

## 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.

20 November 2017 Edition | Issue #539



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**Public health approach to palliative care: Scroll down to [Specialist Publications](#) and 'What is the role of community at the end of life for people dying in advanced age? A qualitative study with bereaved family carers' (p.15), in *Palliative Medicine*.**

## Canada

### Science must be the guiding factor when diagnosing brain death

ONTARIO | CBC News (Toronto) – 16 November 2017 – Ontario courts have ordered artificial breathing machines remain attached to Taquisha McKitty and Shalom Ouanounou after their families launched legal challenges in order to prolong treatment. Both families have claimed that their loved ones are not dead by their respective religions' definitions of death. Teams of doctors in each case, however, have established irreversible death of the brain, which means that medically speaking, McKitty and Ouanounou are gone. The courts are nevertheless being asked to reaffirm decades of science, medicine and ethics, while also weighing the value of religious belief. But medical expertise must be the guiding principle here: brain death is certain death. Traditionally, death was diagnosed by doctors when the heart ceased to beat. But the heart has a "cruise control" feature – automaticity – that forces cardiac contraction 70 times each minute; a heart can go on beating so long as there is oxygen delivered to the lungs. With advances in technology, mechanical respirators can theoretically sustain a heartbeat indefinitely, as is being done in these two cases. Evolutions in medicine have led to the development of criteria to diagnose death while the heart is artificially supported. First in 1968, and most recently in 2006, expert guideline dictate when a brain is known to have irreversibly ceased functioning. These neurological criteria for death, which determine the loss of consciousness, brain stem function and the ability to breathe, dictate when a doctor can declare brain death and have been entrenched in law around the world. <https://goo.gl/9TACZ9>

**N.B.** Recent news media coverage on the McKitty and Ouanounou cases is noted in the 13 November 2017 issue of Media Watch (#538, pp.1-2).

Noted in Media Watch 4 September 2017 (#528, p.9):

- *JOURNAL OF MEDICAL ETHICS* | Online – 28 August 2017 – **'Do the "brain dead" merely appear to be alive?'** The established view regarding "brain death" in medicine and medical ethics is that patients determined to be dead by neurological criteria are dead in terms of a biological conception of death, not a philosophical conception of personhood, a social construction or a legal fiction. Although such individuals show apparent signs of being alive, in reality they are (biologically) dead, though this reality is masked by the intervention of medical technology. **Full text:** <https://goo.gl/LhrX3f>

**N.B.** Additional articles on defining "brain dead" are noted in this issue of Media Watch and also in the 23 May 2016 issue of the weekly report (#463, p.14).

## Faith-based health care should end with Saskatchewan's health region amalgamation

SASKATCHEWAN | CBC News (Saskatoon) – 14 November 2017 – There are at least five Catholic-run hospitals in Saskatchewan. They all receive public funding to provide a public service, yet are permitted to deny citizens their right to reproductive health care. Now, they are refusing to provide medically assistance dying, too. Some publicly funded faith-based care homes are also refusing to assist with medically assisted dying. This begs the question: Why are we still allowing publicly funded, faith-based organizations to run health-care facilities when they unabashedly discriminate in the health care they provide? The health care being denied to citizens at Catholic-run hospitals are rights that have been fought for and won through the courts on the basis that such health care is to be provided to all citizens, free of discrimination. In the cases of reproductive health and medically as-

sistance dying, the Supreme Court of Canada ruled that access to these health services are fundamental to a person's security and liberty – and, further, that these rights cannot be denied on the basis of sex or disability. Despite this, faith-based institutions in Saskatchewan remain unabated and publicly funded. The only institutional palliative care unit within the current Saskatoon Health Region is located in St. Paul's Hospital. <https://goo.gl/Es9cq3>

### [Specialist Publications](#)

**'Palliative medicine: Becoming a subspecialty of the Royal College of Physicians & Surgeons of Canada'** (p.13), in *Journal of Palliative Care*.

Noted in Media Watch 26 June 2017 (#518, p.2):

- BRITISH COLUMBIA | *The Times Colonist* (Victoria) – 23 June 2017 – **'Vancouver Island Health opts to move Comox hospice beds to secular facility.'** The Comox Valley's four hospice beds are hosted in Hospice at the Views, which is run by St. Joseph's General Hospital. As a faith-based facility, it does not allow assisted dying. Those four beds, as well as two new ones, will be located together in a different location. <https://goo.gl/se2Jv6>
- MANITOBA | *The Winnipeg Free Press* – 21 June 2017 – **'The beliefs of some, paid for by all.'** St. Boniface Hospital landed in a political firestorm after the Catholic Health Corporation of Manitoba took the controversial step of reconfiguring the hospital's board after passage of a motion to allow medically assisted death under "rare circumstances" forcing a re-vote that effectively bans assisted dying at the hospital – which, ironically, is the province's primary palliative care centre. <https://goo.gl/C9GyCM>

Noted in Media Watch 3 October 2016 (#482, p.2):

- ALBERTA & NORTH WEST TERRITORIES | CBC News (Edmonton) – 29 September 2016 – **'Alberta, Northwest Territories bishops issue guidelines that refuse funerals in assisted-death cases.'** The Catholic Bishops of Alberta and the Northwest Territories have issued guidelines that say priests should refuse funerals for some people who die by assisted suicide. In the guidelines the bishops are careful to draw a distinction between suicide and assisted suicide.<sup>1</sup> <https://goo.gl/3RPXox>
  1. 'Guidelines for the Celebration of the Sacraments with Persons and Families Considering or Opting for Death by Assisted Suicide or Euthanasia,' Roman Catholic Bishops of Alberta & Northwest Territories, September 2016. **Download/view at:** <https://goo.gl/2YNfnA>
- ONTARIO | *The Ottawa Citizen* – 27 September 2016 – **'Patients must be transferred out of Catholic hospitals to discuss assisted dying.'** Patients are being discouraged from even having conversations about assisted death within Catholic hospitals, according to draft guidelines that the Catholic Health Association of Ontario says it believes comply with assisted dying legislation. Instead, patients who request assisted death will be transferred off-site for consultation. <https://goo.gl/ZLGUCv>

## U.S.A.

### “Oh God, I have lost myself”: Palliative care and Alzheimer’s dementia

MINNESOTA | RAC Monitor (St. Paul) | Online – 16 November 2017 – The course of Alzheimer’s dementia (AD) is a prolonged, inexorable slide towards death, which can make meeting the six-month hospice benchmark [difficult. It is hard to predict when an AD patient will die. There is also a more terrifying aspect of AD that cancer patients [for example] do not experience. As humanly horrible as a cancer death can be, it is only a single death. Those whose lives have been invaded by malignancy remain themselves – perhaps in pain, but sentient of who they are, who loves them, and who they love, until the end. Those stricken with 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. It is harrowing to contemplate losing one’s identity, control of one’s life, the ability to care for loved ones, and instead becoming a burden to them. At this moment, an estimated 5.5 million people are living with AD. 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 (PC). 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. The role of PC in dementia remains the same as in every terminal illness: prevent unnecessary suffering of the patient and their loved ones. The protracted courses of AD and the inevitable loss of patient competency make early planning especially crucial. Simply put, the PC plan must be devised not at the end stages of the dementia, but in the beginning, before the patients “lose themselves.” **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).

