

## 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.

10 July 2017 Edition | Issue #520



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**End-of-life care for the homeless:** The public health issue is the focus of three separate studies published in the last week or so. Scroll down to [International](#) and ‘London’s homeless “dying in hostels rather than hospices”’ (p.5), a U.K. newspaper’s report on a study published in *Palliative Medicine* ...and, [Specialist Publications](#) for the findings of a Canadian study published in *Current Oncology* and a U.S. study reported on in *Medscape* (p.9).

## [Canada](#)

### What my dying wife and I never knew about palliative care

ONTARIO | *The Ottawa Citizen* – 7 July 2017 – The American Society of Clinical Oncology recommends that patients with advanced cancer receive palliative care (PC) soon after diagnosis. In Suzanne’s case, this would have meant roughly 2½ years before she died. Officially in Ontario, PC can begin at any point in the progress of the disease. However, according to the Canadian Cancer Society, about 40% of cancer patients in the province do not receive any palliative assessment in the last year of their lives. In Suzanne’s case she did get an assessment by a social worker about five months before her death, but it concerned her physical needs while she remained at home, which were minimal. What she wanted and needed was to talk to a PC physician about the end stage of her disease, the situations she was likely to encounter and the decisions she (and I) would likely have to make. As a practical matter, what we found was that it was impossible to get assigned to a PC physician while she was still under active treatment. Suzanne’s medical oncologist referred her to see a PC physician six months before she died. But the referral was refused because Suzanne’s radiation oncologist was still caring for her. The radiation she was getting was itself purely palliative – aimed at managing her symptoms and providing some quality of life in her final months. But that did not matter. Suzanne met with her radiation oncologist for the last time just a week before her collapse. He referred her once again to be assigned to a PC physician, but it was too late. <https://goo.gl/xdCqPk>

### Demand increasing for Prince Edward Island paramedics palliative home care program

PRINCE EDWARD ISLAND | CBC News (Charlottetown) – 6 July 2017 – Almost two years after the Paramedics Providing Palliative Care at Home program was started on Prince Edward Island, those involved say it meets a need in the community and demand is increasing. The program allows paramedics to provide their services to palliative care (PC) patients living at home especially for pain and symptom management. Paramedics and doctors develop a plan that is best suited for the patient. In 2016, paramedics had a total of 315 PC calls and of that amount, 35% of the patients were able to remain at home, exceeding their goal... <https://goo.gl/pEuJPX>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | *The Globe & Mail* – 6 July 2017 – ‘**Ontario’s assisted-dying law plagued by service woes.**’ The number of Ontario clinicians registered to participate in medical aid in dying (MAiD) has fallen dramatically since the provincial government set up a new co-ordination program that was supposed to improve access for the grievously ill while easing the moral burden on physicians who object to referring patients for assisted death. Only 74 doctors and nurse practitioners have signed up for the new care co-ordination service, down from 181 when the Ontario Ministry of Health & Long-Term Care shut down its old confidential referral list of MAiD) providers 31 May. The provincial government has expressed confidence that more clinicians will register as the new service matures, but front-line providers say the shortcomings of the care co-ordination service are turning off some doctors, which could make it harder for eligible patients to find someone to help them end their lives. <https://goo.gl/EZydoH>
- *THE GLOBE & MAIL* | Online – 3 July 2017 – ‘**Canadian doctors turn away from assisted dying over fees.**’ A year after the passage of Canada’s medical-aid-in-dying law (MAiD), concerns among doctors over how they are paid to administer assisted deaths – a new medical service that is unlike any other – are not limited to the West Coast. In Nova Scotia, nearly half of the billing claims submitted so far for MAiD are stuck in processing, with some physicians saying they have yet to be paid for any of their assisted-death cases. In two provinces, Ontario and Newfoundland and Labrador, there are still no specific billing codes for hastening the deaths of the seriously ill. Determining how doctors should be paid for assisted dying is a delicate question, one that is difficult to separate from larger conversations about physician compensation and patient access to assisted death. <https://goo.gl/dftvva>
- ONTARIO | *The Toronto Star* – 1 July 2017 – ‘**Ontario’s privacy commissioner calls for transparency in assisted dying.**’ In his annual report,<sup>1</sup> privacy commissioner Brian Beamish took aim at the Medical Assistance in Dying Statute Law Amendment Act (Bill 84), which became law in Ontario last month. The act, in part, is a green light for secrecy. Any information that could identify hospitals, long-term care homes or hospices that offer medically assisted death is now exempt from freedom of information laws. “The government views protecting facilities as a logical and justifiable extension of protecting clinicians,” [said] health ministry spokesperson David Jensen... There’s nothing in Bill 84 to explicitly prevent a facility from ‘proactively releasing’ their policies,” he added. To Beamish, that decision veers alarmingly off-path from transparency and accountability. <https://goo.gl/bWGTtd>

1. ‘Facing Challenges Together,’ 2016 Annual Report (p.35), Information & Privacy Commissioner of Ontario, June 2017. <https://goo.gl/w8Acgw>

## U.S.A.

### Push grows for “right-to-try” laws that loosen access to experimental treatments

MINNESOTA | *The Star Tribune* (Minneapolis) – 5 July 2017 – Dying patients want quicker access to experimental drugs that could extend their lives, and 37 states, including Minnesota, have enacted laws since 2014 granting that wish. Supporters say a federal law would strengthen protections, and Congress is now considering the issue. That’s focusing debate on whether such “right-to-try” laws have practical positive effects or just create false hope while undercutting patient safety. <https://goo.gl/gMubKM>

**N.B.** Additional articles on “right-to-try” laws in the U.S. are noted in the 17 April 2017 issue of Media Watch (#508, p.2).

