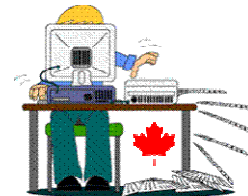


## Media Watch...

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

Clinically relevant, culturally sensitive, transparent, and evidence-based approach to care determinations: Scroll down to [Specialist Publications](#) and 'Multi-dimensional approach to end-of-life care: The Welfare Model' (p.14), in *Nursing Ethics*.

## Canada

### Assisted (or facilitated) death

#### Vancouver Island records highest rate of assisted death in Canada

BRITISH COLUMBIA | *The Vancouver Sun* – 16 October 2018 –The rate of medically assisted deaths on Vancouver Island is about five times higher than in the rest of Canada, a new report from Island Health shows. Researchers determined there were 504 deaths on the Island in the two years after medically assisted dying became legal on 17 June 2016. The total accounted for 3.6% of expected deaths over the same time period compared with a rate of less than one per cent across the country. The rate is even higher now at about 4%, the report says. By contrast, it took more than 15 years for the

rate of medically assisted deaths in The Netherlands to reach 3.9% of all deaths, the report notes. <https://goo.gl/vXvrdW>

### Specialist Publications

'Institutional non-participation in assisted dying: Changing the conversation' (p.17), in *Bioethics*.

'Problematic ethics: Public opinion surveys in medico-legal disputes' (p.17), in *HEC Forum*.

### Related

- SASKATCHEWAN | CBC News (Saskatoon) – 16 October 2018 – 'Delays block access to medically-assisted dying for some Saskatchewan patient's.' A Saskatchewan doctor says systematic changes are coming to address delays that have stopped some seriously-ill patients from getting medical assistance to die. Dr. Lilian Thorpe, a member of the medical assistance in dying (MAiD) team in Saskatoon, said it can take a long time for people to get approval for the procedure. Less than half of people in the Saskatoon area who request MAiD actually go through with the process. Dr. Thorpe said patients sometimes find there are alternatives or they die naturally without deciding to pursue a medically assisted death. <https://goo.gl/9LNX4B>

## U.S.A.

### Travel ban is keeping dying children from their families

GEORGIA | *The Huffington Post* (Atlanta) | Online – 16 October 2018 – Lanise Shortell, a pediatric hospice nurse and certified grief recovery specialist in Atlanta, has witnessed how family separation affects both the dying and the bereaved. In March an 11-year-old boy from the Democratic Republic of the Congo died under her care before he could be reunited with his mother and four siblings... She cared for a newborn in May who never got to meet her grandparents from Venezuela, adding indescribable layers of grief to an already horrifying reality. Shortell and her team are currently caring for a teenage boy originally from Syria. He will likely never see his adult sisters again, who aren't allowed into the country under the travel ban. The refusal to allow immediate family members to be with dying children is an infringement on their human rights. If the U.S. government truly sought to create immigration and travel policies that strengthen our country, it would consider the purpose of palliative care and hospice. At their core, they exist to provide as much comfort as possible to individuals with life-limiting, terminal illnesses; in the case of pediatric hospice particularly ... to provide physical and emotional

support that enhances quality of life for children and their families after a life-limiting diagnosis. When families aren't together before the death of a child, it not only severely negatively affects the child but also leads to considerable emotional and physical distress for the surviving family members. <https://goo.gl/89hdDH>

#### Specialist Publications

**'Tools for deprescribing in frail older persons and those with limited life expectancy: A systematic review'** (p.11), in *Journal of the American Geriatric Society*.

**'Differences in Medicare utilization and expenditures in the last six months of life among patients with and without Alzheimer's disease and related disorders'** (p.12), in *Journal of Palliative Medicine*

**'Biting the dust with medical help: Should state law legitimize physician-assisted suicide?'** (p.18), in *Journal of Thoracic & Cardiovascular Surgery*.

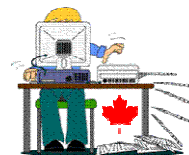
### Many caregivers neglecting their own health, poll shows

ASSOCIATED PRESS | Online – 15 October 2018 – Caring for an older loved one is a balancing act, and a new poll shows that too often it's the caregivers' health that's neglected.<sup>1</sup> The survey ... found about a third of caregivers have gone without a routine physical or dental care, skipped or didn't schedule a test or treatment or even forgot to fill a prescription or failed to see a doctor for their own illness or injury because they were too busy with their caregiving duties. Doctors miss opportunities to help. Most caregivers go to medical appointments with the seniors they care for, yet the poll found they're less likely to get information about self-care, support programs or other services during those visits than if they make time to see their own physicians for advice. <https://goo.gl/MtLE8c>

1. 'Long-Term Caregiving: The True Costs of Caring for Aging Adults,' The Associated Press-NORC Center for Public Affairs Research, October 2018. **Download/view at:** <https://goo.gl/YKAVeF>

#### Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://goo.gl/5CHoAG>



## International

### **Doctors are told to “talk to terminally ill patients about death” and not see it as a professional failure**

U.K. | *The Daily Mail* (London) – 19 October 2018 – Doctors need to get better at talking to patients about dying, a report has suggested.<sup>1</sup> The Royal College of Physicians (RCP) said confidence is one of the main barriers, with many – from medical students to consultants – feeling uncomfortable about initiating such conversations. Some doctors also avoid the topic as they feel death could be perceived as failure as modern medicine is expected to cure all ailments, the report found. The RCP said that as nearly half of all deaths in the U.K. occur in hospital, and many patients admitted to hospital are within the last year of life, it is vital doctors and other healthcare professionals have the knowledge and skills to undertake sensitive conversations at the appropriate time. It found evidence from patients and carers that many people do want to talk about death, and planning for it helps patients feel more empowered about their care and decision-making. The report, which is based on conversations with doctors at all le-

vels, along with patients, carers and medical organisations, highlights how



**Royal College of Physicians**

medical students and junior doctors often have little practice in talking about the subject with real patients. Another issue is confusion over whether hospital doctors or the patient's GP should be having the conversation, along with reluctance to begin conversations if the doctor is not going to be responsible for the patient's care going forward. <https://goo.gl/5qYAGw>

#### Specialist Publications

**'Emotional labour in palliative and end-of-life care communication: A qualitative study with generalist palliative care providers'** (p.15), in *Patient Education & Counseling*.

1. 'Talking about dying: How to begin honest conversations about what lies ahead,' Royal College of Physicians, October 2018. **Download/view at:** <https://goo.gl/4bh27r>

### **Plans for palliative care respite centre as hospitalisations rise**

AUSTRALIA (Australian Capital Territory) | *The Canberra Times* – 18 October 2018 – Figures released by the Australian Institute of Health & Welfare showed the Australian Capital Territory (ACT) had the highest rate of palliative care (PC) patients in public hospitals in the country in 2015-2016 at 33 per 10,000.<sup>1</sup> That rate has increased from 19.8 in 2011-2012, 9.2 in 2012-2013, 20.8 in 2013-2014 and 25.9 in 2014-2015. There's been a 79% increase in the number of PC patients in public hospitals in the same period – from 736 patients in 2011-2012 to 1319 in 2015-2016. On top of this palliative patients stayed in ACT public hospitals longer than anywhere else, except the Northern Territory, on average 11.6 days. PC staff in the ACT also worked the longest hours in the country – 36.3 hours per week for nurses and 51.3 hours per week for specialist palliative medicine physicians. <https://goo.gl/iQw1hS>

1. 'Profile of palliative care-related hospitalisations,' Australian Institute of Health & Welfare, October 2018. **Download/view at:** <https://goo.gl/LrpFiC>



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<http://goo.gl/frPgZ5>

**“He chose to die at home. The hostel was his home.”**

IRELAND | *The Journal* (Dublin) – 15 October 2018 – Many homeless men live with chronic illness. Often people who have spent years on the streets age far before their time. They are old by the time they reach their forties. Studies have shown life expectancy is not the same as the rest of the population. There are hundreds of men currently living in hostel accommodation that require the equivalent to nursing home care or full-time carers. In Ireland many hostels *de facto* operate as nursing homes for the men we once knew as the “street drinkers.” Staff and medical practitioners work tirelessly to try meet the high needs of this vulnerable group. With not enough services, support and expertise this has meant that on many occasion they have not been cared for in the way they should. Hence the new intermediate care centre or ‘Step Up Step Down’ provided by the Dublin Simon Community with Safety Net Primary Care. The twelve bed unit will provide a step down from hospital or step up from the hostel environment and will play a vital role in delivering the health interventions that this group so desperately needs. For this particular group we also need to think about palliative care (PC). As we have an aging homeless population, the provision of PC to people without homes will continue to arise and must be flexible and respectful in how we meet their health needs. <https://goo.gl/vZFDEA>

Noted in Media Watch 8 October 2018 (#584, p.17):

- *NURSE EDUCATION TODAY*, 2018;71(12):135.144. ‘**Evaluation of training on palliative care for staff working within a homeless hostel.**’ This study suggests that training can be beneficial for improving knowledge, confidence, openness and work related stress for hostel staff that support people with deteriorating health who are homeless. Recommendations for implementing changes in how people experiencing homelessness are supported include embedding training into routine practice, promoting multidisciplinary working, incorporating flexibility within the recovery focused approach of services, and recognising the need for emotional support for staff. **Full text:** <https://goo.gl/Yf1vGh>

### Elder care in England

#### **Steep fall in home help despite rise in the number of old people**

U.K. | *The Guardian* (London) – 13 October 2018 – The number of old people receiving social care support in their homes has fallen sharply over the last three years, despite a rapid rise in the elderly population and repeated government promises to tackle a crisis of provision, new figures reveal. Data obtained through Freedom of Information requests to local authorities in England show more than half of council are now providing fewer so-called “care packages” to old people than they were in 2015, although the number of elderly people has increased by 400,000 during that period. Of the 122 local authorities that

### Specialist Publications

‘**Tua o te Aria. Doorways into dying: Meaningful encounters at end of life**’ (p.5), in *Ata: Journal of Psychotherapy Aotearoa New Zealand*.