### Dignity, death and America’s crisis in elder care

*TIME MAGAZINE* | Online – 16 November 2017 – From senior living centers to hospice, the country is struggling to adapt a rickety system to handle the demographic wave that is crashing over it. At stake are the health, wealth and dignity of a generation. The existing safety net for older Americans – a mixture of Social Security, Medicare and Medicaid – was built for a society that no longer exists. When Congress created Social Security in 1935, the average life expectancy in the U.S. was 61; now it is nearly 80. When Congress created Medicare and Medicaid in 1965, it was still common for people to die of acute medical issues, like heart attacks; now many survive those traumas and go on to live, with some assistance, for decades longer. In 1960, the U.S. was overwhelmingly young: just 10% of the population was over 65. By 2040, 1

in 5 of us will be eligible for that senior ticket at the theater. As more people live longer, the social and economic systems designed to care for them are changing. At stake the health, wealth and dignity of a generation. <https://goo.gl/irzkT3>

#### Extract from *Time Magazine* article

Hospice care, beloved by many, is seen as a potential profit center by companies seeking government contracts while providing diminished service to those at the end of their lives. And Medicaid, once intended to be a last-ditch safeguard for the poorest of the poor, is creaking under the weight of new obligations. Medicaid is now the default payer for 61% of all nursing-home residents in the U.S.



#### 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.19.

## Learning to care for dying's forgotten

THE CONVERSATION | Online – 14 November 2017 – In most U.S. medical schools, lessons about death naturally focus on the care of the dying patient. But there is another group of people to whom health professionals need to learn to attend: the dying patient's family and friends. In nearly every case, mortality's collateral damage reaches more widely and endures longer than the patient's travails, which cease at the moment of death. Our preoccupation with the dying patient is not difficult to understand. For one thing, medical students are taught to put the patient first, which means others come second. Moreover, revenues and quality measures in health care revolve around the patient. As a result, grieving family and friends may languish in neglect, particularly in the weeks and months after a patient has died. Consider these words of the daughter of a deceased elderly patient I know. "The whole time Dad was in the intensive care unit, the doctors and nurses seemed more interested in the machines than in us. When they talked to us, it was always because a medical

decision had to be made. They never asked us how we were doing. After Dad died, we never heard from them or the hospital again." Such complaints are not rare, in part because death is such a ubiquitous fact of daily life. About 2.6 million Americans die every year, which works out to an average of 7,200 deaths per day and 300 deaths per hour. If people were dying at home, health professionals might have little opportunity to care for the grieving, but 63% of Americans die in hospitals and another 17% in chronic care facilities. <https://goo.gl/D2AD5n>

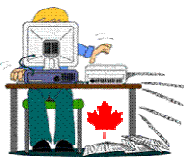
### Specialist Publications

'Development, implementation, and evaluation of a curriculum to prepare volunteer navigators to support older persons living with serious illness' (p.9), in *American Journal of Hospice & Palliative Medicine*.

## Families turn to death midwives for help with final passage

WISCONSIN | *Wisconsin News* (Madison) – 12 November 2017 – Before Valli Warren's husband died last year after a long illness, the Stoughton couple knew they wanted a home funeral and green burial. But they weren't sure how to make those things happen. They turned to Sharon Stewart, who delivered ice packs to preserve the body, shared videos about how to wrap it in a shroud and taught pallbearers how to carry it out of the house on a board. Stewart also helped Warren file paperwork, including a permit letting her transport her husband to Circle Cemetery, near Barneveld, where he was laid to rest without being embalmed or using a casket or vault. Stewart is a death midwife, a new kind of occupation that provides emotional, spiritual and practical support to families before and after death – in addition to, or instead of, hospice care and funeral homes. The service, which has emerged around the country over the past decade, is analogous to what birth midwives do compared to obstetricians. Some who offer the assistance call themselves death doulas or end-of-life midwives. <https://goo.gl/QukeqU>

**N.B.** Selected articles on "death doulas" or "end-of-life midwives" are noted in the 18 September 2017 issue of *Media Watch* (#530, p.5).



### 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

### Bereavement benefits for U.K. families

#### **Freedom of Information request reveals bereaved children are “effectively invisible” to government**

U.K. (England) | *The London Economic* – 17 November 2017 – Just seven months after the government cut the benefits available to bereaved U.K. families, a Life Matters task force has revealed that there is no central record of the number of children affected by the bereavement of a parent. The alarming revelation comes as a result of an Freedom of Information request asking for the number of children bereaved of a parent in the U.K., to which both the General Register Office and the Department of Work & Pensions stated: “The information is not held by the department.” This information has been released by the Life Matters task force, which was brought together by comparethemarket.com in April 2017 in response to the significant changes to bereavement benefits. The changes will leave

75% of U.K. families affected by bereavement worse off financially than they would have been under the old system, with the average working widowed parent losing out on over £12,000. Today, in response to this new information, the task force is introducing its recommendations for policymakers on how best to support those affected by bereavement – both emotionally and financially. <https://goo.gl/VHJKM9>

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

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

**N.B.** Life Matters task force. <https://goo.gl/zBnc1C>

#### **We urgently need to tackle inequalities in end-of-life care in Wales**

U.K. (Wales) | Click on Wales (Cardiff) – 16 November 2017 – It is a sad reality that many people with life-limiting conditions are missing out on vital care that could transform the precious time they have left and also help support their families. This is partly because of socio-cultural resistance to talking openly about death and dying, and also due to a complex interaction of demographic factors that mean some groups in society do not have equal access to expert palliative care (PC). Earlier research ... shows that across the U.K. as a whole 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 (EoL), 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. However, we know that at least 24,000 people each year could benefit from some form of hospice or (PC). Around half of these people will be supported by hospices and others will be supported by their GP or specialists in the National Health Service. However, there will be a significant number of people who are not given access to the appropriate care that could support them at the EoL. 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>

**iwa**

Sefydliad Materion Cymreig  
Institute of Welsh Affairs

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>

## U.K. banker being kept alive against wishes of family and doctors

U.K. (England) | *The Guardian* (London) – 15 November 2017 – An investment banker who sustained severe brain damage after a cardiac arrest is being kept alive against the wishes of his family and doctors because the official solicitor has intervened to prevent his death. The unusual case, which is likely to be referred to the supreme court for an emergency hearing, tests whether relatives and medical staff must seek judicial permission before life-support treatment is withdrawn. Mrs. Justice O’Farrell ruled in the high court that the court of protection does not need to be consulted in such cases where clinicians and the patient’s family agree that it is not in the best interests of the patient to be kept alive in a coma. However the judge anticipated that the official solicitor would appeal against her decision. <https://goo.gl/f6oGvt>