### Tricare rules force military families with sick children to pick between hospice or treatment

*STARS & STRIPES* | Online – 5 July 2017 – The rule is usually discovered by parents bracing for their child to die. Already consumed by tragedy, these military families are confronted with a brutal choice: Elect hospice to ease your child’s suffering or choose treatment to keep fighting for your child’s life. Under

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the military's Tricare health insurance program, they can't do both. Tricare does not cover curative treatments and hospice care at the same time. So, when forced to decide, military parents mostly forgo hospice. Because kids – even at their sickest – can rally. Advocates of military children have been struggling behind the scenes to get the hospice rules changed. Military officials acknowledge the “gap” in coverage. With hundreds affected each year, advocates in the coalition Tricare for Kids say the fix is long overdue. For years, hospice care was considered only after all efforts at treatment had been exhausted. But experts say the trend – even with adults – is now to incorporate hospice care into treatment for the illness. <https://goo.gl/3bzRHi>

## We're making it too hard to have a “good” death

STAT | Online – 5 July 2017 – Although most Americans say they prefer to emphasize comfort when they're near death, aggressive treatment remains the norm in American health care. In the last month of life, half of all Medicare patients visit an emergency care room, one-third are admitted to an intensive care unit, and many have surgery. Ironically, this disconnect between what people want and what they often get is facilitated by well-meaning but misguided laws governing the completion of advance directives. Advance directives have two parts. The first is a living will that spells out an individual's wishes for end-of-life care. It might say, for example, whether or not she wants to be placed on a ventilator, or, perhaps more importantly, what types of health states she would consider to be intolerable. The second part is a health care power of attorney that specifies the individual's chosen decision-maker. By law, advance directives usually require the signatures of two witnesses or a no-

tary, with specific rules varying by state. In some states, approved templates drafted by lawmakers – not clinicians – are the preferred ones. Only one-third of Americans with advanced illnesses have advance directives...<sup>1</sup> One research study ... found that only 2% had advance directives in their medical records.<sup>2</sup> Sometimes the documents remain home in a drawer, unavailable to family members and physicians as they gather in the hospital to make decisions. But even when they are available, they often give poor guidance about an individual's true wishes ... each of these failures can be traced, in part, to the law.<sup>3</sup> <https://goo.gl/pE86FY>

### Specialist Publications

'Advanced illness and end-of-life care' (p.10), in a special issue of *Health Affairs*.

1. 'Approximately one in three U.S. adults completes any type of advance directive for end-of-life care,' *Health Affairs*, 2017;36(7):1244-1251. <https://goo.gl/NtyAeE>
2. 'Default options in advance directives: Study protocol for a randomised clinical trial,' *BMJ Open*, published online 6 June 2016. <https://goo.gl/zsLLNW>
3. 'Delegalizing advance directives – facilitating advance care planning,' *New England Journal of Medicine*, 2017;376(22):2105-2107. [Noted in Media Watch 5 June 2017, #515 (p.12)] <https://goo.gl/zEytYr>

## People are choosing to die in their beds over a hospital

STATE OF NEW YORK | *The New York Post* – 2 July 2017 – More New Yorkers are choosing to spend the last moments of their life in the comfort of their own home – rather than a hospital bed. The percentage of terminally ill Big Apple residents who pass away at home has been on the increase for the past eight years. Back in 2007, just 18.9% of deceased New Yorkers passed away in their own home, according to figures compiled by the city's Department of Health & Mental Hygiene. That figure has been climbing every year – reaching 23.4% in 2015, according to the most recent data available. City hospitals still remain the most preferred the place to pass, but hospital deaths have been sliding down for years – from 51.4% in 2011 to 46.4% in 2015. While city data doesn't specify what ailment ultimately leads to home death, palliative care researchers and medical ethicists said that dying patients are choosing comfort over more medical treatment. In addition, data on deaths at licensed hospices in the city has risen to 5% from just 1.8% in 2011. <https://goo.gl/poZFKg>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- COLORADO | Associated Press – 4 July 2017 – ‘**10 patients got life-ending drugs in Colorado under new law.**’ Colorado’s law allowing terminally ill patients to seek life-ending drugs is quietly underway, with an estimated 10 prescriptions filled since voters approved the practice last year... Colorado has joined Oregon, California, Montana, Vermont, Washington state and Washington DC in allowing doctor-assisted suicide. But dozens of Colorado hospitals won’t participate in ending someone’s life. About one-third of the state’s hospitals are Catholic-affiliated. Doctors still can choose to write prescriptions in their offices and allow patients to end their lives at home. The Colorado Department of Public Health & Environment plans to report by the end of the year how many doctors handled prescriptions, but it won’t say how many people took the drugs. <https://goo.gl/s53MDh>

### Specialist Publications

‘**Doctor [in the U.S.] support for assisted death rises, but debate continues**’ (p.16), in *Medscape*.

## International

### End-of-life care in England

#### **Patients from deprived areas less likely to get specialist end-of-life care, study finds**

U.K. (England) | *The Independent* – 6 July 2017 – Patients with breast, bowel, prostate or lung cancer living in the most deprived parts of the country are more likely to be admitted to hospital as an emergency case in the last six months of their lives compared to those who live in the most affluent regions. Charity Macmillan Cancer Support, which funded the study,<sup>1</sup> said the findings highlight the variation in access to specialist end-of-life care across the country. It said that having access to the right care and support should not depend on where a patient lives. The study – conducted by researchers from City, University of London and the Economic & Social Research Institute – analysed data on 250,000 patients from the English National Cancer Registry. It found that people with the four most common types of cancer are more likely to be admitted to hospital as an emergency in the last six months of their lives, increasing the cost of their care. They are also more likely to stay in hospital for a longer period of time following an emergency admission. <https://goo.gl/5o2Nq6>

### Specialist Publications

‘**Effect of specialist palliative care services on quality of life in adults with advanced incurable illness in hospital, hospice, or community settings: Systematic review and meta-analysis**’ (p.9), in *British Medical Journal*.

‘**National palliative care capacities around the world: Results from the World Health Organization Non-communicable Disease Country Capacity Survey**’ (p.15), in *Palliative Medicine*.

1. ‘Disparities in cancer care and costs at the end of life: evidence from England’s National Health Service,’ *Health Affairs*, 2017;36(7):1218-1226. <https://goo.gl/yMqDtG>

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## Related

- U.K. (England) | *The Daily Telegraph* (London) – 3 July 2017 – **‘Thousands of cancer patients dying in needless agony, new data reveals.’** Thousands of cancer patients are dying in needless pain because of disjointed care for people who have returned home to be with loved ones, experts have warned. New data reveals one in ten people who die of cancer have inadequate pain relief in their final 48 hours.<sup>1</sup> Charities have criticised Office for National Statistics (ONS) figures<sup>2</sup> as “unacceptable,” and called on the Government to make good on its manifesto pledge to improve the standard of palliative care. Macmillan Cancer Support, which conducted the analysis, said fears of uncontrollable pain were cancer patients’ top concern as they approached the end of life. <https://goo.gl/YCYE8A>
  1. ‘Thousands of cancer patients are spending their final hours in pain,’ Macmillan Cancer Support, February 2016. [Noted in Media Watch 15 February 2016, #449 (p.5)] <https://goo.gl/5uL4Uw>
  2. ‘National Survey of Bereaved People (VOICES),’ Office for National Statistics, April 2016. [Noted in Media Watch 25 April 2016, #459 (p.9)] <https://goo.gl/8uT6ni>