‘**Volunteer involvement in the organisation of palliative care: A survey study of the healthcare system in Flanders and Dutch-speaking Brussels, Belgium**’ (p.10), in *Health & Social Care in the Community*.

‘**End-of-life care: Beliefs, attitudes, and experiences of Iranian physicians**’ (p.10), in *Indian Journal of Palliative Care*.

‘**Palliative care in women’s cancer care: Global challenges and advances**’ (p.11), in *International Journal of Gynecology & Obstetrics*.

‘**Forecasting life expectancy, years of life lost, and all-cause and cause-specific mortality for 250 causes of death: Reference and alternative scenarios for 2016-2040 for 195 countries and territories**’ (p.13), in *The Lancet*.

Cont.

responded, 68 said they were providing help in fewer cases. In total these local authorities alone were providing 20,000 fewer care packages in England. Most councils blame funding pressure and cuts to budgets, which in many cases have been reduced by well over 40% since 2010. <https://goo.gl/ZpFDWJ>

Noted in Media Watch 23 July 2018 (#573, p.3):

- U.K. (England) | *The Daily Mail* (London) – 17 July 2018 – ‘**Dying patients are being neglected by councils, with budgets for end-of-life care as low as £52 per person.**’ Dying patients are still being neglected by councils. End-of-life (EoL) care is being prioritised by only 4% of town halls in England, according to analysis by experts at King’s College London.<sup>1</sup> Councils, which have responsibility for social care, face increasing numbers of elderly people needing EoL support. Demand is set to increase 42% by 2040. <https://goo.gl/2Ey6tH>

1. ‘Is end-of-life care a priority for policymakers? Qualitative documentary analysis of health care strategies,’ *Palliative Medicine*, published online 17 July 2018. **Full text:** <https://goo.gl/dVrfKj>

## Specialist Publications

### **Doorways into dying: Meaningful encounters at end of life**

*ATA: JOURNAL OF PSYCHOTHERAPY AOTEAROA NEW ZEALAND*, 2018;22(1):37-47. As we age or become terminally ill, we are confronted by our mortality. Being confronted by our own or another’s death can be a time of accelerated and profound growth and development. Using examples from research and personal experience working in a hospice, this article explores challenges facing our own dying as well as that of clients and family members. It discusses the relevance and benefits of psychotherapy at end of life. Throughout the dying process, disturbances can occur that may be dismissed or pathologized. This article goes further and suggests that the dying person’s apparent confusion, complex language, agitation or unusual movements, dreams and visions are some of the ways they communicate their needs and let us know what is happening to them. These phenomena are doorways through which we can connect and assist the dying to find meaning in what is happening. The dying may also experience altered and extreme states of consciousness such as coma. It is believed that in these deep inner states they are continuing their development and making spiritual connections. Rather than leaving them alone to fend for themselves, innovative interventions such as joining the world of the patient and pacing their breath are suggested. **Abstract:** <https://goo.gl/dq3xpX>

**N.B.** Click on PDF icon to access complete text of this article.

### **What do chaplains do: The views of palliative care physicians, nurses and social workers**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 18 October 2018 – It is well accepted that attention to spiritual concerns is a core dimension of palliative care (PC). It is similarly well accepted that chaplains are the spiritual care specialists who should address such concerns. However, what chaplains do when they provide care for patients and families is often poorly understood by their PC colleagues. Having a clear understanding of what chaplains do is important because it contributes to improved utilization of the spiritual care and other resources of the PC team and thereby to better care for patients and families. Brief surveys were distributed to participants at two workshops for PC professionals in 2016. The majority [of the 110 respondents] reported that they understood what chaplains do moderately well or very well. Thirty-three percent of the written comments were very general; 25% were more specific. Only a small proportion of the participants were aware that chaplains provide care for the team, are involved in facilitating treatment decision-making, perform spiritual assessments, and bridge communication between the patient/family/team/community. These findings point to the need for ongoing education of palliative teams about what chaplains do in PC. **Abstract:** <https://goo.gl/srpeyg>

Cont.

