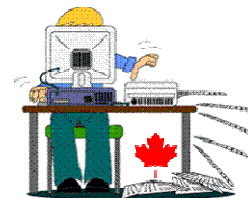


## Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

**Evidence-based professional development: 'Online learning in palliative care: Does it improve practice' (p.10), in *European Journal of Palliative Care*.**

## Canada

### Offshore firm accused of publishing junk science takes over Canadian journals

CTV NEWS | Online – 29 September 2016 – An offshore publishing company accused of disseminating junk science and duping researchers has taken over the publishing of several respected Canadian medical journals, a joint CTV News/Toronto Star investigation has found. Researchers and editors are sounding the alarm about a company called OMICS Group Inc., saying it could hijack the Canadian journals' names and reputations. OMICS, a Nevada corporation with headquarters in India, purports to offer hundreds of "leading-edge," peer-reviewed medical and scientific journals on its website. It claims to work with thousands of "esteemed reviewers" and scientific associations around the world. But in August, the U.S. Federal Trade Commission

(FTC) filed a lawsuit against OMIC, alleging the company is "deceiving academics and researchers about the nature of its publications," and falsely claiming its journals follow rigorous peer-review protocols.<sup>1</sup> OMICS has attracted controversy around the globe. Even before the FTC launched its lawsuit, critics have accused OMICS of being a so-called "predatory publisher," by leading inexperienced researchers to believe their work is being vetted by well-respected scientists and academics. <https://goo.gl/yLi42q>

The OMICS Group of publications include the *Journal of Palliative Care & Medicine*: <http://goo.gl/ieTbLZ>.

1. Federal Trade Commission charges academic journal publisher OMICS Group deceived researchers,' 26 August 2016. [Noted in Media Watch 5 September 2016, #478 (p.3)] <http://goo.gl/9gQpbt>

Noted in Media Watch 5 September 2016, #478 (p.14):

- *NURSING EDUCATION PERSPECTIVES*, 2016;37(5):275-277. 'The dark side of dissemination: Traditional and open access versus predatory journals.' Characteristics of scholarly open access (OA) journals are compatible with many characteristics of traditional journals, including the four key criteria of archiving/preservation, reputable board members, indexing, and peer review. Characteristics of predatory OA journals are not compatible with the identified traditional journal characteristics. <http://goo.gl/dAKfSs>

**N.B.** Additional articles on predatory journals noted in Media Watch 30 May 2016, #464 (p.11), 11 April 2016, #457 (p.7), 29 February 2016, #451 (p.9), and 8 February 2016, #448 (p.9).

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALBERTA & NORTH WEST TERRITORIES | CBC News – 29 September – ‘**Alberta, North West 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. <https://goo.gl/3RPXox>
- ALBERTA | *The Calgary Sun* – 28 September 2016 – ‘**Up to four Albertans a week dying from assisted-suicide.**’ Federal legislation legalizing medically-assisted death has opened the floodgates in Alberta, with as many as four people every week saying their final goodbyes with help from a doctor. Dr. James Silvius, Alberta Health Service’s lead for Medical Assistance in Dying Preparedness, said while officials expected to see high demand once the still controversial practice was legalized, he didn’t expect it to remain at this level three months later. <https://goo.gl/eCZWmL>

Noted in Media Watch 19 September 2016, #480 (p.1):

- *THE GLOBE & MAIL* | Online – 13 September 2016 – ‘**We can’t debate the assisted dying law without data.**’ How many legal assisted deaths have there been? No one is really saying – at least not officially. <http://goo.gl/rZcsGd>
- 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.

### Most hospital palliative care programs are understaffed

*KAISER HEALTH NEWS* | Online – 30 September 2016 – Most hospitals offer palliative care services that help people with serious illnesses manage their pain and other symptoms and make decisions about their treatment, while providing emotional support and assistance in navigating the health system. But hospital programs vary widely, and the majority fail to provide adequate staff to meet national guidelines, a recent study found.<sup>1</sup> <https://goo.gl/wxxUbO>

#### **Specialist Publications**

‘**Future of the palliative care workforce: Preview to an impending crisis**’ (p.6), in *The American Journal of Medicine*.

1. ‘Few hospital palliative care programs meet national staffing recommendations,’ *Health Affairs*, 2016; 35(9):1690-1697. [Noted in Media Watch 12 September 2016, #479 (p.2)] <http://goo.gl/zs3UUU>

### The forgotten providers

*FORBES* | Online – 29 September 2016 – As the American population gets older and the health-care system caters more and more to the needs of elderly and disabled people, the growing army of millions of home care workers will be one of the most valuable elements in keeping the whole system afloat. Home-care workers are not, however, afforded wages or protections commensurate with their importance, with over a quarter living under the poverty line and more than half reliant on public assistance. A new report<sup>1</sup> ... describes home care workers as personal aides, independent providers, home health aides, nursing assistants, and even informal networks of family members that provide living assistance, housekeeping chores, medication management, and a host of other services for elderly people and people with disabilities. <https://goo.gl/lrPaCC>

1. ‘U.S. Home Care Workers: Key Facts,’ Paraprofessional Healthcare Institute, New York City, September 2016. <https://goo.gl/a3jiRI>

## Push to take end-of-life forms digital reveals complicated path ahead

STATE OF NEW YORK | WXXI News (Rochester) – 28 September 2016 – For years physicians in New York state have asked seriously sick patients to fill out this paper document, capturing their wishes in case of emergency. Most Americans don't plan ahead for end of life. But for those who do ... there's a risk that the right people won't even see the document when it really matters. After all, a piece of paper is easily lost or left behind in an emergency. Advocates and lawmakers in New York are now pushing to shift the paper system to a mandatory electronic database for better access. But the requirement would call for a technology fix that's not coming easily. <https://goo.gl/iSd01j>

### [Specialist Publications](#)

**'Decisions by default: Incomplete and contradictory MOLST in emergency care'** (p.14), in *Journal of Post-Acute & Long-Term Care Medicine*.

## When a spouse dies, resilience can be uneven

THE NEW YORK TIMES | Online – 26 September 2016 – Psychologists have long maintained that after a brief period of sometimes intense bereavement, the vast majority of surviving spouses adjust well, returning to their previous work, daily routines and prior state of contentment within a few months to a year – a psychological outcome referred to as resilience. Studies by George A. Bonanno and colleagues at Columbia University as well as others, for example, have found that 60% of people who lost a spouse were resilient – satisfied with their lives and not depressed.<sup>1</sup> But new research is calling this global assessment inadequate to describe the aftermath of spousal loss for many if not most people, suggesting a need for more effective and specific ways to help them return to their prior state of well-being. Someone who ranks high in life satisfaction may nonetheless be having considerable difficulty in other domains that can diminish quality of life, like maintaining a satisfying social life, performing well at work or knowing who can help when needed. <https://goo.gl/mbV8OC>

### [Specialist Publications](#)

**'Improving the understanding and treatment of complex grief: An important issue for psychotraumatology'** (p.11), in *European Journal of Psychotraumatology*.