## Elder care in England

### **One in four care homes unsafe, says watchdog as experts criticise “Russian roulette” in social care**

U.K. (England) | *The Daily Telegraph* (London) – 6 July 2017 – The Care Quality Commission (CQC) has released a report after it completed inspections of all 24,000 providers in England.<sup>1</sup> It found that of 10,858 residential care homes inspected, more than 2,600 were rated either inadequate or requires improvement for safety. Meanwhile of the 4,042 residential nursing homes visited by the CQC, 1,496 – or 37% – were unsafe. Across the entire adult social care sector, including domiciliary and community social care, 23% of services were found to require improvement for safety, and 2% were judged to be inadequate – approximately 6,000 organisations. The CQC began inspecting every registered adult social care provider, including domiciliary care and special needs services, both private and publicly funded, in October 2014. <https://goo.gl/Dazb9C>

1. ‘The State of Adult Social Care Services 2014 to 2017,’ Care Quality Commission, July 2017. <https://goo.gl/WWuKxT>

### **London’s homeless “dying in hostels rather than hospices”**

U.K. (England) | *The Evening Standard* (London) – 4 July 2017 – Homeless people in London who are terminally ill face the distressing process of dying in hostels rather than hospices due to a lack of community support, a study has suggested.<sup>1</sup> Hostel staff often end up caring for some of the sickest homeless people, despite not having palliative care training. The research ... was carried out by Marie Curie Palliative Care researchers at University College London. It found that homeless people, who are more likely to die young from conditions often associated with mental health issues or substance abuse, are failing to get the support they need from the community. Experts warned this resulted in “distressing” unplanned and emergency hospital admissions in the last weeks or days of their life. <https://goo.gl/MSZUbw>

1. ‘End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care,’ *Palliative Medicine*, published online 3 July 2017. <https://goo.gl/b3eQ42>

#### **Extract from Care Quality Commission report**

The Commission will be publishing a separate report later this year that looks at quality in hospice services. From 2017-2018 hospices services will be assessed under the healthcare assessment framework. They will, therefore, become part of the responsibility of the Chief Inspector of Hospitals. Hospice services are included in the data for “all” adult social care services in this report.

#### **Specialist Publications**

**‘Palliative care as a public health issue: Understanding disparities in access to palliative care for the homeless population living in Toronto [Ontario, Canada] based on a policy analysis’** (p.9), in *Current Oncology*.

**‘Homeless and dying in America: Facing the end of life alone’** (p.9), in *Medscape*.

## Specialist Publications

### **Dementia, decision making, and quality of life**

*AMERICAN MEDICAL ASSOCIATION JOURNAL OF ETHICS*, 2017;19(7):637-639. Evidence suggests ... that many people with dementia, even those with more advanced disease, can still articulate their values, preferences, and choices in a reliable manner. Indeed, people with dementia maintain a strong desire to remain central in decision-making processes that directly impact their lives. Consequently, it is an ethical priority in the care of people with dementia to maximize the likelihood that they will have opportunities to live lives reflective of their values and maintain active, central roles in decision making. Decisions that present challenges for people with dementia and surrogate decision makers are not limited to decisions regarding medical care, treatment decisions, or end-of-life preferences but also include decisions regarding everyday concerns, from financial matters to intimate relationships. The theme of this issue [of the journal] reflects this diversity of decisional stakes by focusing on how decisions of all kinds made in various settings (e.g., long-term care, medical offices, and research) can fundamentally impact the autonomy and well-being of people with dementia. <https://goo.gl/wTYkrG>

**N.B.** Journal contents page: <https://goo.gl/1wzGfx>

Noted in Media Watch 3 July 2017, #519 (p.9):

- *HEALTH EXPECTATIONS* | Online – 22 June 2017 – ‘**A qualitative study exploring the difficulties influencing decision making at the end of life for people with dementia.**’ The authors identified four key themes: 1) Challenges of delivering coherent care in dynamic systems; 2) Uncertainty amongst decision makers; 3) Internal and external conflict amongst decision makers; and, 4) A lack of preparedness for the end of life. <https://goo.gl/oJdYaR>

**N.B.** Selected articles on end-of-life care for people living with Alzheimer’s and other forms of dementia are noted in the 19 June 2017 issue of Media Watch (#517, p.15). Articles focused specifically on communications and advance care planning for this patient population are noted in the 8 May 2017 issue of Media Watch (#511, p.7).

### End-of-life care in Australia

#### **Does anyone ever expect to die?**

*ANAESTHESIA & INTENSIVE CARE*, 2017;45(4):466-468. Patients can be admitted to the intensive care unit (ICU) unexpectedly ... or as unplanned but not necessarily truly “unexpected” admissions. These patients often have significant underlying chronic health issues ... with a high likelihood of death in the ensuing months. Using the Australian & New Zealand Intensive Care Society Clinical Trials Group Point Prevalence Program, a prospective single-day observational study across 46 Australian hospitals in 2014 and 2015, the authors found less than 9% of ICU patients had an advance directive available. The authors provide two suggestions to increase intensive care’s understanding of patients’ end-of-life (EoL) wishes. First, systematically target “high risk of dying” patient groups for goals-of-care conversations in the outpatient setting. Such groups include those where one would not be “surprised” if they died within a year. Second, as a society, more conversations about EoL wishes are needed. <https://goo.gl/euw4zz>

#### **Related**

- *THE HEALTH SURGERY FORUM*, 2017;20(3):e111-e115. ‘**Knockin’ on heaven’s door: End-of-life decisions and discussions.**’ For the majority who live out their final days in various institutions or in hospice care, decisions must be made about which treatments to administer, which treatments to stop, which treatments to continue, and which treatments to back off of. While death remains inevitable, its timing is often very much a function of human agency. Once it was common to speak of “nature taking its course,” but now it has become as common to view death as something about which people have some control. <https://goo.gl/tAK4e6>

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- *JAMA INTERNAL MEDICINE* | Online – 3 July 2017 – ‘**A research agenda for communication between health care professionals and patients living with serious illness.**’ The authors consider 7 broad topics: 1) Shared decision making; 2) Advance care planning; 3) Communication training; 4) Measuring communication; 5) Communication about prognosis; 6) Emotion and serious illness communication; and, 7) Cultural issues. They identified 5 areas in which further research could substantially move the field forward and help enhance patient care: 1) Measurement and methodology, including how to determine communication quality; 2) Mechanisms of communication, such as identifying the specific clinician behaviors that patients experience as both honest and compassionate, or the role of bias in the clinical encounter; 3) Alternative approaches to advance care planning that focus on the quality of serious illness communication and not simply completion of forms; 4) Teaching and disseminating communication skills; and, 5) Approaches, such as economic incentives and other clinician motivators, to change communication behavior. <https://goo.gl/16ita1>