## Review of targets and indicators for health and social care in Scotland: End-of-life care

U.K. (Scotland) | Convention of Scottish Local Authorities (Edinburgh) – 15 November 2017 – Palliative and end-of-life care (P&EoLC) are often grouped together. Here palliative care (PC) is understood to mean the provision of good care to people whose health is in irreversible decline, with any illness or condition, whose lives are coming to an inevitable close; they may continue to live life well, with their symptoms alleviated through good care for a period which may extend for months or even years. The care provided includes but is not limited to specialist PC. PC includes, but is not limited to end-of-life care, which is about supporting people as they enter the process of dying. At present, the indicator for improved P&EoLC is the proportion of the last six months of life spent at home or community setting. This indicator says little about the quality of care. In December 2015, the Scottish Government published the Strategic Framework for Action on Palliative & End-of-Life Care.<sup>1</sup> It sets out a vision for the next five years, outcomes and ten commitments to support improvements in the delivery of P&EoLC across Scotland. **Download/review report at:** <https://goo.gl/ytz8c7>



1. ‘Strategic Framework for Action on Palliative & End-of-Life Care,’ Scottish Government, December 2015. [Noted in the 21 December 2015 issue of Media Watch (#441, p.8)] **Download/view at:** <http://goo.gl/CKePjU>

Noted in Media Watch 25 September 2017 (#531, p.8):

- U.K. (Scotland) | *The Evening Times* (Glasgow) – 19 September 2017 – **‘One in four terminally ill Scots are not getting the end-of-life care they need.’** One in four terminally ill people are not getting the care they need. Marie Curie, which runs a hospice in Glasgow and one in Edinburgh, as well as providing care and support services across Scotland, said a lack of specific funding for end-of-life care has caused a gap in services. In a response to the Scottish Parliament Health & Sport Committee it said there are 56,000 people who die every year in Scotland and it is estimated that 46,000 of those will need some sort of palliative care. <https://goo.gl/MVDLrP>

Noted in Media Watch 7 August 2017 (#524, pp.5-6):

- U.K. (Scotland) | *The Scotsman* (Edinburgh) – 2 August 2017 – **‘Scotland in top 10 countries for palliative care.’** Scotland is in the top ten countries in Europe for levels of palliative care (PC), although a new study has said there remains “room for improvement.”<sup>1</sup> There are 23 specialist PC inpatient units in Scotland, containing a total of 349 beds. In addition, there are 27 specialist PC hospital support teams and 38 specialist PC home care teams. Relative to other European Union countries, Scotland ranked seventh for provision of specialist PC inpatient units and hospital support teams, and fifth for home care teams. Statistics for Scotland had only been included with U.K. data before, but the Scottish Atlas of Palliative Care ... means more detailed information is available.<sup>2</sup> <https://goo.gl/6xxSuT>

1. ‘The level of provision of specialist palliative care services in Scotland: An international benchmarking study,’ *BMJ Supportive & Palliative Care*, published online 2 August 2017. **Full text:** <https://goo.gl/vDU2L5>.
2. ‘Scottish Atlas of Palliative Care,’ End-of-Life Studies Group, University of Glasgow, September 2016. [Noted in the 26 September 2016 issue of Media Watch (#481, p.4)] **Download/view at:** <https://goo.gl/Sf3DCy>

## End-of-life care in Ireland

### ***Palliative Care Services Three Year Development Framework (2017-2019)***

IRELAND | Health Service Executive (Dublin) – 14 November 2017 –



The objective of the Framework was to inform and direct the development of adult palliative care (PC) services, both generalist and specialist, in Ireland for the three-year period. In so doing, the focus of the Framework was to identify the gaps that exist in the current level of service provision and to present a set of recommendations and actions which over the duration of the Framework (and at times beyond) would seek to address these service issues/deficits, subject to available resources. In order to achieve this objective a Steering Group, with representation from the key stakeholders in PC, both statutory and voluntary, was appointed, and assigned the task of overseeing the project. **Download/view at:** <https://goo.gl/CGRdoq>

**N.B.** Selected articles, etc., on end-of-life care in Ireland are noted in the 17 July 2017 issue of Media Watch (#521, p.14).

### **From glimpses of heaven to revealing their secret regrets, nurses describe the heart-wrenching last words of dying patients**

U.K. (England) | *The Daily Mail* (London) – 13 November 2017 – Nurses who care for the terminally ill have revealed the heart-wrenching last words of terminally ill patients before they die, including their biggest regrets, fears and witnessing glimpses of heaven. Macmillan palliative care nurses at Royal Stoke University Hospital in Stoke-on-Trent, Staffordshire, say patients often wish to see their beloved pet one last time, while others simply request a cup of tea. One nurse described how an unwell couple asked for their beds to be pushed together before dying within 10 days of each other. Many patients' last words include them complaining life is too short and regretting they spent their hard-earned retirement in ill health. Previous research from the University of North Carolina found the terminally ill and those on death row are more positive than might be expected, with many calling on family and religion to ease the anxiety of their passing.<sup>1</sup> <https://goo.gl/VWsyvi>

1. 'Dying is unexpectedly positive,' *Psychological Science*, published online 1 June 2017. [Noted in the 5 June 2017 issue of Media Watch (#515, p.2)] **Abstract:** <https://goo.gl/uekQfg>

## End-of-life care in England

### **End-of-life care for terminally ill children slammed as “patchy and inconsistent”**

U.K. (England) | *The Daily Mirror* (London) – 11 November 2017 – Palliative care (PC) for tens of thousands of terminally ill children has been slammed as “patchy and inconsistent” by a leading charity.<sup>1</sup> While 93% of National Health Service clinical commissioning groups (CCGs) commission community children's nursing teams, just two thirds commission them to provide care out of hours and at weekends. If this support is not in place, families say they have to call an ambulance or go to accident and emergency departments. The government says children should be cared for at home with the support of community of services where possible. But new research seen by the BBC's 'Radio 5 live Investigates' programme shows that only a third of CCGs in England are implementing this.<sup>2</sup> The charity Together for Short Lives submitted

Freedom of Information requests to every CCG in England asking what services they commission for children who need PC. It is estimated there are 40,000 children ... living with life-limiting and life-threatening conditions in England alone. <https://goo.gl/X2pfuw>

#### **Specialist Publications**

**'Risk and resilience factors related to parental bereavement following the death of a child with a life-limiting condition'** (p.11), in *Children*.

**'Two futures: Financial and practical realities for parents of living with a life-limited child'** (p.11), in *Comprehensive Child & Adolescent Nursing*.

Cont.