1. 'Resilience to loss and potential trauma,' *Annual Review of Clinical Psychology*, 2011;7:511-535. <https://goo.gl/vq952c>

## Lawmakers seek to provide relief to family caregivers

NEW JERSEY | *The Burlington County Times* (Willingboro) – 25 September 2016 – Two years ago, New Jersey became the second state to pass a version of the Caregiver Advise, Record, Enable (CARE) Act, which is designed to assist the estimated 1.75 million residents who provide home care for a loved one. The law aims to help caregivers deliver proper treatment and reduce hospital readmission by having health care facilities identify caregivers, notify them when the patient will be discharged, and provide instructions on how to perform necessary medical tasks at home. Such training ... must be conveyed in "non-technical language, to the extent possible." According to a 2014 survey of New Jersey caregivers, 72 percent were performing "nursing/medical tasks." And in 2013, family caregivers provided 37 billion hours of care nationwide, worth an estimated \$470 billion... <https://goo.gl/LFI7ig>

### Related

- PENNSYLVANIA | *The Intelligencer* (Doylestown) – 25 September 2016 – **'New CARE Act designed to help home caregivers.'** Beginning next spring, Pennsylvania hospitals will be required to train family caregivers prior to their loved ones' discharge from the hospital. This change comes via the Caregiver Advise, Record, Enable (CARE) Act, which goes into effect April 2017. The Care Act is one of several ways state legislators are attempting to address the needs of the 1.6 million Pennsylvanians who provide some of home care to a loved one. <https://goo.gl/8hw1WB>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- COLORADO | CBS News (Denver) – 24 September 2016 – ‘**This time voters will decide on “right-to-die” law In Colorado.**’ This November Colorado voters will be asked to decide on Proposition 106 which is the Colorado End of Life Options Act... The Colorado Legislature took up three bills in the past and they didn’t even make it out of committee, but voters often don’t agree with lawmakers. Proposition 106 is arguably the most emotional issue on the ballot. <https://goo.gl/xR6usk>

## International

### Reducing emergency admissions in the U.K.

#### **Carers’ Accident & Emergency visits can be preventable, says report**

U.K. | BBC News – 30 September 2016 – One in 10 unpaid carers who called 999 or took their loved one to Accident & Emergency (A&E) did so because they did not know where else to go, a report by Carers UK suggests.<sup>1</sup> Their snapshot online survey also found that one in five used A&E because they could not get hold of a GP or district nurse. The charity said a lack of local care and support services was contributing to a rise in A&E visits. There are about 6.5 million unpaid carers in the U.K. looking after a family member. <https://goo.gl/hwPYAL>

1. ‘Pressure Points,’ Carers UK, September 2016. <https://goo.gl/va5XRC>

### End-of-life care in England

#### **Number of people dying with dementia more than doubles in past decade**

U.K. (England) | *The Sun* – 30 September 2016 – One in six deaths in 2014 had dementia on the certificate, against one in 15 in 2001. Victims are less likely to die at home than people with cancer, circulatory or respiratory illnesses. Two-thirds of adults want to see their days out in familiar surroundings and 21% aged 65-plus do. That falls to eight per cent for dementia patients. A report by Public Health England says the condition is “not routinely identified as a terminal illness,” meaning patients have less access to end-of life-care. <https://goo.gl/pSZeAj>

1. ‘Dying with dementia,’ Public Health England, September 2016. <http://goo.gl/eK1ewa>



Living and dying in pain:  
It doesn’t have to happen

75% of the world population (5.5 billion) does not have adequate access to controlled medications for pain relief

Millions of people suffer from pain which is avoidable and could be managed with proper access to the correct medications. Each year about 18 million people die in pain

National laws, gaps in healthcare workers’ education and economic barriers prevent people from getting pain relief

**8 October 2016**

<http://goo.gl/iKZH4k>

## Elder care in England

### Nursing homes “closing each week”

U.K. (England) | BBC News – 28 September 2016 – Nursing homes (NH) are closing at the rate of at least one per week in England, due mainly to a shortage of nurses, official figures suggest. It means the number of NH and nursing beds has fallen for the first time in five years. A total of 73 homes cancelled their registration in the first six months of 2016, the Care Quality Commission said, partly due to recruiting problems. The Department of Health said nurse training places were being increased. In the year 2015-2016, the number NH in England fell from 4,697 to 4,633 and the number of their beds reduced from 224,674 to 224,026, reversing the increase seen over the previous five years. And 73 homes cancelled the element of their registration that is required to operate as a NH in the first half of 2016, compared with 72 in the whole of 2015. <https://goo.gl/8Nrwy9>

#### Specialist Publications

**‘Improving end-of-life care in nursing homes: An innovative model of education and training’** (p.9), in *European Journal of Palliative Care*.

**‘Estimating the need for palliative care at the population level: A cross-national study in 12 countries’** (p.15), in *Palliative Medicine*.

Noted in Media Watch 9 May 2016, #461 (p.5):

- U.K. | BBC News – 4 May 2016 – **‘Quarter of U.K. care homes “at risk of closure.”**“ More than a quarter of care homes in the U.K. are in danger of going out of business within three years, figures obtained by BBC Radio Four suggest. <http://goo.gl/rKWV9Y>.