**Mindfulness and compassion-oriented practices at work reduce distress and enhance self-care of palliative care teams: A mixed-method evaluation of an “on the job” program**

*BMC PALLIATIVE CARE* | Online – 6 July 2017 – Although the work in palliative care (PC) can be highly rewarding, there are inherent stressors that can affect the wellbeing of PC practitioners. Furthermore, there is a necessity for less protection oriented self-care strategies that allow practitioners to still encounter the suffering they are confronted with, with an open and kind attitude. Even though there is emerging evidence for the potential of compassion-oriented practices, there is a lack of applied research investigating the effects of these practices under real work conditions. The authors aimed to address this gap and elucidate how mindfulness and compassion-oriented practices can be implemented within the clinical setting. Although they could not find an enhancement of compassion in general, participants reported a benefit from the training in the areas of self-care, emotional regulation skills, work-related distress, mindfulness at work and interpersonal connection skills, suggesting that highly compassionate individuals benefit differently from these practices. Qualitative interviews also suggest, that based on their expertise, staff members addressed areas they saw as relevant in order to foster sustainability of their compassionate behaviors at work. <https://goo.gl/8JkNft>

**N.B.** Additional articles on compassion fatigue and self-care are noted in the 5 June issue of Media Watch (#515, p.11).

**Piloting a compassionate community approach to early palliative care**

*BMC PALLIATIVE CARE* | Online – 3 July 2017 – A compassionate community approach to palliative care provides important rationale for building community-based hospice volunteer capacity. In this project, the authors piloted one such capacity-building model in which volunteers and a nurse partnered to provide navigation support beginning in the early palliative phase for adults living in community. The goal was to improve quality of life by developing independence, engagement, and community connections. Seven volunteers were partnered with 18 clients. Over the one-year pilot, the volunteer navigators conducted visits in home or by phone every two to three weeks. Volunteers 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. Clients and family rated the service as highly important to their care because of how the volunteer helped to make the difficult experiences of aging and advanced chronic illness more liveable. Significant 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. Overall the program was perceived to be well-designed by stakeholders and meeting an important need in the community. Sustainability, however, was a concern expressed by both clients and volunteers. <https://goo.gl/2vvZe6>

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Noted in Media Watch 13 February 2017, #499 (p.3):

- *AUSTRALIAN AGEING AGENDA* | Online – 10 February 2017 – ‘**Aged care providers central to community-led palliative care: Expert.**’ A grassroots campaign of care professionals and services is pushing to embed community-based palliative care (PC) in Australia to provide more inclusive end-of-life care (EoLC). The “compassionate communities” movement aims to promote and integrate social approaches to dying, death and bereavement by building community capacity around EoLC and support. <https://goo.gl/Dc1YWY>

Noted in Media Watch 30 January 2017, #497 (p.12):

- *UNIVERSITY OF OTTAWA JOURNAL OF MEDICINE* | Online – Accessed 28 January 2017 – ‘**Compassionate communities and their role in end-of-life care.**’ Given the need for support throughout all aspects of end-of-life care (EoLC), an emerging paradigm shift shows compassionate communities as a new standard for placing responsibility back in the community and promoting respectful and compassionate care. Development of Compassionate Communities promotes quality EoLC designed to meet the individualized needs of the dying as well as their caregivers. <https://goo.gl/rqQDj>

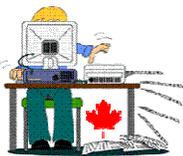
### **Health and death literacy and cultural diversity: Insights from hospital-employed interpreters**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 3 July 2017 – The aim of this qualitative study is to better understand, through the experiences and insights of hospital interpreters, how people from culturally and linguistically diverse (CALD) communities might respond to advance care planning (ACP) and end-of-life discussions. Hospital interpreters from five Melbourne metropolitan health services were recruited for in-depth semi-structured interviews that explored the question: “What can be learnt from hospital interpreters about cultural issues related to ACP and end-of-life decision-making?” Thirty-nine interpreters, representing 22 language groups, were interviewed. Thematic analysis identified three major themes: 1) Moral difference; 2) Health and death literacy; and, 3) Diversity within culture. A value-based approach to ACP is recommended as a way to capture the person’s individual values and beliefs. Health and death literacy have been identified as areas that may be over-estimated; areas that can be addressed and improved, if recognised. <https://goo.gl/WAqfjS>

Noted in Media Watch 10 April 2017, #507 (p.13):

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 3 April 2017 – ‘**Understanding patient needs without understanding the patient: The need for complementary use of professional interpreters in end-of-life care.**’ The authors present a case that generated a triple-layered ethical dilemma: 1) How to safeguard patient autonomy against paternalistic interventions by family members; 2) How to respect the relational context in which patient autonomy can be realized; and, 3) How to respect the ethno-cultural values of the patient and his family. <https://goo.gl/thpFmR>

**N.B.** Additional articles on the use of interpreters in the context of end-of-life care are noted in the 20 June 2016 issue of Media Watch (#467, p.15).



#### **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>

## **Effect of specialist palliative care services on quality of life in adults with advanced incurable illness in hospital, hospice, or community settings: Systematic review and meta-analysis**

*BRITISH MEDICAL JOURNAL* | Online – 4 July 2017 – The integration of specialised palliative care (SPC) was associated with a small effect on quality of life (QoL), whereas the results for pain and other secondary outcomes were inconclusive. The effect on QoL might be more pronounced for patients with cancer and for those who received SPC early. This effect was observed even though all trials also provided SPC to patients who did not have symptoms nor had any other needs for palliative care. Instead, it was initiated according to diagnosis and stage of disease. Moreover, the true effects of SPC might have been underestimated because of various methodological issues. The authors hypothesise that SPC could be most effective if it is provided early and if it identifies patients with unmet needs through screening (“care as needed”). They hope that the discussion of the importance of general palliative care and the detailed description of shortcomings of the included studies will increase the quality of further clinical research in the SPC. <https://goo.gl/dXrkp6>

Noted in Media Watch 19 June 2017, #517 (p.14):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 13 June 2017 – ‘**Specialized palliative care in advanced cancer: What is the efficacy? A systematic review.**’ All the studies offered generalizability, but the level of evidence validity varied among them. Due to several methodological limitations, the evidence offered in these studies ranged from low to high. The evidence in this field of study in general is still nascent, but there is growing support for the utilization of SPC to improve the quality of life of adult patients with advanced cancer. The evidence that SPC reduces physical and psychological symptoms is moderate, while the evidence that it prolongs survival is low. <https://goo.gl/AZN1fB>

## **Palliative care as a public health issue: Understanding disparities in access to palliative care for the homeless population living in Toronto [Ontario, Canada] based on a policy analysis**