1. 'Commission Children's Palliative Care in England,' Together for Short Lives, November 2017. **Download/view background information at:** <https://goo.gl/bvWdap>
2. 'Children's Palliative Care,' Radio 5-live Investigates, BBC, 12 November 2017. <https://goo.gl/xhSM3G>

Noted in Media Watch 18 September 2017 (#530, p.7):

- U.K. (England, Northern Ireland, Scotland, Wales) | BBC News – 12 September 2017 – **“Postcode lottery” for dying children’s care, report finds.** The Institute for Policy Research says 49,000 children have life-limiting or life-threatening conditions in the U.K.<sup>1</sup> According to children’s charity Together for Short Lives seriously ill children are “being forgotten or ignored.” Only 73% of clinical commissioning groups provide palliative children’s nursing out-of-hours and at weekends, meaning children have to go into hospital rather than be treated in the community. <https://goo.gl/Gdm3tC>
  1. 'Death, Dying & Devolution,' Institute for Policy Research, University of Bath, September 2017. **Download/view at:** <https://goo.gl/FHj7oU>
- U.K. (England) | National Institute for Health & Care Excellence – 12 September 2017 – **‘End-of-life care for infants, children and young people, September 2017.’** This quality standard, endorsed by National Health Service England, covers end-of-life care for infants, children and young people ... who have a life-limiting condition. Life-limiting conditions are those that are expected to result in an early death for the person. It also covers support for family members and carers. It describes high quality care in priority areas for improvement. **Download/view report at:** <https://goo.gl/a3gLi4>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (New South Wales) | ABC News (Sydney) – 16 November 2017 – **‘Euthanasia debate: New South Wales parliament rejects bill on voluntary assisted dying.’** With 19 voting in support but 20 against, the result came down to the wire. MPs were given a conscience vote on the legislation, with many emotional pleas made for and against euthanasia. The conditions in the assisted dying legislation: 1) Proposed patients must be over the age of 25 and would be expected to die within 12 months due to their illnesses; 2) They must be assessed by a psychologist or psychiatrist and have their decision signed off on by two medical practitioners, including a specialist; and, 3) Close relatives can challenge patient eligibility in the Supreme Court. <https://goo.gl/XYCUno>
- AUSTRALIA (Victoria) | *Lexology* – 15 November 2017 – **‘Update to proposed Victorian assisted dying legislation.’** The Victorian State Government has agreed to a number of amendments to its Voluntary Assisted Dying Bill, in order to ensure that the bill passes the Senate. Under the current bill, adults suffering from a terminal illness who are expected to live less than 12 months would be able to access lethal drugs. However, under the agreed changes the required expected life expectancy has been reduced to six months, unless the person is suffering from a neurodegenerative condition, in which case it remains at 12 months. The changes also increase the funding for palliative care in regional and rural Victoria, restrict eligibility to those who have lived in Victoria for at least 12 months,, and require that the person’s cause of death include reference to the assisted dying. A final vote could be held in the Senate... If the amendments are passed, the bill will be sent back to the Lower House for ratification. <https://goo.gl/YiMYno>
- U.K. | *The Jurist* – 13 November 2017 – **‘U.K. law prohibiting assisted dying negatively impacts terminally ill: Report.’** The U.K. is outsourcing those who want assistance with dying to Switzerland, according to a study<sup>1</sup> ... by the non-profit organization Dignity in Dying, but the price limits those who can afford to take such measures. The study found that more than half of citizens would consider traveling to Switzerland for assistance dying, but only a quarter could actually afford the average cost of €10,000. In October the High Court of Justice a terminally ill individual’s petition for assistance to die, thereby upholding the Suicide Act 1961, which makes it illegal to assist in suicide. The court ruled that the act was necessary “to protect the weak and vulnerable.” <https://goo.gl/ER3dS2>
  1. 'The True Cost: How the U.K. outsources death to Dignitas,' Dying with Dignity, November 2017. **Download/view at:** <https://goo.gl/Pr2LfV>



## Specialist Publications

### **Development, implementation, and evaluation of a curriculum to prepare volunteer navigators to support older persons living with serious illness**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 12 November 2017 – The authors report the development, implementation, and evaluation of a curriculum designed to prepare volunteer navigators to support community-dwelling older persons with serious chronic illness. The role of the volunteer navigator was to facilitate independence and quality of life through building social connections, improving access to resources, and fostering engagement. A curriculum was constructed from evidence-based competencies, piloted and revised, and then implemented in seven subsequent workshops. Workshop participants were 51 volunteers and health-care providers recruited through local hospice societies and health regions. Curriculum was evaluated through satisfaction and self-efficacy questionnaires completed at workshop conclusion. Post-

workshop evaluation indicated a high degree of satisfaction with the training. One workshop cohort of 7 participants was followed for one year to provide longitudinal evaluation data. Participants followed longitudinally reported improved self-efficacy over 12 months and some challenges with role transition. Future improvements will include further structured learning opportunities offered by telephone post-workshop, focusing on advocacy, communication, and conflict management. **Abstract:** <https://goo.gl/R4CDm2>

#### Journal Watch

**‘Conference presentation in palliative medicine: Predictors of subsequent publication’** (p.17), in *BMJ Supportive & Palliative Care*.

Noted in Media Watch 10 July 2017 (#520, p.7):

- *BMC PALLIATIVE CARE* | Online – 3 July 2017 – **‘Piloting a compassionate community approach to early palliative care.’** Volunteer navigators were skilled and resourceful in building connections and facilitating engagement. Although it took time to learn the navigator role, volunteers felt well-prepared and found the role satisfying and meaningful. Benefits cited by clients were making good decisions for both now and in the future, having a surrogate social safety net, supporting engagement with life, and ultimately, transforming the experience of living with illness. **Full text:** <https://goo.gl/2vvZe6>

Noted in Media Watch 23 May 2016 (#463, p.14):

- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 10 May 2016 – **‘The Patient Care Connect Program: Transforming health care through lay navigation.’** Lay navigators are integrated into the health care team. The intervention focuses on patients with high needs to reach those with the greatest potential for benefit from supportive services. Navigator activities are guided by frequent distress assessments, which help to identify patient concerns across multiple domains, triage patients to appropriate resources, and ultimately overcome barriers to health care. **Full text:** <https://goo.gl/6BGRdZ>

### **A research agenda for high-value palliative care**

*ANNALS OF INTERNAL MEDICINE* | Online – 14 November 2017 – Palliative care (PC) has catapulted from being misunderstood and viewed cautiously by many clinicians to being among the most sought-after services by health care systems nationwide. This is the greatest possible testimony to the field’s potential value. However, because demand has quickly outstripped the supply of PC specialists, the field’s ability to sustainably provide high-value care is paradoxically threatened by its own success. The authors propose a research agenda organized around 5 key questions on the optimal organization and allocation of limited resources in specialty PC to close the gap between the workforce and patient need. They provide important considerations and proposed approaches for addressing each research challenge. Amid a growing body of evidence on the potential value of specialty PC, the authors posit that answering these questions is essential to maximize value and inform much-needed policies to support such care. **Abstract:** <https://goo.gl/ZbDzx2>

Cont.