Noted in Media Watch 2 May 2016, #460 (p.3):

- U.K. (England & Wales) | LocalGov.com – 25 April 2016 – **‘Care home insolvencies increase as sector pushed to “breaking point.”**“ New research discovered 47 care home operators in England & Wales became insolvent last year, up from 40 the previous year. <http://goo.gl/cpuK8v>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Victoria) | *The Age* – 25 September 2016 – **‘Growing support for unprecedented assisted dying laws.’** Unprecedented dying with dignity laws could pass the Victorian Parliament with support growing across all sides of politics for assisted dying legislation. A Fairfax Media survey of MPs from all sides of politics has found there is likely to be enough support for assisted dying legislation, “as long as the laws were robust and clearly defined with sufficient protection from abuse.” <https://goo.gl/bVvk3tP>

## Specialist Publications

### Older adults of underrepresented populations and their end-of-life preferences: An integrative review

*ADVANCES IN NURSING SCIENCE* | Online – 26 September – 2016 – This integrative review was conducted to examine the evidence for understanding diversity in end-of-life (EOL) preferences among older adults of underrepresented groups. Findings from 21 studies were critically examined, grouped, and compared across studies, populations, and settings. Five major themes emerged: 1) Advance directives; 2) Hospice and palliative care; 3) Communication; 4) Knowledge and information; and, 5) Home and family. Despite multidisciplinary attention, content and methodological limitations narrowed understanding of what matters most to these groups when making decisions at EOL. Rigorous longitudinal studies with more ethnically diverse samples are needed to detect modifiable factors related to disparities at the EOL. <https://goo.gl/gh2bjx>

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

### Future of the palliative care workforce: Preview to an impending crisis

*AMERICAN JOURNAL OF MEDICINE* | Online – 29 September 2016 – A growing workforce shortage in palliative care (PC) is increasingly recognized. Current estimates report: 6,600 board-certified physicians in practice; a projected shortage of 18,000 physicians (based on optimal need for specialists); and, less than 250 fellowship-trained physicians entering the field annually. Additionally, there is a cap on the number of Medicare funded graduate medical education slots, which means programs have to rely on philanthropy and development to fund fellows. Similar shortages are evident, though not as well studied, among advanced practice providers, nurses, chaplains, and social workers. The authors project no more than a 1% absolute growth in PC physicians in 20 years. During the same two decade period, the number of persons eligible for PC will grow by over 20%, resulting in a ratio of only one physician for every 26,000 patients by 2030. This is simply untenable in meeting the time-intensive, complex, and dynamic needs of those with serious illness. As calls for integration of PC increase, the worsening shortage of specialty physicians presents a significant barrier to realizing patient-centered, serious illness care. Potential solutions should

address the substantial prevalence of burnout in the field, support increased delivery of foundational PC services by non-specialty clinicians, and grow the workforce of trained PC clinicians through traditional and alternative mechanisms. <https://goo.gl/0TkS6L>

#### Workforce for 21st-Century health and health care

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 26 September 2016 – The U.S. needs to make a human investment in health and health care professionals who serve patients at the end of their natural life span. Each year, approximately to 3 million U.S. residents reach the end of their lives. For much too long, the end-of-life care needs of these patients have been served as an extension of the workforce that cares for those with advanced illness. Investing in and training more palliative care and hospice care professionals would help to lessen the dependence on health care professionals whose skills and talents are best suited to caring for individuals with acute or advanced illness or chronic disease. With added capacity in palliative and hospice care, the U.S. could provide people with the end-of-life experience they desire – a choice that everyone deserves. <https://goo.gl/k9hliD>

#### Selected articles on the palliative care workforce in the U.S.

- U.S. (North Carolina) | Fox 8 News (Lexington) – 12 July 2016 – ‘**Doctor shortage affecting local hospices.**’ End-of-life care is a field doctors just aren’t going into. “There’s simply not enough physicians that specialize in hospice and palliative medicine,” said Dr. Jennifer Davis, medical director for Hospice of Davidson County. “I do think it’s a calling to do this kind of work; you have to have a lot of compassion, communication skills, and excellent skills to keep [patients] comfortable.” [Noted in Media Watch 18 July 2016, #471 (p.4)] <http://goo.gl/Rfbs7u>
- *ANNALS OF INTERNAL MEDICINE* | Online – 20 October 2015 – ‘**Evolving the palliative care workforce to provide responsive, serious illness care.**’ The U.S. is currently in the midst of a national crisis in providing accessible and responsive palliative care due to a shortage of professionals trained to provide this care. [Noted in Media Watch 26 October 2015, #433 (p.8)] <http://goo.gl/6LGk3X>
- *HEALTH LEADERS* | Online – 13 July 2012 – ‘**Palliative care challenged by physician shortage.**’ There is about one cardiologist in the U.S. for every 71 people experiencing a heart attack; one oncologist for every 141 newly diagnosed cancer patients; and, only one palliative care physician for every 1,200 people living with a life-threatening illness. [Noted in Media Watch 16 July 2012, #262 (p.10)] <http://goo.gl/0IKQHB>

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## Related

- *HEALTHCARE* | Online – 28 September 2016 – ‘**Scalable principles of community-based high-value care for seriously ill individuals: Diamonds in the rough.**’ As health systems shift to risk-based payment structures, palliative care (PC) will play an increasing role in improving value of care outside of the hospital. Based on successful models of community-based PC, the authors identify six principles – 1) Interdisciplinary team-based care; 2) 24/7 access and responsiveness; 3) Concurrent PC with disease-directed treatment; 4) Targeting services to high-risk patients; 5) Integrated medical and social supports; and, 6) Caregiver support – that are widely implemented because of their impact on improving value for seriously ill individuals. <https://goo.gl/UF8JcF>
- *JOURNAL OF HOSPICE AND PALLIATIVE NURSING* | In Print – Accessed 29 September 2016 – ‘**Nursing care of the end-of-life patient twenty five years after passage of the Patient Self-Determination Act.**’ Based on the results of this study, it appears that there has been a significant increase in aggressiveness of nursing behavioral intentions in the care of the end-of-life (EOL) patient, even if the patient has a DNR order and is attempting to refuse certain nursing or medical procedures. This study has implications for increased teaching on EOL care, quality of life, and rights of patients to self-determination during the EOL. <https://goo.gl/tlFsGp>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 26 September 2016 – ‘“**Who does what?” Ensuring high quality and coordinated palliative care with our oncology colleagues.**’ Palliative care for cancer patients continues to grow at an unprecedented pace. This is exemplified by rapid expansion of specialty teams and services, alongside a remarkable increase in the public discourse about patient-centered care when cure is not possible. <https://goo.gl/M1teO9>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 September 2016 – ‘**Top 10 tips for using advance care planning codes in palliative medicine and beyond.**’ Although recommended for all persons with serious illness, advance care planning (ACP) has historically been a charitable clinical service. Inadequate or unreliable provisions for reimbursement, among other barriers, have spurred a gap between the evidence demonstrating the importance of timely ACP and recognition by payers for its delivery. <https://goo.gl/EI913Z>
- *POLITICS, POLITICS & NURSING PRACTICE* | Online – 27 September 2016 – ‘**Using agency nurses to fill RN vacancies within specialized hospice and palliative care.**’ The use of agency nurses offers flexibility in filling registered nurse (RN) openings during times of shortage, yet little is known about their use in specialized palliative care. Increases in full-time RN vacancies are associated with a significant increase in the use of agency RNs, while part-time RN vacancies are associated with a significant decrease in agency RNs. These results suggest that full-time agency RNs were used as a supplemental workforce to fill vacancies until the full-time position is recruited. However, for part-time vacancies, the responsibilities of those positions shifted onto existing staff and the position was not filled. <https://goo.gl/6Hf9GJ>