*CURRENT ONCOLOGY*, 2017;24(3):187-191. As it stands, the health care system involved in the delivery of palliative care (PC) services is ill-equipped to provide equitable PC for homeless people. To come close to meeting the standards of equitable access to PC, system-wide structural changes to effectively remove barriers and to add the necessary services in the right places are needed. Using a policy and ethics analysis, the authors identify how the current PC system is structurally unable to meet the complex needs of the homeless population. In advocating for a public health approach to improve PC delivery, this article illustrates the ethical need for health prevention and promotion to be developed hand-in-hand with good PC. Care integration and partnerships with homeless shelters and various service providers are crucial in bringing PC services to the places where homeless people feel most comfortable – in their home communities, as defined by them. <https://goo.gl/KdJ72K>

### **Related**

- *MEDSCAPE* | Online – 3 July 2017 – ‘**Homeless and dying in America: Facing the end of life alone.**’ Statistics about the U.S. homeless population are staggering. More than a million people face homelessness each year in the U.S., and these individuals often have multiple complex illnesses and co-morbid mental health conditions. Orchestrating care for the homeless population poses significant challenges. Little is known about the end-of-life (EoL) experiences of homeless persons. A major gap in knowledge exists regarding the symptoms experienced by homeless persons at or near the EoL – information that would help clinicians not only manage these symptoms but also assist homeless persons with advance care planning and decision-making around death and dying.<sup>1</sup> <https://goo.gl/zS6BuL>

1. ‘Homeless individuals approaching the end of life: Symptoms and attitudes,’ *Journal of Pain & Symptom Management*, published online 30 December 2016. [Noted in Media Watch 2 January 2017, #493 (p.18)] <https://goo.gl/szzW4u>

**N.B.** Additional articles on end-of-life care for the homeless are noted in the 15 March 2017 issue of Media Watch (#512, p.12).

## Issues related to family history of cancer at the end of life: A palliative care providers' survey

*FAMILIAL CANCER* | Online – 3 July 2017 – Addressing the concerns of end-of-life (EoL) patients or their relatives about their family history of cancer could benefit patients and family members. Little is known about how palliative care (PC) providers respond to these concerns. A cross-sectional survey was conducted in the Quebec City (Canada) catchment area among PC professionals. Fifty-eight PC professionals working in hospice, home care and hospital-based PC units completed the questionnaire. All physicians and 63% of nurses occasionally addressed concerns of patients and relatives about their family history of cancer, but they reported a low confidence level in responding to such concerns. They also showed knowledge gaps in defining features of a significant family history of cancer, and most (78%) would welcome specific training on the matter. The needs and concerns of EoL patients and their families need to be explored to ensure PC providers can adequately assist patients and their relatives about their family history of cancer. <https://goo.gl/RCfyyb>

### Special issue of *Health Affairs*

#### Advanced illness and end-of-life care [in the U.S.]

*HEALTH AFFAIRS*, 2017;36(7):1167. Few areas of health care are as personal, or as fraught, as care for people with serious illnesses who are approaching death. At a point in their lives when their needs are often as much social and spiritual as they are medical, people are confronted with a fragmented, rescue-driven health care system that produces miraculous results, but also disastrous failures. The U.S.'s formal commitment to providing appropriate care at the end of life remains largely tied to the Medicare hospice benefit, which was created decades ago and was designed around cancer care with its (at the time) fairly predictable poor prognosis. Diane Meier and colleagues argue that it is time for a national commitment to palliative care (PC) – a form of team-based care that focuses on improving the quality of life and relieving suffering. As they note, “The majority of Americans with a serious illness are not dying.” The availability of PC has grown organically; it is time, the authors argue, for it to grow strategically. Amber Barnato argues for a reconsideration of how care can honor patients' preferences. In the process of advance care planning, patients' stated preferences are heavily influenced by context because they are being asked to consider scenarios and options with which they have no experience. Barnato argues that clinicians must be aware of their own biases when engaging patients in such conversations. <https://goo.gl/HtHKxf>

**N.B.** Journal contents page: <https://goo.gl/jebK3j>

#### End-of-life medical spending in last twelve months of life is lower than previously reported

*HEALTH AFFAIRS*, 2017;36(7):1211-1217. Although end-of-life (EoL) medical spending is often viewed as a major component of aggregate medical expenditure, accurate measures of this type of medical spending are scarce. The authors used detailed health care data for the period 2009-2011 from Denmark, England, France, Germany, Japan, The Netherlands, Taiwan, the U.S., and the Canadian province of Quebec to measure the composition and magnitude of medical spending in the three years before death. In all nine countries, medical spending at the EoL was high relative to spending at other ages. Spending

#### CURRENT ISSUE

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#### Advanced Illness & End-Of-Life Care



Alert me to new issues of *Health Affairs*

- From The Editor-In-Chief
- DataGraphic: End-Of-Life Care
- Entry Point: Alzheimer's Care Directives
- Evolving End-Of-Life Care Patterns
- Profiling U.S. End-Of-Life Caregivers
- End-Of-Life Spending In 8 Countries
- Advance Directives And US Adults
- Respecting Patients' Preferences
- National Strategy For Palliative Care
- Increasing Veterans' Hospice Use
- Racial Disparities In Hospice Care
- Web First: Health Spending By State
- Narrative Matters: Dying On Her Terms

Cont.

during the last twelve months of life made up a modest share of aggregate spending, ranging from 8.5% in the U.S. to 11.2% in Taiwan, but spending in the last three calendar years of life reached 24.5% in Taiwan. This suggests that high aggregate medical spending is due not to last-ditch efforts to save lives, but to spending on people with chronic conditions, which are associated with shorter life expectancies. <https://goo.gl/7dBtVi>

### **Communication, comfort, and closure for the patient with cystic fibrosis at the end of life: The role of the bedside nurse**

*INTERNATIONAL JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2017;19(4):298-302. In the terminal care of the patient with cystic fibrosis (CF), the role of the bedside nurse is critical in providing seamless, interdisciplinary care in order to promote a “good death” and ensure that the patient’s and family’s wishes are respected at the end of life (EoL). Key components of the bedside nurse’s role in end-of-life care for the CF patient include the facilitation of interdisciplinary patient/family-centered communication, the provision of comfort to ease suffering from breathlessness and pain, and the promotion of patient and family closure within the family and among caregivers. This case study depicts the critical role of the bedside nurse in a young female patient with CF at the EoL to honor patient and family wishes and promote a peaceful, dignified death. <https://goo.gl/3bnbZC>

**N.B.** Additional articles on palliative care for people living with cystic fibrosis are noted in the 8 May 2017 issue of Media Watch (#511, p.10).