## Related

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 16 October 2018 – ‘**Development of a tool to identify and assess psychosocial and spiritual needs in end-of-life patients...**’ The Psychosocial & Spiritual Needs Evaluation scale was developed through a seven-stage process: 1) Literature review; 2) Expert panel establishment; 3) Discussion and agreement on the most relevant dimensions of psychosocial care; 4) Description of key indicators and consensus-based questions to evaluate such dimensions; 5) Assessment of the scale by external palliative care professionals; 6) Evaluation by patients; and, 7) Analysis of scale’s psychometrics properties. **Abstract (inc. list of references):** <https://goo.gl/ETVDQh>

Noted in Media Watch 6 August 2018 (#575, p.12):

- *JOURNAL OF HEALTH CARE CHAPLAINCY*, 2018;24(3):87-106. ‘**The role of the healthcare chaplain: A literature review.**’ From this review, several key spiritual and pastoral roles in healthcare emerge including a potential contribution to ethical decision making at the end of life. Healthcare chaplains are key personnel, already employed in many healthcare organizations, who are in a pivotal position to contribute to future developments of faith-based care, faith-sensitive pastoral, and spiritual care provision. They also have a new and evolving role in ethical support of patient, families and healthcare teams. **Abstract (w. link to references):** <https://goo.gl/4DrKYF>

**N.B.** Additional articles on the role of chaplains in end-of-life care noted in this issue of Media Watch.

## End-of-life care in England

### **Quality assurance for care of the dying: Engaging with clinical services to facilitate a regional cross-sectional survey of bereaved relatives’ views**

*BMC HEALTH SERVICES RESEARCH* | Online – 10 October 2018 – Globally, having the “patient and /or family voice” engaged when measuring quality of care (QoC) for the dying is fundamentally important. This is particularly pertinent within the U.K., where changes to national guidance about care provided to dying patients has heightened the importance of quality assurance and user-feedback. The authors’ main aim was to engage with clinical services (hospice, hospital and community settings) within a specific English region and conduct a bereaved relatives’ cross-sectional survey about QoC. Their secondary aim was to explore levers and barriers to project participation as perceived by organisational representatives. Overall, most participants perceived good QoC. A notable minority reported poor care for symptom control and communication, especially within the hospital. The potential to be able to benchmark user-feedback against other organisations was thought to help focus on areas to develop services. This type of quality assurance project could form a template model and be replicated on a national and international level. **Full text:** <https://goo.gl/e45ufz>

## Related

- *BMC PALLIATIVE CARE* | Online – 19 October 2018 – ‘**Voices that matter: end-of-life care in two acute hospitals from the perspective of bereaved relatives.**’ Seeking the views of bereaved relatives should be considered by all hospitals and healthcare settings to ascertain the quality of care at end of life (EoL). This study has contributed to understanding and knowledge of what is important to people at EoL, what good EoL care looks like and where care can be improved from the perspective of bereaved relatives thus, informing policy and practice and enabling hospitals to direct and inform quality improvement. **Full text:** <https://goo.gl/jurwsF>



## Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.19.

## End-of-life care in China

### **The experience of caring for patients at the end-of-life stage in non-palliative care settings: A qualitative study**

*BMC PALLIATIVE CARE* | Online – 17 October 2018 – Three themes emerged from interviews [with health care providers from eight health care institutions based in Shanghai]: 1) Definition of the end-of-life (EoL) stage (This is mainly defined based on a change in treatment); 2) Health care at the EoL stage (Most patients spent their last weeks in tertiary/secondary hospitals, transferring from one location to another and receiving disease- and symptom-focused treatment. Family-dominated decision making was common when discussing treatment options. Nurses instinctively provided extra care attention to patients, but nursing care is still task-oriented.); and, 3) Challenges, difficulties, and the future. (From the interviews, it was found that pressure from families was the main challenge faced by health care providers.) Three urgent tasks before the EoL care can become widely available in the future were identified from the interviews, including educating the public on death, extending government support, and creating better health care environment. The EoL care system of the future should involve health care institutions at all levels, with established mechanisms of collaboration between institutions. Care should be delivered to patients with various life-threatening diseases in both palliative and non-palliative care settings. But first, it is necessary to address the obstacles to the development of EoL care, which involve health care providers, patients and their families, and the health care system as a whole. **Full text:** <https://goo.gl/tQjLvx>

**N.B.** Additional articles on palliative care in China noted in 23 July 2018 issue of Media Watch (#573, p.4).

### **Clinical decision-making at the end of life: A mixed-methods study**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 18 October 2018 – The synthesis of findings demonstrated areas of agreement, partial agreement, silence and dissonance when comparing the cohort findings with the interview findings. Trajectories of change are identified as associated with poor prognosis in both approaches, but based on different parameters. Management of patients has a significant impact on decision-making. The decision process requires repeated, iterative assessments and may benefit from a multidisciplinary approach. Uncertainty is a defining characteristic of the overall process, and objective parameters only have a limited role in predicting end of life. The role of uncertainty is important as a trigger for discussions and a defined stage in a patient's illness journey. This is consistent with current approaches to recognising irreversible deterioration in those with serious illness. This study contributes ongoing evidence that these concepts are vital for decision-making. **Abstract:** <https://goo.gl/ZAnwM7>