### **Palliative care in Dutch hospitals: A rapid increase in the number of expert teams, a limited number of referrals**

*BMC HEALTH SERVICES RESEARCH* | Online – 23 September 2016 – Palliative care (PC) in Dutch hospitals is often supported by palliative care teams (PCTs). The number of these teams has rapidly increased over the last few years, but there are substantial differences between teams regarding the disciplines represented, the procedures and the number and timing of referrals. The involvement of PCTs in care for incurably ill patients is relatively limited. To stimulate the further development and implementation of PCTs in hospitals, the authors recommend the development of a formalized quality framework with models for ... PC team consultation, to improve the quality of PC in hospitals. Such a framework, that should be adopted by professional organizations and policymakers, can form the basis for the development of quality criteria and quality assessment of PCTs. The concepts and borders of generalist and specialist PC should be discussed and where possible defined, so that criteria can be set regarding the education of all disciplines involved. Furthermore, adequate staffing of the PCTs is necessary to increase the number of PCT consultations. <https://goo.gl/hmQjS5>

Cont.

Noted in Media Watch 16 November 2015, #436 (p.16):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2015;22(6):309-311. '**Agora: Building bridges in palliative care in The Netherlands.**' Many countries have opted for palliative care (PC) as a specialist field. This is not the case in The Netherlands. Here, the basic principle is that PC is part of regular, mainstream care. General healthcare providers like family doctors and nurses, and institutions such as hospices, nursing homes and hospitals, are all expected to be able to provide good PC. They are supported in that task by specialist multidisciplinary teams.

N.B. Access to this article requires a subscription. Journal home page: <https://goo.gl/0np1l2>

## Caring for people with diabetes at the end of life

*CURRENT DIABETES REPORTS* | Online – 22 September 2016 – While general end-of-life care (EOLC) guidelines apply to diabetes, there are some diabetes-specific issues that need to be considered. These include the usual long trajectory to EOLC that enables clinicians and people with diabetes to proactively discuss when to change the focus of care from preventing diabetes complications (tight control) to a palliative approach. The aim of this paper is to discuss common disease trajectories and their relationship to diabetes care, outline strategies for proactively discussing these issues and suggest indications that palliative care is warranted. <https://goo.gl/S23le5>

Noted in Media Watch 1 February 2016, #447 (p.10):

- *DIABETES CARE*, 2016;39(2):308-318. '**A position statement of the American Diabetes Association.**' The authors address diabetes management at end of life and in those receiving palliative and hospice care. <http://goo.gl/e5k80D>

Noted in Media Watch 9 December 2013, #335 (p.13):

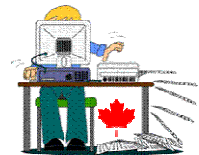
- *PRACTICAL DIABETES*, 2013;30(90):355-356. '**End of Life Diabetes Care: A Strategy Document: Where are we one year on in the light of the review of The Liverpool Care Pathway?**' Access to this article requires a subscription. <http://goo.gl/XAihMI>

## Palliative care in the trauma ICU

*CURRENT OPINION IN CRITICAL CARE* | Online – 21 September 2016 – Misconceptions of palliative medicine as it applies to trauma patients linger among trauma surgeons and many continue to practice without routine consultation of a palliative care (PC) service. Aggressive end-of-life care does not correlate with an improved family perception of medical care received near death. Additionally, elderly patients near the end of life often prefer palliative treatments over life-extending therapy, and their treatment preferences are often not achieved. A new geriatric-specific prognosis calculator estimates the risk of mortality after trauma, which is useful in starting goals of care discussions with older patients and their families. Shifting our quality focus from 30-day mortality rates to measurements of symptom control and achievement of patient treatment preferences will prioritize patient beneficence and autonomy. Ownership of surgical PC as a service provided by acute care surgeons will ensure that our patients with incurable injury and illness will receive optimal patient-centered care. <https://goo.gl/OkkCm8>

### [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>





## End-of-life care in England

### **Improving end-of-life care in nursing homes: An innovative model of education and training**

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(5):222-226. In England, 19.6% of those who die live in care homes, so care home staff need to be trained to provide good end-of-life care (EOLC). A team from the Royal Marsden National Health Service Foundation Trust in London have set up an innovative model of training to help nursing home staff, as well as local GPs, improve EOLC for residents. The model has been rolled out in 33 nursing homes in Sutton and Merton. It encompasses education and training, clinical rounds, advice and guidance, communication, and care co-ordination. Nursing home residents are offered an electronic EOLC plan on Coordinate my Care (CMC). Data show

that around 85% of people who have a CMC record die in their preferred place. The training model is being extended to residential care homes, and potentially to care homes for people with learning disabilities.



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Contents page: <https://goo.gl/IUscng>

#### **Related**

- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 27 September 2016 – ‘**An interim analysis of an advance care planning intervention in the nursing home setting.**’ The time- and resource-intensive nature of robust advance care planning (ACP) must be anticipated when systematically implementing ACP in the nursing home setting. The fact that these conversations [with study [participants] resulted in changes over 2/3 of the time reinforces the importance of deliberate, systematic ACP to ensure that current treatment preferences are known and documented so that these preferences can be honored. <https://goo.gl/43Kyji>

### **Can qualitative interviews have benefits for participants in end-of-life care research?**

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(5):227-231. People approaching the end of life (EOLC) and bereaved relatives are perceived as vulnerable populations to conduct research with. A secondary analysis of existing data from palliative care research was undertaken to identify whether participants in qualitative research interviews (QRIs) derived any therapeutic benefits. Categories drawn from the literature provided an analytical frame. Emotional, cognitive and social benefits were identified, particularly emotional healing, having someone to listen and to talk to, and making sense of situations or life events. QRIs can have therapeutic benefits for people who are bereaved or approaching the EOL, but researchers must have the competences to safeguard both participants and themselves.



### **Palliative care in chronic and progressive neurological disease: Summary of a consensus review**

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(5):232-235. The role of palliative care (PC) for people with progressive neurological disease – such as motor neurone disease, Parkinson’s disease and multiple sclerosis – has already been delineated. Patients with other neurological conditions – such as stroke, brain injury and brain tumours – may also benefit from PC. In collaboration with the European Academy of Neurology, a taskforce of the European Association for Palliative Care has produced a consensus review on the development of PC for people with chronic and progressive neurological disease. It makes recommendations on the early integration of PC, multidisciplinary team care, communication, symptom management, carer support, end-of-life care – including the wish for hastened death – and training and education of professionals. This consensus review will hopefully be followed by further collaboration aimed at increasing the evidence base and include PC in all services for neurology patients.