### **End-of-life transitions and hospice utilization for adolescents: Does having a usual source of care matter?**

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

Noted in Media Watch 9 January 2017, #494 (p.6):

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2016;22(12):608-617. **‘Life transitions of adolescents and young adults with life-limiting conditions.’** A systematic review was conducted to appraise and classify evidence related to the life transitions of adolescents and young adults with life-limiting conditions. Eighteen studies were included in the final review, with two major life transitions identified as pertinent: “illness transition” and “developmental transition.” <https://goo.gl/aIVrcT>

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

- *JAMA PEDIATRICS* | Online – 17 October 2016 – **‘Ethics, emotions, and the skills of talking about progressing disease with terminally ill adolescents: A review.’** The authors reviewed the ethical justifications for and against truth-telling, and considered the published ethical and practice guidance, as well as the perspectives of patients, parents, and clinicians involved in these cases. They also explored particular challenges with respect to the cultural context, timing, and content of conversations at the end of adolescents’ lives. <https://goo.gl/v91oh0>



#### 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.18.

## Palliative care development in Africa: Lessons from Uganda and Kenya

*JOURNAL OF GLOBAL ONCOLOGY* | Online – 30 June 2017 – Despite increased access to palliative care (PC) in Africa, there remains substantial unmet need. The authors examined the impact of approaches to promoting the development of PC in ... Uganda and Kenya, and considered how these and other strategies could be applied more broadly. Both countries have implemented strategies across all five domains [i.e., education and training, access to opioids, public and professional attitudes, integration into national health systems, and research] to develop PC. In both countries, successes in these endeavors seem to be related to efforts to integrate PC into the national health system and educational curricula, the training of health care providers in opioid treatment, and the inclusion of community providers in PC planning and implementation. Research in PC is the least well-developed domain in both countries. A multidimensional approach to development of PC across all domains, with concerted action at the policy, provider, and community level, can improve access to PC in African countries. <https://goo.gl/RP8FWv>

Noted in Media Watch 22 May 2017, #513 (p.14):

- INSTITUTE OF CULTURE & SOCIETY, UNIVERSITY OF NAVARRA (Madrid, Spain) | Online – 20 May 2017 – **‘First mapping study for palliative care development in the Eastern Mediterranean Region and Africa.’** There is limited palliative care (PC) development in Africa, but there is also a significant improvement in the number of countries with hospice and PC services, compared to previous reports. Improvements in advocacy are identified, with more than half of the countries in Africa reporting a national PC association. <https://goo.gl/NDtpYQ>

**N.B.** Additional articles on end-of-life care (EoLC) in Uganda are noted in the 20 March 2017 issue of Media Watch (#504, pp.5-6), and on EoLC in Kenya in the 6 February 2017 issue of the weekly report (#498, pp.4-5).

## Determinants of home death in patients with cancer: A population-based study in Ontario, Canada

*JOURNAL OF PALLIATIVE CARE* | Online – 29 June 2017 – The authors analysed data on 193,783 deaths, 9.1% of which occurred at home. In urban areas, home death was more likely for patients living in richer neighborhoods. The odds of dying at home when living in a rural area were no different from those living in the poorest urban neighborhood. Other variables associated with lower odds of home death were co-morbidities, certain cancers, and year of death. These findings underline the importance of targeting proper populations for public support at the end of life. <https://goo.gl/3zf4oH>

### Related

- *DEATH STUDIES* | Online – 5 July 2017 – **‘Informal care networks’ views of palliative care services: Help or hindrance?’** Three principles guide the reorientation of health services and enable their transition from hindrance to help: 1) Re-evaluation of organisational values; 2) Recognition of the primacy of caring networks; and, 3) Realignment of the inherent paternalism in health care provision. <https://goo.gl/ySh5YQ>
- *JOURNAL OF PALLIATIVE CARE* | Online – 29 June 2017 – **‘Engagement of primary care physicians in home palliative care.’** Of 302 survey respondents, 295 provided hospice and palliative care (HPC), 76 were engageable with further support, and 118 were not engageable regardless of support. The most substantial barrier to HPC was time to provide home visits (81%). <https://goo.gl/c4JgTQ>
- *PROFESSIONAL CASE MANAGEMENT*, 2017;22(4):174-180. **‘Supporting the support system: How assessment and communication can help patients and their support systems.’** Case managers can use their communication skills ... with patients and their support systems to identify stresses and issues that can impact the pursuit of health goals. In addition, case managers ensure that individuals and their support systems are kept informed about the health condition, stage of disease, plan of care, treatment options, and care transition plan. <https://goo.gl/DypCk1>

## End-of-life care in Australia's Northern Territory

### **The gap reversed: A review of site of death in the Top End**

*MEDICAL JOURNAL OF AUSTRALIA*, 2017;207(1):39. Indigenous Australians comprise 2.5% of the population of Australia, but 32.5% of people in the Northern Territory (NT). Studies have documented the critical importance for indigenous people from rural and remote areas of “finishing up” (the culturally appropriate reference to death and dying) on “country” (ancestral community and lands). Transferring sacred knowledge, providing culturally appropriate care, and returning their “animal spirit” to the land are all facilitated by dying on country. Finishing up on country in rural and remote NT usually takes place in dwellings in the person’s ancestral community and lands, either in their own home or the home of a relative or close community member who has assumed responsibility for their care. Territory Palliative Care Top End is the sole provider of palliative care services to the Top End of the NT. The authors have previously described the barriers and challenges faced in providing a culturally appropriate death on country. The proportion of deaths of non-indigenous people in institutions was comparable with the national figure; Indigenous people, however, were three times as likely as non-indigenous people to die in a residential dwelling. <https://goo.gl/gDi8fq>

Noted in Media Watch 13 May 2013, #305 (p.16):

- *RURAL & REMOTE HEALTH* | Online – 8 May 2013 – ‘**Considering Aboriginal palliative care models: The challenges for mainstream services.**’ Aboriginal people regard their land as spiritual and their culture dictates that an aboriginal person needs to know their origins, emphasising the value placed on kin and also demonstrating a strong desire to remain within their own country. Currently aboriginal people tend to not access palliative care (PC) services in mainstream facilities; and, there is little data on aboriginal admissions to PC centres. Over the last two decades only two models of PC focusing on and developed in aboriginal communities have been implemented. <https://goo.gl/K53vEi>