### **Advance care planning and parent-reported end-of-life outcomes in children, adolescents, and young adults with complex chronic conditions**

*CRITICAL CARE MEDICINE* | Online – 9 October 2018 – Advance care planning (ACP) outcomes research has previously focused on seriously ill adults and adolescents with cancer where it is correlated with high-quality end-of-life (EoL) care. The impact of ACP on EoL outcomes for children, adolescents, and young adults with complex chronic conditions is unknown...One-hundred fourteen parents were enrolled ... and all parents reported that ACP was important, with a majority (70%) endorsing that discussions should occur early in the illness course. Parents who reported ACP (65%) were more likely to be prepared for their child's last days of life, to have the ability to plan their child's location of death, and to rate their child's quality of life during EoL as good to excellent. Notably, ACP which included specific assessment of family goals was associated with a decrease in reported child suffering at EoL and parental decisional. Further studies should evaluate strategies to ensure high-quality ACP including specific assessment of family goals. **Abstract:** <https://goo.gl/Aw6t2p>

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Noted in Media Watch 8 October 2018 (#584, p.7):

- *ARCHIVES OF DISEASE IN CHILDHOOD* | Online – 28 September 2018 – ‘**Not the whole story – considering children’s spirituality and advance care planning.**’ In a society of diverse views, faiths and beliefs, what can paediatric palliative care contribute to our understanding of children’s spirituality? The authors explore how developments in advance care planning ... are addressing these issues. Since children’s spirituality is elusive and rarely explored in practice, they aim to clarify our understanding of it with a variety of examples and offer suggestions for hearing the voice of the child amid the needs of parents and professionals. **Abstract:** <https://goo.gl/1KYnUm>

Noted in Media Watch 30 April 2018 (#561, p.8):

- *BEHAVIORAL SCIENCES* | Online – 26 April 2018 – ‘**Ethics of end-of-life decisions in pediatrics: A narrative review of the roles of caregivers, shared decision-making, and patient centered values.**’ While a paternalistic approach is typically applied to children with life-limiting medical prognoses, the cognitive, language, and physical variability in this patient population is wide and worthy of review. In end-of-life discussions in pediatrics, the consideration of a child’s input is often not reviewed in depth, although a shared decision-making model is ideal for use, even for children with presumed limitations due to age. **Full text:** <https://goo.gl/Py1bVH>

**N.B.** Additional articles on the patient’s voice in paediatric end-of-life and palliative care noted in this issue of Media Watch.

### Instruments to evaluate complexity in end-of-life care

*CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE* | Online – 12 October 2018 – The growing number of patients with terminal and chronic conditions and co-morbidities constitutes a challenge for any healthcare system, to provide effective and efficient patient-centred care at the end of life. Resources are limited, and complexity is rising within patients’ situations and healthcare professionals interventions. This review presents the state of art of the role of complexity in specialist palliative care (PC) provision. Although studies related to complexity in PC are still limited, interesting reviews on complexity frameworks in co-morbidity conditions and PC are growing more present in current literature. They identify multidimensional issues, resources utilization, and the relationship between them as fundamental aspects of complexity constructs, helping to define and understand complexity, and to therefore design validated tools to support healthcare professionals identifying the most complex patients... There is an urgent need to guarantee quality and equity of care for all the patients eligible for PC, from those who need a PC approach to those needing specialist intensive PC. Implementing complexity theory into practice is paramount. In this review, complexity science, complexity frameworks, as well as tools evaluating complexity in PC are described. **Abstract:** <https://goo.gl/5VJwcZ>



Noted in Media Watch 26 February 2018 (#552, p.17):

- *PALLIATIVE MEDICINE* | Online – 19 February 2018 – ‘**A framework for complexity in palliative care: A qualitative study with patients, family carers and professionals.**’ Complexity included how patients interact with family/professionals, how services respond to needs and societal perspectives on care. “Pre-existing,” “cumulative” and “invisible” complexity are further important dimensions to delivering effective palliative and end-of-life care. The dynamic nature of illness and needs over time was also profoundly influential. **Full text:** <https://goo.gl/jthL2S>

Noted in Media Watch 8 January 2018 (#545, p.8):

- *BMC PALLIATIVE CARE* | Online – 4 January 2018 – ‘**What does “complex” mean in palliative care? Triangulating qualitative findings from three settings.**’ Palliative care services need to recognize that while complexity may be defined by inherent patient needs, in one of more dimensions of care, which are difficult to manage, it is also perceived by clinicians considering referral. Perceived complexity is highly dependent on individual factors such as time constraints, training, alternative treatments and referrals, resources and relationships with specialists. **Full text:** <https://goo.gl/qPfoSt>