Cont.

## Related

- *PALLIATIVE MEDICINE* | Online – 28 September 2016 – ‘**Palliative care for Parkinson’s disease: Patient and carer’s perspectives explored through qualitative interview.**’ People with Parkinson’s disease and their carers [i.e., study participants] were unfamiliar with the term palliative care (PC). When informed of the role of PC, most felt that they would benefit from this input. People with Parkinson’s disease and carers experienced a high illness burden and wanted extra support. <https://goo.gl/SMHhHt>

Noted in Media Watch 20 June 2016, #467 (p.14):

- *NEUROLOGICAL SCIENCES* (Italian Neurological Society) | Online – 14 June 2016 – ‘**Need for palliative care for neurological diseases.**’ The realization of an effective palliative approach to neurological diseases requires specific skills and expertise to adapt the concept of palliation to the peculiarities of these diseases; this approach should be realized through the cooperation of different services and the action of a multidisciplinary team in which the neurologist should play a central role to identify and face the patient’s needs. <http://goo.gl/kOQ9z7>

Noted in Media Watch 16 May 2016, #462 (p.8):

- *BMC NEUROLOGY* | Online – 10 May 2016 – ‘**How integrated are neurology and palliative care services? Results of a multicentre mapping exercise.**’ The mapping exercise showed heterogeneity in service provision and integration between neurology and specialist PC services, which varied not only between sites but also between diseases. This highlights the need and opportunities for improved models of integration, which should be rigorously tested for effectiveness. <https://goo.gl/qaAeO0>

**N.B.** Additional articles on the palliative care needs of people living with a neurodegenerative disorder are noted in this issue of Media Watch.

## Online learning in palliative care: Does it improve practice

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(5):236-239. There are now many palliative care (PC) e-learning courses, ranging from stand-alone, non-moderated one-off courses to blended learning programmes leading to higher education degrees. A literature review found no firm evidence of an improvement in patient outcomes that can be attributed to online learning. A recent pilot study of an online learning module on pain management for specialist PC nurses attempted to measure the actual impact of the course on patients’ pain levels. Some authors suggest that successful courses are those that combine participative and online interactive methods. The evidence base for online learning may be compromised by variables such as programme design, system requirements, degree of interactivity, educational styles and topics. The lack of evidence needs to be addressed. There is a need for more research, but also greater conceptual clarity, and methods that can evaluate the effectiveness of training courses at design stage.



Noted in Media Watch 26 November 2012, #281 (p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2012;2(4):292-293. ‘**Can e-learning be used to teach end-of-life care?**’ Many clinicians and educators regard e-learning with scepticism, especially in relation to a subject as personal and sensitive as end-of-life care. This is especially the case if they have been exposed to poorly designed e-learning programmes, or those that appear irrelevant, simplistic or not rooted in the real world of practice. The increasing pressure to complete requirements for statutory and mandatory training through e-learning programmes has increased the aversion that some clinicians have toward this whole way of learning. <https://goo.gl/2je3Y0>



### Closing the Gap Between Knowledge & Technology

Fostering education and interaction, and the exchange of ideas, information and materials.  
<http://goo.gl/OTpc8l>

### **End-of-life care at home out of hours: Think 3 a.m.**

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(5):244-245. The “in-hours” period is only between 9 a.m. and 5 p.m., or thereabouts, while the out-of-hours period represents all the rest; that is, approximately two thirds of the time. The same number of people die every hour, whether this is during the day or at night, during the week or at the weekend. Therefore, out of all people who die, two thirds die during the out-of-hours period. When end-of-life care is done well out of hours, it can be of great benefit to all ... provide comfort, compassion and great care, despite the fact that they have just met the patient and their family, and provided care has been thoroughly thought through and well prepared. So when you’re planning the discharge of a patient in their last weeks or days of life who is going home, put yourself in the shoes of the doctor or nurse who has never met them but will manage their care at 3 a.m. in case of a sudden deterioration. Think of that phone call in the middle of the night.



### **Improving the understanding and treatment of complex grief: An important issue for psychotraumatology**

*EUROPEAN JOURNAL OF PSYCHOTRAUMATOLOGY* | Online – 23 September 2016 – In The Netherlands, every year 500,000 people are confronted with the death of a close relative. Many of these people experience little emotional distress. In some, bereavement precipitates severe grief, distress, and dysphoria. A small yet significant minority of bereaved individuals develops persistent and debilitating symptoms of persistent complex bereavement disorder (PCBD) (also termed prolonged grief disorder), posttraumatic stress disorder, and depression. Knowledge about early identification of, and preventive care for complex grief has increased. Moreover, in recent years there has been an increase in treatment options for people for whom loss leads to persistent psychological problems. That said, preventive and curative treatments are effective for some, but not all bereaved individuals experiencing distress and dysfunction following loss. <https://goo.gl/GJFzma>

#### **Related**

- *WORLD PSYCHIATRY*, 2016;15(3):266-275. “**Prolonged grief disorder**” and “**persistent complex bereavement disorder**,” but not “**complicated grief**,” are one and the same diagnostic entity: An analysis of data from the Yale Bereavement Study.’ There exists a general consensus that prolonged grief disorder, or some variant of, represents a distinct mental disorder worthy of diagnosis and treatment. Nevertheless, confusion remains over whether different names and proposed symptom criteria for this disorder identify the same or different diagnostic entities. This study aimed to determine whether PGD, complicated grief, and persistent complex bereavement disorder as described by the DSM-5 are substantively or merely semantically different diagnostic entities. <https://goo.gl/GksBNx>

### **End-of-life care in Italy**

#### **Hospital, local palliative care network and public health: How do they involve terminally ill patients?**

*EUROPEAN JOURNAL OF PUBLIC HEALTH* | Online – 28 September 2016 – Several authors highlighted that over one quarter of the entire health care expenditure is spent on patients in the last year of life that represent about 1% of the entire population. Overall, in the authors’ experience about half the patients underwent at least one hospitalization in the last month of life accounting for mean hospitalization costs of 3,037 Euros per patient. Hospitalization costs, hospital stay and number of hospital admissions were significantly lower in patients referred to palliative care (PC) compared with patients who underwent usual care. PC consultation seems to lower hospital costs for patients with serious and advanced illnesses and reduce the probability of dying in hospital. The authors findings support a progressive shift of the economic burden of end-of-life care from the hospital sector to the long-term care sector, with consequent implications for the supply, organization and funding of both these sectors. <https://goo.gl/bFG5wo>

Cont.