Noted in Media Watch 7 August 2017 (#524, p.12):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2017;20(8):813-820. **‘Research priorities in subspecialty palliative care: Policy initiatives.’** Palliative care (PC) demonstrably improves quality of life for the seriously ill in a manner that averts preventable health crises and their associated costs. Because of these outcomes, PC is now broadening its reach beyond hospitals, and hospice care for those near death, to patients and their families living in the community with chronic multi-morbidities that have uncertain or long expected survival. The authors address research needed to enable policies supportive of PC access and quality, including changes in regulatory, accreditation, financing, and training approaches in the purview of policy makers. **Abstract:** <https://goo.gl/oWRi3w>

Noted in Media Watch 24 July 2017 (#522, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2017;54(3):428-440 (first published online 18 July 2017). **‘State of the science of spirituality and palliative care research: Research landscape and future directions (Part 1).’** Spirituality frequently plays a central and complex role in patients’ and families’ experiences of incurable illness, including influencing quality of life and medical decision-making. Advances in this field that expand the understanding of the relationships between spirituality and health outcomes and lead to the rigorous development of interventions to address patient and family spiritual needs hold tremendous potential for improving a comprehensive approach to care in serious illness. **Abstract:** <https://goo.gl/uNe8G3>

**N.B.** ‘Screen, assessment and interventions (Part 2):’ <https://goo.gl/EiWqdd>

Noted in Media Watch 5 December 2016 (#490, p.8):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(6):290-293. **‘Does current U.K. research address priorities in palliative and end-of-life care?’** The Palliative & End-of-Life Care Priority Setting Partnership (PeolcPSP) report is being used to guide research funding.<sup>1</sup> This project highlights that research spending in palliative and end-of-life care (P&EoLC) remains low, with pockets of good news. It also highlights the need for more research proposals and testing interventions to tackle the problems encountered in P&EoLC. The number one PeolcPSP priority – how to provide palliative care out-of-hours – is one of the questions most in need of further research investment.

1. ‘Putting patients, carers and clinicians at the heart of palliative and end-of-life care research,’ Palliative & End-of-Life Care Priority Setting Partnership (P&EoLC), January 2015. **Download/view at:** <https://goo.gl/UNq9jd>

**N.B.** Access to the journal requires a subscription. Contents page for the November/December 2016 issue: <https://goo.gl/qGVJCP>

## **Providing high-quality care at the end of life: The role of education and guidance**

*BRITISH JOURNAL OF NURSING* | Online – 10 November 2017 – Palliative care (PC) in the U.K. has been ranked as the best in the world.<sup>1</sup> So where did PC go so wrong that a 168-page document is required to inform staff how to care for dying patients if it has been going so well for so long? Those nearing the end of their life deserve to be given optimum care, attention, compassion and consideration, but this is not always the case. The Liverpool Care Pathway was a tool originally devised to help health professionals provide high-quality end-of-life care (EoLC) to people in the final phase of life.<sup>2</sup> This tool, when used in the correct way, could provide the “gold standard” of EoLC for patients. However, a national review found that rather than a tick-box exercise, care of the dying should be centred around individualised care planning for the dying patient, as highlighted in ... ‘One Chance to Get It Right.’<sup>3</sup> Care of the dying is a complex skill that requires nurses to provide some of the most challenging care, and for which many nurses have received little or no training. The implementation of this guidance into practice will require thoughtful change management, abandoning an old way of working in order to ensure excellence and high-quality care for patients nearing the end of life. **Abstract:** <https://goo.gl/8tKA5Y>

Cont.

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>
2. '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>
3. One Chance to Get it Right: Improving People's Experience of Care in the Last Few Days and Hours of Life,' Leadership Alliance for the Care of Dying People, June 2014. [Noted in the 30 June 2014 issue of Media Watch (#364, p.7)] **Download/view at:** <https://goo.gl/bCg4UY>

### **Risk and resilience factors related to parental bereavement following the death of a child with a life-limiting condition**

*CHILDREN* | Online – 9 November 2017 – This paper reviews the theoretical and empirical literature on risk and resilience factors impacting on parental bereavement outcomes following the death of a child with a life-limiting condition. Over the past few decades, bereavement research has focussed primarily on a risk-based approach. In light of advances in the literature on resilience, the authors propose a Risk & Resilience Model of Parental Bereavement, endeavouring to give more holistic consideration to a range of potential influences on parental bereavement outcomes. The literature is reviewed with regard to the role of: 1) Loss-oriented stressors (e.g., circumstances surrounding the death and multiple losses); (2) Inter-personal factors (e.g., marital factors, social support, and religious practices); 3) Intra-personal factors (e.g., neuroticism, trait optimism, psychological flexibility, attachment style, and gender); and, 4) Coping and appraisal, on parental bereavement outcomes. Challenges facing this area of research are discussed, and research and clinical implications considered. **Abstract:** <https://goo.gl/2GKyQQ>

#### **Related**

- *COMPREHENSIVE CHILD & ADOLESCENT NURSING* | Online – 10 November 2017 – '**Two futures: Financial and practical realities for parents of living with a life-limited child.**' During a project on parental coping the author became aware of the ways in which parents were restructuring their working lives in order to meet the demands of the nursing and medical care needs of their children. In this paper she relates the stories discovered in this qualitative study and discusses the tensions between parental and state's responsibility for children, carers and the political and cultural rights and responsibilities pertaining to children's care. **Abstract:** <https://goo.gl/Maqz1L>

**N.B.** Recent articles on the the medical decision-making process in the context of pediatric palliative care are noted in the 13 November 2017 issue of Media Watch (#538, p.8).

### **Christians and the global palliative care movement**

*CHRISTIAN JOURNAL FOR GLOBAL HEALTH*, 2017;4(3). This issue of the journal and features responses to a call for papers relating to Christians and the global palliative care (PC) movement. This is an auspicious year for PC, being the 50th anniversary of the establishment of St. Christopher's Hospice in London by Dame Cicely Saunders.<sup>1</sup> Then, in September, the comprehensive report of the Lancet Commission of Palliative Care was released.<sup>2</sup> This 64-page guide includes a section that outlines the huge inequality in access to PC and appropriate pain relief in low- to middle-income countries compared to high-income countries. The commission report also outlines the importance of clergy and faith-based organizations in PC, but then concludes, perhaps unsatisfactorily, that little is known about their involvement and more research is required. **Journal contents page:** <https://goo.gl/6CbmZs>

1. 'History and Dame Cicely Saunders,' St Christopher's: <https://goo.gl/c1ZTFi>
2. '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 the 16 October 2017 issue of Media Watch (#534, p.14)] **Full text:** <https://goo.gl/i7r9M1>

## One teacher's experiences: Responding to death through language

*ENGLISH JOURNAL*, 2017;107(2):41-46. A survey by the American Federation of Teachers and New York Life Foundation found that “nearly 7 in 10 teachers reported having at least one grieving student currently in their classrooms.” However, 93% of classroom teachers said they have “never received bereavement training,” only 1% received training as part of their coursework in college, and just 3% said their school or district offers it. That’s significant, since another study found that one in 20 children will lose a parent by age 16, and a majority of children will experience a significant loss before they complete high school. These statistics support the idea that it’s our responsibility as teachers to prepare ourselves to deal with death in the classroom. If you teach long enough, you’ll likely have many experiences with death. Do an Internet search for anything similar to “death in the classroom” and you’ll find resources for helping students deal with the death of everyone from a pet to a parent. The challenge is how to apply all of the advice to meet students’ needs in specific circumstances. As important, I believe that English teachers have the unique opportunity to respond appropriately because of our understanding of context and our grounding in writing, reading, speaking, and communication. **Full text:** <https://goo.gl/ogDLQf>



Noted in Media Watch 30 October 2017 (#536, p.16):

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 24 October 2017 – “**Mourning with the morning bell”: An examination of secondary educators’ attitudes and experiences in managing the discourse of death in the classroom.**’ This study used focus groups to explore teachers’ experiences with and beliefs about death, dying, coping, student death, and preparedness to address student death in the classroom. Some themes explored include teachers’ views of death, death versus dying, initial and long-term coping, difficulties in addressing student death, the teachers’ role after a student’s death, feelings of being prepared versus unprepared to address student death in the classroom. **Abstract:** <https://goo.gl/XvHdmT>

**N.B.** Selected articles on including the topic of dying and death into the school curriculum are noted in the 27 February 2017 issue of Media Watch (#501, pp.1-2).