### **Assumptions and moral understanding of the wish to hasten death: A philosophical review of qualitative studies**

*MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 1 July 2017 – It is not uncommon for patients with advanced disease to express a wish to hasten death (WTHD). Qualitative studies of the WTHD have found that such a wish may have different meanings, none of which can be understood outside of the patient’s personal and socio-cultural background, or which necessarily imply taking concrete steps to ending one’s life. The starting point for the present study was a previous systematic review of qualitative studies of the WTHD in advanced patients. Here the authors analyse in greater detail the statements made by patients included in that review in order to examine their moral understandings and representations of illness, the dying process and death. They identify and discuss four classes of assumptions: 1) Assumptions related to patients’ moral understandings in terms of dignity, autonomy and authenticity; 2) Assumptions related to social interactions; 3) Assumptions related to the value of life; and, 4) Assumptions related to medicalisation as an overarching context within which the WTHD is expressed. The authors’ analysis shows how a philosophical perspective can add to an understanding of the WTHD by taking into account cultural and anthropological aspects of the phenomenon. They conclude that the knowledge gained through exploring patients’ experience and moral understandings in the end-of-life context may serve as the basis for care plans and interventions that can help them experience their final days as a meaningful period of life, restoring some sense of personal dignity in those patients who feel this has been lost. <https://goo.gl/cpiKba>

Noted in Media Watch 30 January 2017, #497 (p.9):

- *CHISHOLM HEALTH ETHICS BULLETIN*, 2016;21(4):7-11. ‘**Making sense of a wish to hasten death.**’ The expression of a wish to hasten death does not necessarily imply a genuine desire to hasten death or to be helped to die. While inadequate pain relief may be one such factor, more typically concerns are social and spiritual, such as loneliness, social isolation, feeling oneself to be a burden on others, hopelessness, and fears about the process of dying. <https://goo.gl/YCeivB>

Cont.

Noted in Media Watch 24 October 2016, #484 (p.13):

- *PALLIATIVE MEDICINE* | Online – 19 October 2016 – ‘**Assessment of the wish to hasten death in patients with advanced disease: A systematic review of measurement instruments.**’ Of the instruments identified, the Desire for Death Rating Scale or the Schedule of Attitudes toward Hastened Death featured in 48 of the 50 articles reviewed. The latter is the most widely used and is the instrument whose psychometric properties have been most often analysed. <https://goo.gl/tgJmM4>

**N.B.** Additional articles on the desire to hastened death are noted in past issues of Media Watch, e.g., 2 January 2017 (#493, p.10), and 7 March 2016 (#452, pp.8-9).

### **Improving interdepartmental communication following a patient death**

*NURSING MANAGEMENT*, 2017;24(4):23-27. This article describes how a new, tick-box-style death-in-department checklist was introduced in a London hospital adult emergency department (ED) to increase and improve communication and information sharing between the ED, the mortuary and the bereavement office. Audits undertaken before and after the introduction of the checklist show a 75% increase in the recording and sharing of information between relevant departments. The positive effect of the new checklist has led to its introduction in another, associated ED, and it has been incorporated into the trust’s end-of-life care policy. <https://goo.gl/tcwSfd>

### **Paediatric palliative care in the U.K.**

### **Nursing shortfall puts vital children’s palliative care services at risk**

*NURSING TIMES* | Online – 5 July 2017 – The worrying finding from the Nursing & Midwifery Council (NMC) that, for the first time in nearly a decade, more nurses and midwives are leaving the profession than are joining it will not be a surprise to those working in children’s palliative care (PC).<sup>1</sup> Together for Short Lives’ recent nursing survey echoes the NMC report,<sup>2</sup> with voluntary sector children’s PC providers across the U.K. facing the same nursing vacancy rate (11%) as the National Health Service in England. Unless things change radically, the long-term impact of this nursing gap could be devastating. Put simply, as things stand we do not have sufficient number of qualified nurses and consultants in this country to meet the complex needs of babies, children and young people with life-limiting and life-threatening conditions. In fact, children’s PC services are already being cut – including vital short breaks provided by children’s hospice services. As a result, despite the brilliant dedication and hard work of those providing children’s PC, our ability, as a society, to provide all these children with the quality of life and end-of-life care they deserve is inconsistent and patchy – largely dictated by geography and a post code lottery of provision. This is desperately frustrating for families and for the dedicated children’s PC charities, but should also be frustrating for the U.K. government in their ambitions to deliver on their commitment to choice for children and young people in England who reach the end of their lives.<sup>3</sup>

1. ‘The Nursing & Midwifery Council Register 2012/13-2016/17,’ Nursing & Midwifery Council, July 2017. <https://goo.gl/hrs4GL>
2. ‘The state of the UK children’s hospice nursing workforce: A report on the demand and supply of nurses to children’s hospice,’ Together for Short Lives, April 2017. [Noted in Media Watch 1 May 2017, #510 (p.12)] <https://goo.gl/GCMmgx>
3. ‘Choice in End-of-Life Care: Government response to the report of the Choice in End-of-Life Care Programme,’ Department of Health, July 2016. <https://goo.gl/xyQxfR>

**N.B.** ‘What’s Important to Me: A Review of Choice in End-of-Life Care,’ Choice in End-of-Life Care Programme was published in February 2015 and noted in Media Watch 2 March 2015 (#399, p.4).

## **National palliative care capacities around the world: Results from the World Health Organization Non-communicable Disease Country Capacity Survey**

*PALLIATIVE MEDICINE* | Online – 5 July 2017 – Previous estimates of global palliative care (PC) development have not been based on official country data. The World Health Organization (WHO) Non-communicable Disease Country Capacity Survey of WHO member state officials monitors countries' capacities for the prevention and control of non-communicable diseases. In 2015, for the first time, questions were included on a number of PC development metrics to generate baseline data for monitoring global PC development. This survey reveals: 1) A minority (37%) of countries have an operational national policy for non-communicable diseases that includes PC; 2) PC is least likely to have funding available compared with other core non-communicable disease services; and, 3) There is a large country-income gradient for PC funding, oral morphine availability, and integration of PC services at the primary levels of the health system. PC for non-communicable disease patients must be strengthened in a majority of countries. These data provide a baseline for trend measurement of official country-level and global PC development. A repeat assessment is taking place in the first half of 2017. <https://goo.gl/2Sn8o3>

## **Attitudes of palliative care clinical staff toward prolonged grief disorder diagnosis and grief interventions**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 3 July 2017 – The provision of psychological support to caregivers is an important part of the role of the clinical staff working in palliative care (PC). Staff knowledge and attitudes may determine their openness to referring caregivers to a psychological intervention. The authors developed a self-help intervention for grief and psychological distress among caregivers and were interested in exploring the extent to which staff knowledge and attitudes might affect future implementation. Overall, clinical staff [i.e., survey respondents] were positively oriented toward self-help for caregivers and intervention for grief. They were also basically confident in their skills and knowledge. While it was positive PGD attitudes that were associated with acceptability of self-help for caregivers, it was both positive and negative PGD attitudes that were associated more specifically with a willingness to refer caregivers to such an intervention. <https://goo.gl/yWsCmX>