Noted in Media Watch 1 June 2015, #412 (p.12):

- *RECENTI PROGRESSI IN MEDICINA*, 2015;106(5):201-202. **'Early palliative care.'** Several randomized controlled trials have demonstrated the efficacy of early palliative care (PC), in particular in cancer patients and, more recently, also in patients with other advanced life-threatening illnesses. Results have been consistent in showing that early PC improves quality of life without negatively affecting survival compared with more aggressive treatment options. <https://goo.gl/OrCyCi>

N.B. Italian language article.

### **Communicating delicately: Introducing the need to make a decision about the use of life-sustaining treatment**

*HEALTH COMMUNICATION* | Online – 26 September 2016 – The purpose of this study was to explore how clinicians introduce the need to make a decision about the use of life-sustaining treatment and how surrogates respond to these introductions during family conferences... This article focuses on the use of the perspective-display sequence as a way to introduce the decision-making conversation. In the family conferences, the perspective-display sequence involved: 1) The clinician's perspective-display invitation of the surrogates' assessment of the patient's wishes; 2) The surrogates' reply or assessment; and, 3) The clinician's decision proposal, which often incorporates the surrogates' assessment. Asking about the patient's wishes is a delicate way to ease into the decision-making conversation. By using the perspective-display sequence, clinicians are also participating in shared decision making; their decision

proposal is co-constructed with surrogates' understanding of the patient's wishes regarding the treatment. <https://goo.gl/HPEkYL>

#### **Harmful emotional responses that patients and physicians may have when their values conflict**

*JOURNAL OF CLINICAL ETHICS*, 2016;27(3):187-200. One of the most difficult decisions a clinician may face is when, if ever, to decline what a patient wants, based on the clinician's own moral conscience. Regardless of what the clinician decides, the outcome may be deeply emotionally painful for both parties, and the pain may last. The author discusses this pain, how it occurs, and what we can do to try to reduce it before, during, and after a conflict arises. Approaches include explaining how we are like the patient or doctor, that no one is perfect, and that what we do is not who we are. <https://goo.gl/BkZHBz>

Noted in Media Watch 22 August 2016, #476 (p.10):

- *JOURNAL OF ADVANCE NURSING* | Online – 10 August 2016 – **'An integrative review of how families are prepared for, and supported during withdrawal of life-sustaining treatment in intensive care.'** Greater understanding is needed of the language that can be used with families to describe death and dying in intensive care. Clearer conceptualisation of the relationship between the medically focussed withdrawal of life-sustaining treatments and patient/family centred end-of-life care is required making the nursing contribution at this time more visible. <http://goo.gl/xVM3jG>

#### **Related**

- *EUROPEAN HEART JOURNAL* | Online – 26 September 2016 – **'Age-specific prognostication after out-of-hospital cardiac arrest: The ethical dilemma between 'life-sustaining treatment and 'the right to die' in the elderly.'** While prognostic values on survival after out-of-hospital cardiac arrest have been well investigated, less attention has been paid to their age-specific relevance. The authors aimed to identify suitable age-specific early prognostication in elderly patients suffering out-of-hospital cardiac arrest in order to reduce the burden of unnecessary treatment and harm. <https://goo.gl/jOhax5>
- *HEALTH COMMUNICATION* | Online – 26 September 2016 – **'The Grim Reaper, Hounds of Hell, and Dr. Death: The role of storytelling for palliative care in competing medical meaning systems.'** This study addresses what tensions palliative care (PC) providers experience in their institutions and what communicative strategies they use at the interpersonal level in managing those tensions. <https://goo.gl/sq8HZ9>

## Psychiatry and the dying prisoner

*INTERNATIONAL REVIEW OF PSYCHIATRY* | Online – 26 September 2016 – Due to the growing number of ageing prisoners in the American correctional system, penal institutions are increasingly caring for patients with chronic and potentially terminal medical conditions. To address this problem states have attempted sentencing reform initiatives and adopted compassionate release programmes; however, these efforts have failed to significantly reduce the number of elderly or seriously ill inmates. Correctional mental health services are now called upon to aid in the care of prisoners at the end of life. This article presents the common elements of prison hospice programmes and the role psychiatry plays in this multidisciplinary effort. The

right-to-die movement holds future implications for correctional mental health professionals. The historical and legal background of this international movement is presented with attention given to landmark cases and statutes protecting institutionalized patients. <https://goo.gl/JC7OIO>

### Prison Hospice: Backgrounder

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of the articles, reports, etc., noted in past issues of the weekly report available at: <http://goo.gl/ZpEJyQ>

## No matter the species

### **American Animal Hospital Association/ International Association for Animal Hospice and Palliative Care end-of-life guidelines**

*JOURNAL OF THE AMERICAN ANIMAL HOSPITAL ASSOCIATION* | Online – 30 September 2016 – End-of-life (EOL) care and decision making embody the critical final stage in a pet's life and are as important and meaningful as the sum of the clinical care provided for all prior life stages. EOL care should focus on maximizing patient comfort and minimizing suffering while providing a collaborative and supportive partnership with the caregiver client. Timely, empathetic and non-judgmental communication is the hallmark of effective client support. Veterinarians should not allow an EOL patient to succumb to a natural death without considering the option of euthanasia and ensuring that other measures to alleviate discomfort and distress are in place. Animal hospice care addresses the patient's unique emotional and social needs as well as the physical needs traditionally treated in clinical practice. An EOL treatment plan should consist of client education; evaluating the caregiver's needs and goals for the pet; and, a collaborative, personalized, written treatment plan involving the clinical staff and client. Primary care practices should have a dedicated team to implement palliative and hospice care for EOL patients. How the healthcare team responds to a client's grief after the loss of a pet is a key factor in the client's continued loyalty to the practice. <https://goo.gl/7fCW8A>

Noted in Media Watch 11 April 2016, #457 (p.14):

- *VETERINARY RECORD* (British Veterinary Association), 2016;178(15):369-374. **'Veterinary hospice and palliative care: A comprehensive review of the literature.'** Interest in hospice and palliative care (PC) for companion animals is on the rise, yet there has been limited scholarly research in these areas to date. <http://goo.gl/zGG0kH>