## The impact of personal and professional loss on advance care planning and effective care delivery for healthcare social workers

*FAMILIES IN SOCIETY: THE JOURNAL OF CONTEMPORARY SOCIAL SERVICE* | Online – 12 October 2018 – The connection between past experiences with death and social workers' practice has been underexplored. As such, this study surveyed social workers about their personal and professional experiences of loss, personal advance care planning, and professional practices. Results demonstrated that social workers that experienced prior loss were more likely to complete an advance directive and communicate their end-of-life wishes. Additionally, those who had experienced personal and professional loss showed greater effectiveness on measures of patient- and family-centered communication and care delivery. Findings suggest positive outcomes for encouraging social workers to connect their personal and professional experiences surrounding death and dying to effectively serve in their professional capacity.

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

### Related

- *BMC PALLIATIVE CARE* | Online – 15 October – '**Attitudes to specialist palliative care and advance care planning in people with chronic obstructive pulmonary disease: A multi-national survey of palliative and respiratory medicine specialists.**' Respiratory doctors reported being comfortable providing a palliative approach and acknowledged the role of both specialist palliative care and advance care planning, yet in reality people with advanced obstructive pulmonary disease (COPD) rarely access these elements of care. Additionally, current models of care for people with COPD were considered inadequate and fragmented. **Full text:** <https://goo.gl/tJ7SWF>
- *GERIATRIC NURSING* | Online – 11 October 2018 – '**A systematic evaluation of advance care planning patient educational resources.**' The authors present a comprehensive evaluation of 20 educational resources to support advance care planning (ACP). Their review allows clinicians to identify aspects of each resource that may be helpful in preparing older adults for future healthcare decisions. There is a need, however, to continue to refine these resources so that they can reach a broad population with varying needs. **Abstract (w. link to references):** <https://goo.gl/BG3A8G>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 18 October 2018 – '**Advance care planning experiences and preferences among people with cystic fibrosis.**' Few subjects [interviewed] reported talking with their cystic fibrosis (CF) team about care preferences or completing advance directives detailing desired medical treatments. However, most worried about living with advanced disease (84%) and felt comfortable discussing care preferences with CF providers (92%). Subjects largely preferred that advance care planning conversations occur when they are generally healthy, in the outpatient setting, and with any familiar CF team member. **Abstract:** <https://goo.gl/Cp3KTR>

### Palliative care: Taking the long view

*FRONTIERS IN PHARMACOLOGY* | Online – 16 October 2018 – As a society, we are drowning in information, but starving for the wisdom required for making clinical care more effective, efficient and agreeable by getting care as good as it can be wherever the person is – at all stages – care that matches the person's preferences as closely as possible and meet needs as far as possible. Last year was the 30th anniversary of palliative medicine being recognized as a medical specialty. Much has been achieved, but there is still much that needs to be done to ensure good palliative care (PC) – and supportive/end-of-life (EoL) care – for everyone. Equally, we face new challenges, especially relating to service provision, and staff need appropriate and specialist training too have confidence to take their skills into other parts of care – i.e., further upstream and laterally to start reducing the inequality gap. Research shows that those who die at home experience more peace and a similar amount of pain than those who die in hospital and their relatives also experience less grief. Too much emphasis might be put on the place of death; home might not always be the best or preferred place of death. Public health focus on place of death distracts attention from the experience of dying and deflects attention from many more pressing factors that limit patients' options, such as availability of resources, quality of PC, and symptom management. We must be

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aware of the projected increase in institutional deaths; the hospital needs to be reinvented as a viable alternative and place of excellent care for dying patients and their families. How to deliver consistently compassionate and effective support for dying people and their families in all settings remains a crucial challenge while caring for a growing aging Western population. Strong social networks facilitate palliation and everybody feeling responsible for playing a positive part in EoL care will end up showing care to be about return on humanity, not return on investment. **Full text:** <https://goo.gl/kzMAVK>

#### Related

- *JOURNAL OF HOUSING FOR THE ELDERLY* | Online – 15 October 2018 – ‘**Care pathways for the dying patients: Physician perspective.**’ The overriding care philosophy in medicine is to prevent death, rather than focus on dying. However, increasing longevity in most parts of the world has resulted for many people in prolonged periods of declining health toward the end of life. This has complicated understanding of when the dying process begins. As a result, there has been a growing movement within society and among health care systems to focus on finding ways to contribute to the quality of life of patients just before they die. The hospice and palliative care movement has gained distinction as an alternative way of looking at health care. **Abstract:** <https://goo.gl/SQ5beh>

#### **Volunteer involvement in the organisation of palliative care: A survey study of the healthcare system in Flanders and Dutch-speaking Brussels, Belgium**

