/LW4hyb>

### When authors get caught in the predatory (illegitimate publishing) net

THE SCHOLARLY KITCHEN | Online – 11 December 2017 – Are we losing good articles to predatory journals, with little recourse for unsuspecting authors? Or are authors becoming increasingly complicit and symbiotic in their relationships with illegitimate publishing entities with disregard for the greater good? Maybe it’s both. Predatory publishing can no longer be called an aberration or a fly in the chardonnay of scholars. In less than ten years, it has wreaked havoc on unsuspecting researchers and academics... But what happens when – and what are the ethics surrounding – an author accidentally submitting to a predatory journal, realizing the error, then trying to submit to a legitimate academic journal? The Committee on Publication Ethics posted advice in 2016 based on specific case.<sup>1</sup> An author received an invitation and submitted a paper without realizing the journal was predatory in nature. When she realized her error, she asked the journal to remove the article from its website. Despite her reticence to sign a copyright form or pay the publication fees, it remained published on the website, therefore hindering her from submitting to a quality scholarly journal – as it would constitute duplicate publication. After explaining the situation to the editor in chief of the legitimate journal, the submission was permitted. <https://goo.gl/oAVFHJ>



1. ‘Withdrawal of accepted manuscript from predatory journal,’ (Case 16-22), Committee on Publication Ethics, 2016. <https://goo.gl/DWNQ1b>

Cont.

## Related

- COLLEGE & RESEARCH LIBRARIES NEWS, 2017;78(11):603. 'Open access, power, and privilege: A response to 'What I learned from predatory publishing.' While predatory publishing is a problem, it's actually an information literacy problem for which we currently have the knowledge and skills to address. We should acknowledge that librarianship and publishing participate in social and political power structures and narratives, and we should challenge any structure that perpetuates discrimination. While we wrestle through the complicated issues that arise in the course of this work, we need to affirm that both academic freedom and human dignity have a place in the scholarly conversation, and we must to do a better job practicing them in concert. **Full text:** <https://goo.gl/qMdkzx>

1. 'What I learned from predatory publishers,' *Biochemia Medica*, 2017;27(2):273-279. [Noted in the 19 June 2017 issue of Media Watch (#517, p.7)] **Full text:** <https://goo.gl/TknXDS>

**N.B.** Additional articles on predatory journals are noted in the 5 June and 19 June 2017 issues of Media Watch (#515, p.6 and #517, p.7, respectively). The issue of *Biochemia Medica* cited includes several articles on predatory journals. **Journal contents page:** <https://goo.gl/GZLYvu>.

## [Media Watch: Online](#)

### International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/m9u1bB>

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

PALLIATIVE CARE NETWORK-e: <http://goo.gl/8JyLmE>

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

[Scroll down to 'Aggregators' and 'Media Watch by Barry Ashpole']

### Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/XO4mD>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <https://goo.gl/JL3j3C>

### Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLqxy2>  
[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | Acclaim Health (Palliative Care Consultation): <https://goo.gl/wGi7BD>  
[Scroll down to 'Additional Resources']

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

ONTARIO | Mississauga Halton Palliative Care Network: <https://goo.gl/ds5wYC>  
[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

### Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W>  
[Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Magyar Hospice Alapítvány: <http://goo.gl/5d1I9K>

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

### 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.

### Links to Sources

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