## **Burnout in families. The emotional burden of the "traumatized" families**

*JOURNAL OF FAMILY MEDICINE & DISEASE PREVENTION*, 2016;2(4). Family members of people with chronic health problems can be affected by burnout. A person who assists a suffering person, beyond the professional role, is indicated generally by the term "caregiver." The definition of burnout in families is fairly recent, because the psychology of trauma has ignored a large segment of the traumatized and disabled subjects (family and other assistants of the "suffering" people) unwittingly, for a long time. The intervention on families requires family psychotherapeutic techniques performed by experienced professionals. One of the most common models of intervention is based on the principle that the observation unit for the understanding of the disorder is not the single individual but the relationship between individuals. <https://goo.gl/cCmhCs>

## Decisions by default: Incomplete and contradictory MOLST in emergency care

*JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE* | Online – 27 September 2016 – Sixty-nine percent of forms reviewed had at least one section left blank. Inconsistencies were found in patient wishes among a subset (14%) of patients, wherein their desire for “comfort measures only” seemed contradicted by a desire to be sent to the hospital, receive IV fluids, and/or receive antibiotics. Patients and proxies may believe that making choices and documenting some, but not all, of their wishes on the Medical Orders for Life-Sustaining Treatment (MOLST) form is sufficient for directing their end-of-life care. The result of making some, but not all, choices may result in patients receiving undesired, extraordinary, or invasive care. <https://goo.gl/2Ew9LH>

Noted in Media Watch 19 October 2015, #432 (p.14):

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 14 October 2015 – ‘**Toward evidence-based end-of-life care.**’ More than two thirds of U.S. states have implemented Physician (or Medical) Orders for Life-Sustaining Treatment (POLST/MOLST) programs despite the absence of compelling evidence that they improve patient outcomes. <http://goo.gl/9gFs4X>

## Final transitions to place of death: Patients and families wishes

*JOURNAL OF PUBLIC HEALTH* | Online – 21 September 2016 – This four-country study (Belgium, The Netherlands, Italy and Spain) examines prevalence and types of final transitions between care settings of cancer patients and the extent to which patient/family wishes are cited as a reason for the transition. The authors included 2,048 non-sudden cancer deaths; 63% of patients had at least one transition between care settings in the final 3 months of life. Hospital death from home (25-55%) and home death from hospital (16-30%) were the most frequent types of final transitions in all countries. Patients’ or families’ wishes were mentioned as a reason for a final transition in 5-27% and 10-22% across countries. Hospital deaths from home is the most prevalent final transition in three of four countries studied, in a significant minority of cases because of patient/family wishes. <https://goo.gl/f9wefd>

## Palliative care practices in maternity wards: Focus on the delivery room

*MÉDECINE PALLIATIVE* | Online – 29 September 2016 – Eighty-three percent of maternity wards [i.e., survey respondents] are faced at least once a year with palliative care (PC) initiated in the delivery room. Moreover, 90% of maternity wards declare that PC is part of the mission of the professionals working in the delivery room. Regarding training, 44% of maternity wards have personnel trained in PC, and 65% have identified a need for training in their unit. Protocol for PC initiated in delivery room is available for 31% of maternity ward and 81% of protocols are less than 5 years old. On average, more than four professionals have participated in its creation. The majority of end-of life’s practices are similar in most maternity wards (put the babies in parent’s arms or in “skin to skin” contact, creation of memory traces). Those using a protocol differ on pain assessment and consideration of the newborn’s environment among other things. <https://goo.gl/SPOGrP>

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

Noted in Media Watch 2 May 2016, #460 (p.4):

- *ZEITSCHRIFT FÜR GEBURTSHILFE UND NEONATOLOGIE*, 2016;220(2):53-57. ‘**Palliative care in the delivery room.**’ Basic background information of palliative care of newborns in the delivery room are presented. Recommendations are given focusing on: 1) Non-pharmacological and pharmacological ways of symptom control in PC of dying newborns; and 2) Meeting the individual psychological, emotional and spiritual needs of the parents. <http://goo.gl/gcgnAC>

**N.B.** German language article.

## Estimating the need for palliative care at the population level: A cross-national study in 12 countries

*PALLIATIVE MEDICINE* | Online – 28 September 2016 – To implement the appropriate services and develop adequate interventions, detailed estimates of the needs for palliative care (PC) in the population are needed. The aim of this study was to estimate the proportion of decedents potentially in need of PC across 12 European and non-European countries: Belgium, Czech Republic, France, Hungary, Italy, Spain, Sweden, Canada, the U.S., Korea, Mexico, and New Zealand. The proportion of individuals who died from diseases that indicate PC needs at the end of life (EOL) ranged from 38-74%. The authors found important cross-country variation: the population potentially in need of PC was lower in Mexico than in the U.S. and varied from 31-83% in Hungary to 42-79% in Spain. Irrespective of the estimation methods, female sex and higher age were independently associated with the likelihood of being in need of PC near the EOL. Home and nursing home were the two places of deaths with the highest prevalence of PC needs. These estimations of the size of the population potentially in need of PC provide robust indications of the challenge countries are facing if they want to seriously address PC needs at the population level. <https://goo.gl/DpLJ9O>

## What cost components are relevant for economic evaluations of palliative care, and what approaches are used to measure these costs? A systematic review

*PALLIATIVE MEDICINE* | Online – 26 September 2016 – The authors' findings point to an urgent need for further research on the economic costs of palliative care. Research which captures the full economic cost should be prioritised in order to gain insight into the inter-relationships between different cost domains and different provider viewpoints and could build on the cost framework proposed here. Methodological developments are also required to generate novel approaches to data collection which provide more accurate cost estimates. These may include economic modelling approaches such as those which have recently been used to estimate costs of care in cancer. While some approaches will be country- or region specific, the value of internationally comparative economic data is significant and should drive further methodological developments in this area. <https://goo.gl/AEa86E>

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

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 18 May 2016 – ‘**Analyzing the impact of palliative care interventions on cost of hospitalization: Practical guidance for choice of dependent variable.**’ Both the magnitude of an intervention’s cost-saving effect and the relative impact of different interventions vary according to which dependent variable is used. Cost of hospitalization provides the most useful results of the three options for evaluating an intervention’s impact on resource use. Alternative approaches visible in the literature can be misleading with respect to cost-effects. <http://goo.gl/Y6RyNo>

### Related

- *BMC PALLIATIVE CARE* | Online – 23 September 2016 – ‘**Case conference primary-secondary care planning at end of life can reduce the cost of hospitalisations.**’ This intervention significantly reduced hospitalisations and emergency department visits. The annualised total cost per patient was AUD\$90,060 before a CC and AUD\$11,841 after a CC. The mean per person cost saving was AUD\$41,023 (\$25,274 excluding one service utilisation outlier). For every 100 patients with end-of-life heart failure and lung disease each year, the CC intervention would save AUD\$4.1 million (AUD\$2.5 million excluding one service utilisation outlier). <https://goo.gl/90Hdya>