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 16 October 2018 – Facing resource constraints in professional healthcare, some governments expect informal caregivers like volunteers to assume a greater share of care provision. We know volunteers are present in palliative care (PC) and perform many roles, ranging from administration to providing companionship. However, we do not know how involved they are in the organisation of care and how healthcare organisations appraise their involvement. To address this, the authors provide an extensive description of the involvement of volunteers who provide direct patient PC across the Flemish healthcare system in Belgium. They conducted a cross-sectional postal survey of 342 healthcare organisations in Flanders and Brussels in 2016, including full-population samples of PC units, palliative day care centres, palliative home care teams, medical oncology departments, sitting services, community home-care services, and a random sample of nursing homes. Response was obtained for 254 (79%) organisations. Volunteers were often informed about and consulted regarding the organisation of care, but healthcare organisations did not wish for more autonomous forms of volunteer involvement. Three clusters of volunteer involvement were found: “strong involvement” (31.5%), “restricted involvement” (44%), and “uninvolved” (24.5%). Degree of involvement was found to be positively associated with volunteer training and performance of practical and psychosocial care tasks. Dedicated PC services displayed a strong degree of volunteer involvement, contrary to generalist PC services, suggesting volunteers have a more important position in dedicated PC services. **Abstract:** <https://goo.gl/bo2TAz>

#### **End-of-life care: Beliefs, attitudes, and experiences of Iranian physicians**

*INDIAN JOURNAL OF PALLIATIVE CARE*, 2018; 24(4):431-435. There are a number of important implications of this study. First, the study demonstrates that the familiarity of Iranian physicians’ with end-of-life (EoL) care is low and in contrast with the frequent contact with mentioned patients. Second, there is not any kind of structured or organized system to deliver services for EoL patients. Third, in Iran, there is a noticeable absence of EoL education, in both medical school curriculums, and in continuous medical education programs. The participation rate in this study was 38.3%, which was lower than that of similar international studies in Hungary (54%), U.S. (48%), and Pakistan (63.6%). Most of the Iranian physicians (72%) in the current study claim that they did not have any knowledge about hospice care, which is more than Pakistani physicians (57.1%) who stated that they had heard about a hospice. In contrast to the most of the U.S. physicians who were quite knowledgeable, most of the Hungarian physicians had only a

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basic knowledge. However, there is a high level of interest shared among physicians in the U.S., Hungary, Iran, and Pakistan to participate in continuing medical education to learn more about hospice care. These findings are consistent with previous studies that indicate physicians' common interest in continuing medical education for EoL care. In this study, 72% of EoL patients received medical care in the hospital and 23% at home, while only 27% of Iranian physicians mentioned that the preferred place of providing terminal care is the hospital. **Full text:** <https://goo.gl/Kre2gd>

**N.B.** See 'Country Information: Iran' (pp.48-49) in the 'Atlas of Palliative Care in the Eastern Mediterranean Region,' a joint project of the Lebanese Center for Palliative Care and the Institute for Culture & Society, at the University of Navarra, Spain, 2017. [Noted in 22 May 2017 issue of Media Watch (#513, p.14)] **Download/view at:** <https://goo.gl/i5Lc4e>

### **Palliative care in women's cancer care: Global challenges and advances**

*INTERNATIONAL JOURNAL OF GYNECOLOGY & OBSTETRICS*, 2018;143(S3):153-158. Women's cancer rates are increasing in low- and middle-income countries, with presentations that are often far advanced requiring intense symptom management, thus advancing the urgent need to address palliative care (PC). Most resource settings have some options available to assist women with advanced gynecologic cancer, and a combination of leveraging these and expanding on emerging models for PC could lessen suffering and improve care for women with gynecologic cancers globally. Providing PC for women with cancer is constrained by resources (human and physical), lack of equipment, lack of access, and policy absence or barriers. There is important work to be done in advocating for appropriate infrastructure development and legislation to assure that these options are available to women and their families. Access to adequate opioid and other pain relief options for cancer-related pain is a particular concern given that availability, cost, and legislative prohibitions create barriers that cause suffering for patients and grief for their families who are unable to address their suffering. All of these require ongoing advocacy for continual advances to improve access and infrastructure for PC. **Full text:** <https://goo.gl/2gmeY4>

### **Tools for deprescribing in frail older persons and those with limited life expectancy: A systematic review**

*JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 13 October 2018 – The authors identified 15 tools and organized them into three main categories: 1) Tools that described a model or framework for approaching deprescribing; 2) Those that outlined a deprescribing approach for the entire medication list; and, 3) Tools that provided medication-specific advice. The complexity of the tools ranged from simple lists to detailed, step-wise protocols. The development methodology varied widely, and the methods used to synthesize the tools were generally not well described. Most tools were based on expert opinion. Only four of the 15 tools have been tested in clinical practice (in very low-quality studies). **Abstract:** <https://goo.gl/bo2Yeg>