## **Care professional's experiences about using Liverpool Care Pathway in end-of-life care in residential care homes**

*SCANDINAVIAN JOURNAL OF CARING SCIENCES* | Online – 29 June 2017 – Residential care homes (RCHs) play an important role in end-of-life care (EoLC), being the most common place of death for elderly people in several European countries. Care pathways such as the Liverpool Care Pathway for the Dying Patient (LCP) are used to improve and ensure quality care at the end of life. There is a lack of scientific evidence supporting the use of care pathways. Care professionals [i.e., study participants] expressed that they became confident through a shared approach to care, were supported to tailor the care according to the residents' individual needs, were supported to involve family members in decision-making and care and became more aware of the care environment. The results of this study indicate the LCP might be a useful tool for care professionals in improving EoLC in RCHs through increased attention to the goals of care, the individual needs of residents and family involvement. <https://goo.gl/ffYUYg>

Noted in Media Watch 12 December 216, #491 p.13):

- *PALLIATIVE MEDICINE* | Online – 8 December 2016 – '**Hospital doctors' understanding of use and withdrawal of the Liverpool Care Pathway: A qualitative study of practice-based experiences during times of change.**' The Liverpool Care Pathway (LCP) was used in U.K. hospitals (late 1990s to July 2014) in an attempt to generate hospice-style high-quality end-of-life care (EoLC) in acute settings. Despite being widely established, there was limited research or contextual evidence regarding this approach or its impact. Growing criticism from the public, media, politicians and healthcare professionals culminated with a critical independent review and subsequent withdrawal of the LCP.<sup>1</sup> This research explores experiences of doctors using the LCP, prior to and during its withdrawal, to better understand short-fallings and inform future initiatives in hospital EoLC. <https://goo.gl/bzP06I>

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

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *EUROPEAN PSYCHIATRY*, 2017;41:S11. **‘Euthanasia, physician assisted suicide in the Netherlands in dementia and late life psychiatric illness.’** Although controversial in many countries, in The Netherlands euthanasia or physician assisted death has increased in patients with early stages of dementia, psychiatric illness and in conditions described as “being tired of life” in the oldest old. There is a strong debate about this practice in the community and among professionals often with exclamation marks ranging from medical murder to providing ultimate care. There are few studies on the important issue of capacity making in psychiatric patients. The research that was performed does not show that a high threshold of capacity is required for granting euthanasia. Research on physician-assisted death in early dementia is scarce. With regard to end of life questions the debate in The Netherlands is still ongoing. <https://goo.gl/BAX7uM>
- *EUROPEAN PSYCHIATRY*, 2017;41:S11-S-12. **‘Mental health and social care providers facing requests of assisted suicide from elderly in nursing homes in Switzerland.’** The requests of assisted suicide questioned the professional mission, the quality of accompaniment provided to the older people, and both professional and personal values. Health and social care providers were required to ponder over ethical dilemmas or decisions. Several challenges were reported [by study participants], such as taking into account and articulating personal freedom or needs with collective functioning or organizational constraints before, during and after the assisted suicide, and reconciling self-determination with protection towards vulnerable people. <https://goo.gl/so8zrk>
- *EUROPEAN PSYCHIATRY*, 2017;41:S11. **‘Suicide and assisted suicide in Switzerland: Consequences for suicide prevention.’** The number of assisted suicide cases has doubled during the last five years and is expected to increase. It is mainly committed by women. To reduce the number of suicides by 25% by 2030, the federal authorities issued a national action plan in November 2016. There has been a position paper of Swiss public health concerning suicide prevention in the elderly. Concerning assisted suicide there is a broad discussion on the control of the state and on the role of physicians in the process. A survey of Swiss physicians showed much ambivalence. Position papers of gerontological and geriatric societies focused on the role loneliness and the provision of adequate psychiatric help, e.g., for depression, and the overestimation of autonomy. <https://goo.gl/GwC4Fv>
- *MEDSCAPE* | Online – 7 July 2017 – **‘Doctor [in the U.S.] support for assisted death rises, but debate continues.’** The number of physicians who support the concept of assisted death seems to be on the rise, but even in states where it is legal to provide a prescription to a patient who wants to die, few doctors have done so. Sixteen percent of almost 300 physicians who responded to a recent *Medscape* Medical News poll said they practice in states with a physician-assisted dying law. Only 17% of those physicians said they have used it with a patient. Thirteen percent said they'd received a request but had declined, and 70% said they'd never been asked to facilitate a patient's death. Some 62% of doctors who practice in states that do not allow assisted death said they had been in a situation in which they wished the patient could have been able to exercise that right. <https://goo.gl/hCs1sBf>
- *PATIENT EDUCATION & COUNSELING* | Online – 1 July 2017 – **‘Information needs about palliative care and euthanasia: A survey of patients in different phases of their cancer trajectory.’** Around 80% [of study participants] received information about their illness course and treatments. Ten percent received information about palliative care (PC) and euthanasia. Most information ... was given when the patient had a life expectancy of less than six months. However, a quarter of those in earlier phases in their illness trajectory, particularly those who experienced high pain, fatigue or nausea requested more information on these topics. Many patients want more information about PC and euthanasia than what is currently provided, also those in an earlier than terminal phase of their disease. Healthcare professionals should be more responsive, already from diagnosis, to the information needs about PC and possible end-of-life decisions. This should be patient-tailored, as some patients want more and some patients want less information. <https://goo.gl/bsmhTU>

## Worth Repeating

### Literature review

#### **When frailty should mean palliative care**

*JOURNAL OF NURSING EDUCATION & PRACTICE*, 2013;3(7):75-91. There is difficulty for practitioners in recognising frailty and in establishing palliative care (PC). This clinical entity is the sum of several illnesses or syndromes that are curable if taken separately. Practitioners have difficulty integrating the inevitably fatal nature of the situation. The aim of this work is to assist physicians in providing proper care for the frail elderly. It consists in a systematic review of the literature available, intended to answer the following questions: 1) Is frailty an appropriate indication for the instatement of PC? 2) When is the right moment to instate PC for the frail elderly subject? 3) What tools are available to assist care teams? 4) Are there efficient organisational models that integrate the frail elderly into PC? There are answers to these questions. But the level of evidence is low. It can be concluded that frailty is an indication for the instatement of PC. <https://goo.gl/hjzC8S>

### 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/nZMuK7>

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

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

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

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

### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/IXO4mD>

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

### **Canada**

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>

### **Europe**

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

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1I9K>

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

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