### 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.

## “The horse has bolted I suspect”

### **A qualitative study of clinicians’ attitudes and perceptions regarding palliative rehabilitation**

*PALLIATIVE MEDICINE* | Online – 26 September 2016 – In total, 20 physicians participated, representing specialist palliative care (PC) services across Australia. A total of 11 (55%) were males with an average of 12.5 years’ experience working in PC. Most participants believed rehabilitation was an important aspect of PC; however, few felt adequate rehabilitation programmes were available. Participants varied in their concepts of what palliative rehabilitation entailed. The term rehabilitation was seen by some as helpful (fostering hope and aiding transitions) and by others to be misleading (creating unrealistic expectations). Four key themes emerged when describing physicians’ attitudes: 1) Integrating rehabilitation within PC; 2) the intervention; 3) Possibilities; and, 4) The message of rehabilitation. <https://goo.gl/LbXE8k>

Noted in Media Watch 21 July 2014, #367 (p.8):

- *BMJ CASE REPORTS* | Online – 9 July 2014 – ‘**The role of palliative rehabilitation in the preservation of personhood at the end of life.**’ The authors highlight the impact of rehabilitative measures on efforts to preserve the personhood of a patient with metastatic renal cell carcinoma and thus maintain her dignity and quality of life and provide her with appropriate and effective holistic care at the end of life. <http://goo.gl/FWPd5T>

### **How parents and physicians experience end-of-life decision-making for children with profound intellectual and multiple disabilities**

*RESEARCH IN DEVELOPMENTAL DISABILITIES*, 2016;59:283-293. End-of-life decisions (EoLD) often concern children with profound intellectual and multiple disabilities. Yet, little is known about how parents and physicians discuss and make these decisions. [Among study participants] a long-lasting relationship appeared to facilitate the EoLDM process, although previous negative healthcare encounters could also lead to distrust. Parents and physicians encountered disagreements during the EoLDM process, but these disagreements could also improve the decision-making process. Most parents, as well as most physicians, considered the parents to be the experts on their child. In making an EoLD, both parents and physicians preferred a shared decision-making approach, although they differed in what they actually meant by this concept. <https://goo.gl/uT7T9h>

Noted in Media Watch 4 January 2016, #443 (p.14):

- *RESEARCH IN DEVELOPMENTAL DISABILITIES*, 2016;49-50:235-246. ‘**End-of-life decision-making for children with severe developmental disabilities: The parental perspective.**’ The authors identified nine studies that met all inclusion criteria. Parental involvement in end-of-life decision-making varied widely, ranging from having no involvement to being the sole decision-maker. Most preferred to actively share in the decision-making process regardless of their child’s specific diagnosis or co-morbidity. The main factors that influenced their decision-making were their strong urge to advocate for their child’s best interests and to make the best (possible) decision. In addition, parents felt influenced by their child’s visible suffering, remaining quality of life and the will they perceived in their child to survive. <https://goo.gl/haPv2V>

#### **Related**

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 29 September 2016 – ‘**A comparison of circumstances at the end of life in a hospital setting for children with palliative care involvement versus those without.** Children [whose charts were reviewed] who received an inpatient pediatric palliative care consult (25% of the sample) experienced: 1) A higher rate of pain assessments; 2) Better documentation around specific actions to manage pain; 3) Greater odds of receiving integrative medicine services; 4) Fewer diagnostic/monitoring procedures (e.g., blood gases, blood draws, placements of intravenous lines) in the last 48 hours of life; and, 5) Nearly eight times greater odds of having a do-not-resuscitate order in place at the time of death. <https://goo.gl/EhcAaE>

Cont.



- *MÉDECINE PALLIATIVE* | Online – 1 October 2016 – ‘**End-of-life care of children and adolescents with multiple disabilities in social medical institutions.**’ As for 74% of survey respondents, there is no mention of end-of-life care... To every child and adolescent supported in these institutions, 21% had advanced progressive, non-curable illness and somatic fragility; 8 % were at the end of their life. In half of those institutions, there were no professionals trained in palliative care (PC); 43% stated that their staff should be more trained. <https://goo.gl/Rxh7fZ>

N.B. French language article.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *ANNALS OF INTERNAL MEDICINE* | Online – 27 September 2016 – ‘**A call for a patient-centered response to legalized assisted dying.**’ The authors argue that refusal by many physician professional organizations to provide clinical guidance on the care of patients actively seeking assistance in dying does a disservice to their members. They propose that organizations’ active engagement can better help clinicians responsibly meet the needs of their patients while still respecting the diverse opinions and choices about participation in physician assisted suicide. <https://goo.gl/slocTW>
- *PALLIATIVE MEDICINE* | Online – 26 September 2016 – “‘**It’s not all just about the dying**” – **Kaumātua Māori attitudes towards physician aid-in dying: A narrative enquiry.**’ Five closely interrelated themes were identified from kaumātua [Māori elders] narratives: 1) Attitudes and understandings of physician aid-in dying; 2) Influence of power; 3) Significance of kawa [i.e., ceremony]; 4) Whānau [i.e., extended family] relationships; and, 5) The significance of wairua [i.e., the spirit of a person which extends beyond death]. The study demonstrated that for these kaumātua, medical practices that hasten death such as physician aid-in dying are “not all just about the dying.” Tikanga [i.e., in broad terms, the Māori way of doing things] and kawa are important processes and concepts to understand during death and dying, and whānau are central to such processes being respected by those involved in the dying process. These factors are so closely intertwined that they cannot be considered in separation of each other. <https://goo.gl/lhDm7T>

### 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.

## Worth Repeating

“Yes it’s sad, but what should I do?”

### **Moving from empathy to action in discussing goals of care**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 17 December 2013 – The communication skills of noticing emotional cues and responding empathically are necessary, but insufficient for some conversations about redefining goals of care. For some patients, an empathic response by a clinician is insufficient to move the conversation forward. The authors describe an expert approach that links empathy to action. In this approach, they outline: 1) How affect provides a spotlight that illuminates what is important; 2) How empathy affords a way to connect with patients and families that engages deep values; 3) How clinicians can infer deep values through an associative process with patients; and, 4) How clinicians can then design actions with patients and families and nurture their commitment to the actions. [Noted in Media Watch, 23 December 2013, #337 (p.14)] <https://goo.gl/CQM1XI>

### Media Watch: Online

#### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://goo.gl/m98B1D>

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 Barry Ashpole and Media Watch]

#### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://GOO.GL/JNHVMB>

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

#### **Canada**

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <http://goo.gl/AhlqvD>

#### **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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