## Are physician orders for life-sustaining treatments the answer to the end-of-life care quality conundrums in cancer care?

*JOURNAL OF ONCOLOGY PRACTICE* | Online – 16 November 2017 –Pedraza *et al* identified patients with advanced cancer for whom POLST completion – by an affirmative response to the question, “Would I be surprised if this patient died in the next year?” – was appropriate.<sup>1</sup> Moss *et al* have demonstrated that this question has some prognostic validity in identifying patients for whom palliative care services are appropriate.<sup>2</sup> Whereas this question may be an appropriate trigger for POLST completion, ongoing discussions regarding a patient’s care goals and preferences for advanced treatments must still occur much earlier and longitudinally in the process of patient-centered, comprehensive cancer care. In this study, in addition to being associated with higher rates of out-of-hospital death and hospice utilization, patients in the POLST group were noted to have completed the forms much closer to the time of death (mean, 3.0 months before death) compared with advance directive completion, which occurred much earlier in the care trajectory (mean, 8.6 months before death). This is a crucial finding that suggests that discussion of care goals and reflection on patient values and care preferences seems to be happening at an earlier point in the care process. **Full text:** <https://goo.gl/GT5WPv>

1. ‘Association of Physician Orders for Life-Sustaining Treatment form use with end-of-life care quality metrics in patients with cancer,’ *Journal of Oncology Practice*, 2017;13(10):e881-e888. **Abstract:** <https://goo.gl/gQmPNu>
2. ‘Prognostic significance of the “surprise” question in cancer patients,’ *Journal of Palliative Medicine*, 2010;13(7):837-840. **Abstract:** <https://goo.gl/y8z1cQ>

**N.B.** Selected articles on the “surprise question” for predicting death in seriously ill patients are noted in the 7 August 2017 and the 10 April 2017 issues of Media Watch (#524, p.4 & #507, pp.10-11, respectively).

Cont.

## Related

- *FAMILY PRACTICE* | Online – 13 November 2017 – ‘Interactions with the healthcare system influence advance care planning activities: Results from a representative survey in 11 developed countries.’ Out of 25,530 survey respondents, 13,409 (53%) reported completion of any advance care planning (ACP) activity; 11,579 (45%) had discussed treatment preferences. Generalized linear mixed model results suggest that hospitalization..., multi-morbidity..., informal caregiving..., higher education level..., income..., access to higher quality primary care..., and emergency department visits ... were associated with higher rates of ACP activities. Male gender ... and higher perceived health status ... were associated with lower rates. Individuals with greater interaction with the healthcare system through hospitalization, multi-morbidity, access to quality primary care, and informal caregiving reported more ACP activities. **Abstract:** <https://goo.gl/8ZtLSy>

## Developing a path to improve cultural competency in Islam among palliative care professionals

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 14 November 2017 – An evolving body of health care disparity research consistently demonstrates lower quality of care and significant access difficulties for seriously ill minority populations receiving palliative care. Several factors contribute to minority health care disparities, including widespread misunderstandings of various minority cultural and religious beliefs among the general public and clinicians. **Abstract:** <https://goo.gl/fu4hBw>

**N.B.** Selected articles on the Islamic perspective on end-of-life and end-of-life care are noted in the 14 August 2017 issue of Media Watch (#525, p.15).

## Palliative medicine: Becoming a subspecialty of the Royal College of Physicians & Surgeons of Canada

*JOURNAL OF PALLIATIVE CARE* | Online – 13 November 2017 – The discipline of palliative medicine (PM) in Canada started in 1975 with the coining of the term “palliative care.” Shortly thereafter, the provision of clinical PM services started, although the education of the discipline lagged behind. In 1993, the Canadian Society of Palliative Care Physicians (CSPCP) started to explore the option of creating an accredited training program in PM. This article outlines the process by which, over the course of 20 years, PM training in Canada went from a mission statement of the CSPCP, to a one year of added competence jointly accredited by both the Royal College of Physicians & Surgeons of Canada (Royal College) and the College of Family Physicians of Canada, to a 2-year subspecialty of the Royal College with access from multiple entry routes and a formalized accrediting examination. **Abstract:** <https://goo.gl/nPzxxS>

## Cirrhosis with ascites in the last year of life: A nationwide analysis of factors shaping costs, health-care use, and place of death in England

*THE LANCET GASTROENTEROLOGY & HEPATOLOGY* | Online – 14 November 2017 – Liver disease mortality increased by 400% in the U.K. between 1970 and 2010, resulting in rising pressures on acute hospital services, and an increasing need for end-of-life care. Between 1 January 2013, and 31 December 2015, 13,818 people in England died from liver disease and had large-volume paracentesis within their last year of life. For all patients, mean cost of the last year of life was £21,113..., 17,888 (52.5%) of 34,068 readmissions occurred within 30 days of discharge, and 10,341 (74.8%) of 13,818 deaths occurred in hospital, of which 10,045 (97.1%) followed an emergency hospital admission. Patients who attended a day-case large-volume paracentesis service within their last year of life had significant reductions in cost..., number of inpatient bed days, probability of early readmission..., and probability of dying in hospital after unplanned admission..., compared with patients who had unplanned care. For patients enrolled in day-case services, improvements in outcomes correlated with the proportion of large-volume paracentesis procedures done in a day-case (vs unplanned) setting. Wider adoption of day-case models of care could reduce costs and improve outcomes in the last year of life. **Abstract:** <https://goo.gl/qEDjZs>

Cont.

Noted in Media Watch (#538, p.15):

- *LIVER INTERNATIONAL* | Online – 7 November 2017 – ‘**Palliative care in decompensated cirrhosis: A review.**’ Studies have demonstrated some benefit of palliative care (PC) in patients with decompensated cirrhosis, but the literature is limited to small observational studies. There is evidence that PC consultation in other patient populations lowers hospital costs and ICU utilization, and improves symptom control and patient satisfaction. **Abstract:** <https://goo.gl/Sfk4sh>

**N.B.** Additional articles on palliative and end-of-life care for people living with kidney disease noted in the 4 September 2017 issue of Media Watch (#528, pp.5-6).

### Early palliative care in advanced cancer: Who and when?

*MEDSCAPE* | Online – 15 November 2017 – Mounting evidence of the benefits of early referral to specialist palliative care (PC) for patients with advanced cancer is putting pressure on oncologists to consider this option, but there is a lack of clarity on which patients should be referred, and when. With the aim of offering guidance as to who and when, a team of experts has developed an international consensus on referral criteria.<sup>1</sup> This document ... was developed after consultation with 60 outpatient PC specialists from North America, Europe, Asia, and Australia. It gives details of 11 major and 36 minor referral criteria that 70% or more of the experts agreed upon. These criteria should help clinicians to identify patients suitable for outpatient specialty PC, the authors write. **Full text:** <https://goo.gl/cg3whw>

1. ‘Referral criteria for outpatient specialty palliative cancer care: An international consensus,’ *Lancet Oncology*, 2016;17(12):e552-e559. **Summary:** <https://goo.gl/YrSZJQ>

#### Related

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 15 November 2017 – ‘**Role of patient coping strategies in understanding the effects of early palliative care on quality of life and mood.**’ The state of oncology care has seen tremendous advances in precision medicine and targeted therapies; however, patients’ supportive care needs have never been greater, and early integration of oncology and palliative care (PC) represents a novel, efficacious approach toward alleviating suffering and improving quality of life (QoL) for those with advanced disease. This study provides evidence suggesting that PC clinicians help improve QoL and mood outcomes in patients with incurable cancer in part by enhancing effective coping processes. **Full text:** <https://goo.gl/bYsCUG>

### Palliative care in patients with haematological neoplasms: An integrative systematic review

*PALLIATIVE MEDICINE* | Online – 13 November 2017 – Palliative care (PC) was originally intended for patients with non-haematological neoplasms and relatively few studies have assessed PC in patients with haematological malignancies. The authors findings indicate that PC is often limited to the end-of-life phase, with late referral to PC. The symptom burden in haematological malignancies patients is more than the burden in non-haematological neoplasms patients. Patients and families are generally satisfied with PC. Home care is seldom used. Tools to predict survival in this patient population are lacking. **Abstract:** <https://goo.gl/fuQRPi>

Noted in Media Watch 5 June 2017 (#515, p.15):

- *MÉDECINE PALLIATIVE* | Online – 31 May 2017 – ‘**Haematologists’ perceptions about end-of-life discussion: A qualitative study.**’ Haematological patients have half as much access to palliative care (PC) than their counterparts with solid malignancies. The main objective of the study was to understand what makes an end-of-life discussion easy or difficult at the time of relapse of an aggressive haematologic malignancy. A side issue was to explore the consequences of such discussions on integration of PC in haematology. **Abstract:** <https://goo.gl/7eAWso>

**N.B.** French language article.

## Communication about palliative care: A phenomenological study exploring patient views and responses to its discussion

*PALLIATIVE MEDICINE* | Online – 13 November 2017 – Three major themes evolved: 1) Death as unspeakable (death was expressed using only implicit, ambiguous or technical terms and perceived to be outside the parameters of medical interactions); 2) Palliative care (PC) as a euphemism for death (the term “palliative care” was perceived to be used by health professionals as a tool to talk about dying and understood by patients as a euphemism for death); and, 3) PC as unspeakable (“palliative care” was personified by patients to mean not just death, but my death, in turn, also becoming unspeakable). This study provides important new patient insights and responses to the discussion of PC. Results demonstrate that the task of discussing PC remains complex, difficult and limited by our language. Greater consistency, sensitivity and sophistication are required when talking about PC to patients who may benefit from this care. **Abstract:** <https://goo.gl/9Ft2GY>

### Related

- *PALLIATIVE MEDICINE* | Online – 13 November 2017 – ‘Development and evaluation of the ‘Dignity Talk’ question framework for palliative patients and their families: A mixed-methods study.’ Interventions aimed at facilitating communication between palliative patients and their families are limited. This study developed a list of question prompts, coined ‘Dignity Talk,’ that may provide a viable means of facilitating important, sensitive conversations between palliative patients and their families. **Full text:** <https://goo.gl/DZ9QXF>

### End-of-life care in New Zealand

#### What is the role of community at the end of life for people dying in advanced age? A qualitative study with bereaved family carers

*PALLIATIVE MEDICINE* | Online – 13 November 2017 – New public health approaches to palliative care (PC) prioritise the role of community at end of life (EoL). However, little is known about community support for the increasing numbers of people dying in advanced age. A reduction in the social networks and community engagement of the older person was identified in the EoL period. Numerous barriers to community engagement in advanced age were identified, including poor health (notably dementia), moving into an aged care facility, and lack of access due to transport difficulties. An active withdrawal from community at EoL was also noted. Carers felt limited support from community currently, but identified that communities could play a particular role in reducing social isolation and loneliness among people of advanced age prior to death. This study provides strong support for public health approaches to PC that advocate building social networks around people who are dying and their family carers. However, it also indicates that strategies to do so must be flexible enough to be responsive to the unique EoL circumstances of people in advanced age. **Abstract:** <https://goo.gl/m3KcKe>

#### Compassionate communities in palliative care: review of international experiences and description of an initiative in Medellín, Colombia

*PSICOONCOLOGÍA*, 2017;14(2-3):325-342. Compassionate communities seek to complement health care services through the empowerment of communities towards the care of their members facing advanced illness and the end-of-life (EoL) and the development of caregiving networks. The article describes the development of this movement and a series of international experiences. The main aim of compassionate communities in the world is to improve the quality of life of people with advanced illness and facing EoL, through the empowerment of their social group in the tasks and needs of care they may have. These communities have emerged throughout the world and achieve their goals using different strategies. Their efforts might be useful not only to empower communities in caregiving actions, but to also successfully complement palliative care assistance, particularly in contexts where these are still under development. **Abstract:** <https://goo.gl/7zbGKY>

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

Cont.

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

- *THE HIPPOCRATIC POST* | Online – 5 October 2017 – ‘**Palliative care – carers and supportive networks.**’ Have you ever looked after someone who has died? And if so, what do you think was the most important thing to him or her? In the vast majority of cases, people will answer that question with “being with family members and loved ones.” The fact is that when we are dying, we want to be supported by a tight-knit group of 4-6 people usually in a familiar place. And beyond this inner circle there can be up to 50 people who support the carers in the centre. **Full text:** <https://goo.gl/sd9gbX>

**N.B.** Selected articles on carer’s **support networks** are not in this issue of Media Watch.

Noted in Media Watch 10 July 2017 (#520, p.7):

- *BMC PALLIATIVE CARE* | Online – 3 July 2017 – ‘**Piloting a compassionate community approach to early palliative care.**’ A model of volunteer navigation, N-CARE has the potential to meet three important needs: 1) Early support to improve the quality of life of older adults living with advancing chronic illness; 2) A satisfying and meaningful role for volunteers; and, 3) A way to support a compassionate communities approach to palliative care. N-CARE is currently being implemented and evaluated in diverse rural and urban communities across Canada. **Full text:** <https://goo.gl/2vvZe6>

**N.B.** Selected articles on the concept of “**compassion communities**” in the context of end-of-life care, are noted in this issue of Media Watch.

Noted in Media Watch 13 June 2016 (#466, p.14):

- *PROGRESS IN PALLIATIVE CARE* | Online – 9 June 2016 – ‘**Which public health approach to palliative care? An integrative literature review.**’ There is growing support for an alignment of palliative care (PC) to public health. Given the novel nature of this alignment and the ambiguity of the parent definitions, there is an understandable lack of clarity around this merged model. The aim of this study is to describe the theoretical features of the public health approach to PC as articulated in the current research literature. **Abstract:** <http://goo.gl/4EGYB0>

**N.B.** Selected articles on a **public health approach** to end-of-life care are noted in this issue of Media Watch.

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

Representative sample of recent journal articles:

- *ISSUES IN LAW & MEDICINE*, 2017;32(2):183-204. ‘**Euthanasia in Belgium: Legal, historical and political review.**’ This article describes and evaluates the Belgian euthanasia experience by considering its practice and policy, both before and after the formal decriminalisation of euthanasia in 2002. The pre-legal practice of euthanasia, the evolution of euthanasia legislation, criticism of this legislation, the influence of politics, and later changes to the 2002 Act on Euthanasia are discussed, as well as the subject of euthanasia of minors and the matter of organ procurement. It is argued that the Belgian euthanasia experience is characterised by political expedition, and that the 2002 Act and its later amendments suffer from practical and conceptual flaws. Illegal euthanasia practices remain a live concern in Belgium, something which nations who are seeking to decriminalise euthanasia should consider. **Abstract:** <https://goo.gl/MXf7hj>

Noted in Media Watch 13 November 2017 (#538, p.7):

- BELGIUM | *The Brussels Times* – 6 November 2017 – ‘**Euthanasia and palliative care go hand in hand.**’ Seven out of ten people who were euthanised in 2013 also received support from a palliative care (PC) team. This figure is higher than those who, in the same period, died not through euthanasia but in fact naturally. In the latter group, only 42.5% of those who died received some form of PC. PC teams were involved in the decision-taking and/or the execution relating to the death for nearly six out of ten people who opted for euthanasia. <https://goo.gl/P5M58m>

Cont.



- *PALLIATIVE MEDICINE* | Online – 15 November 2017 – ‘**The views of adults with Huntington’s disease on assisted dying: A qualitative exploration.**’ Four themes were extracted: 1) Autonomy and kindness in assisted dying (the importance of moral principles); 2) Huntington’s disease threatens life and emphasises issues relating to death; 3) Dilemmas in decision-making on assisted dying (“There are no winners”); and, 4) The absence of explicit discussion on dying and Huntington’s disease (“Elephants in the room”). The authors’ findings suggest that talking to patients about assisted death may not cause harm and may even be invited by many patients with Huntington’s disease. The perspectives of those who live with Huntington’s disease, especially given its extended effects within families, add significant clinical and theoretical insights. **Abstract:** <https://goo.gl/QG2mRr>

Noted in Media Watch 16 September 2013 (#323, p.15):

- *JOURNAL OF HUNTINGTON'S DISEASE*, 2013;2(3):323-330. ‘**Euthanasia and advance directives in Huntington’s disease: Qualitative analysis of interviews with patients.**’ The majority of interviewees expressed some kind of wish regarding end of life, probably more than they had revealed to their physician, but were sometimes hesitant to discuss it. In general, patients underestimate the requirement for sound professional support when considering euthanasia or physician assisted suicide and the value of an advance directive. **Abstract:** <https://goo.gl/ER25Qt>

**N.B.** Selected articles on palliative and end-of-life care for patients and family living with Huntington’s disease are noted in the 23 October 2017 issue of Media Watch (#535, p.12).

## Journal Watch

### **Conference presentation in palliative medicine: Predictors of subsequent publication**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 10 November 2017 – Concerns have been raised about poor-quality palliative care (PC) research and low publication rate from conference abstracts. The objective of this study was to estimate the publication rate for European Association for Palliative Care research conference abstracts (2008) and explore associated characteristics and to understand reasons for non-publication. Full published papers were searched to March 2015 ... and data extracted: country of origin, study design/population/topic. Multivariate logistic regression was used to identify predictors of publication. Members of two different PC associations were surveyed to understand reasons for non-publication. Overall publication rate of the 445 proffered abstracts was 57%. In the final model, publication was more likely for oral presentations..., those from Europe, and much less likely for non-cancer topics... Funding status, academic unit or study design were not associated with publication. Survey 407/1546 (26.3%) physicians responded of whom 254 (62%) had submitted a conference abstract. Full publication was associated with: oral presentation, international conference abstracts, and academic clinicians versus clinicians. Reasons for non-publication included: low priority for workload (53%) and time constraints (43%). The publication rate was similar to 2005 clinical conference. Probable quality markers were associated with publication: oral presentations selected by conference committee, international conference abstracts and abstracts from those with an academic appointment. Publication was given a low priority among clinical time pressures. **Abstract:** <https://goo.gl/H9QtEy>

### **The “phantom reference”: How a made-up article got almost 400 citations**

RETRACTION WATCH | Online – 15 November 2017 – Here’s a mystery: How did a non-existent paper rack up hundreds of citations? Pieter Kroonenberg, an emeritus professor of statistics at Leiden University in The Netherlands, was puzzled when he tried to locate a paper about academic writing and discovered the article didn’t exist. In fact, the journal – *Journal of Science Communications* – also didn’t exist. Perhaps Kroonenberg’s most bizarre discovery was that this made-up paper, ‘The art of writing a scientific article,’ had somehow been cited almost 400 times, according to Clarivate Analytics’ Web of Science. <https://goo.gl/Xci9x2>

## Worth Repeating

### A piece of my mind

#### **One last teaching moment**

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 24 April 2013 – Critical conversations can arise at any moment in care settings. How we respond can powerfully affect the patient's perception of being heard and supported, and may influence the patient's capacity to trust us. Our capacity to respond, often with little time to reflect, prepare, and anticipate the interaction, is governed not by whether we have memorized a script designed to show caring or compassion, but our ability to acknowledge and address, by both verbal and non-verbal means, the patient's vulnerability and need for support, even if we cannot offer any other hope than our presence. We can only do this if we are truly able to acknowledge, access and engage the human values that are universally needed in such settings: a genuine desire to care and comfort, to respect, to support, and to validate the patient's circumstances and experience. As physicians, we may have difficulty accessing some of these, as to do so requires us to acknowledge and address our own vulnerability and sense of helplessness in such conversations. [Noted in the 29 April 2013 issue of Media Watch (#303, p.13)] **Abstract:** <https://goo.gl/V4c1uQ>

### 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.

## **Palliative Care Network Community**

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

## Media Watch: Online

### International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/3oecYD>

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

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

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

[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>

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