#### **Related**

- *JAMA INTERNAL MEDICINE* | Online – 15 October 2018 – '**Assessment of attitudes toward deprescribing in older Medicare beneficiaries in the U.S.**' Physicians considering deprescribing as part of comprehensive, patient-centered care should be reassured that a majority of older Americans [i.e., 92% of the 1,752 participants in this study] are open to having one or more of their medicines deprescribed if their physician says it is possible, and more than two-thirds want to reduce the number of medicines that they are taking. **Abstract:** <https://goo.gl/627VC6>

Noted in Media Watch 24 September 2018 (#582, p.14):

- *PALLIATIVE MEDICINE* | Online – 19 September 2018 – '**Barriers and enablers to deprescribing in people with a life-limiting disease: A systematic review.**' The most important barriers that were identified were shortages in staff and the perceived difficulty or resistance of family and/or the patient/resident her/himself. The most prominent enablers were organizational support (e.g., for standardized medication review), involvement of multidisciplinary teams, and the perception of the importance of coming to a joint decision regarding deprescribing. **Abstract:** <https://goo.gl/gptGaF>

## Does disciplinary law protect us from false and misleading health advertising?

*JOURNAL OF LAW & MEDICINE*, 2018;26(1):89-102. Health-related advertisements should not mislead prospective patients. To do so may deprive patients of their ability to give or withhold consent to treatment and, in the case of terminally ill patients, of the opportunity to accept and come to terms with the dying process. Patients should be able to expect that claims in health-related advertising are based on the most recent scientific evidence and are not predatory or exploitative. However, internet advertising and social media continue to provide opportunities for unscrupulous health practitioners to peddle their wares. This article considers whether disciplinary law effectively deals with false, misleading or deceptive health-related advertising in the context of regulated and unregulated practitioners as well as complementary and alternative medicine. The author argues that consideration should be given to amending disciplinary law to specify what evidence is required to substantiate claims made in advertising. **Journal contents page (scroll down to abstract of article):** <https://goo.gl/zGkMh5>

Noted in Media Watch 1 May 2017 (#510, p.3):

- *KAISER HEALTH NEWS* | Online – 27 April 2017 – ‘**Widespread hype gives false hope to many cancer patients.**’ Patients and families are bombarded with the news that the country is winning the war against cancer. The news media hypes research results to attract readers. Drug companies promise “a chance to live longer” to boost sales. Hospitals woo paying customers with ads that appeal to patients’ fears and hopes. “I’m starting to hear more and more that we are better than I think we really are,” said Dr. Otis Brawley, chief medical officer at the American Cancer Society. “We’re starting to believe our own bullshit.” <https://goo.gl/ewWSXJ>

## Triggered palliative care for late-stage dementia: A pilot randomized trial

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 17 October 2018 – This pilot randomized controlled trial enrolled 62 dyads of persons with late-stage dementia and family decision-makers on admission to hospital. Intervention dyads received dementia-specific specialty palliative care (PC) consultation plus post-acute transitional care. Control dyads received usual care and educational information. The primary outcome was 60-day hospital or emergency department visits. Secondary patient and family-centered outcomes were patient comfort, family distress, PC domains addressed in the treatment plan, and access to hospice or community-based PC. Secondary decision-making outcomes were discussion of prognosis, goals of care, completion of Medical Orders for Scope of Treatment, and treatment decisions. Specialty PC consultation for hospitalized patients with for late-stage dementia is feasible and promising to improve decision-making and some treatment outcomes. **Abstract:** <https://goo.gl/9wS5oA>

### Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 18 October 2018 – ‘**Differences in Medicare utilization and expenditures in the last six months of life among patients with and without Alzheimer’s disease and related disorders.**’ Alzheimer’s disease and related disorders (ADRD) patients were overall less expensive than their non-ADRD peers through reduced use of high-cost services, and urban patients were more likely than rural patients to use hospice and other services among both groups. ADRD beneficiaries cost Medicare 11% less than non-ADRD beneficiaries. **Abstract:** <https://goo.gl/Q4xVqW>

**N.B.** Additional articles on advance directives for patients living with Alzheimer’s disease and other forms of dementia noted in 27 August 2018 issue of Media Watch (p.9).



Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>

## Integration of oncology and palliative care

*THE LANCET ONCOLOGY* | Online – 18 October 2018 – While much cancer research is directed towards combating and treating cancer as a disease, much less attention is paid to a patient's wellbeing and quality of life during the course of the disease. In a new Commission from *The Lancet Oncology*, Stein Kaasa and colleagues [see side bar] critically discuss how to integrate oncology and palliative care (PC) using standardised care pathways, referral guidelines, and collaboration to achieve the best outcomes for patient-centred care. Not only does the Commission promote integration of oncology and PC, it also calls for a system-level change in which the activities of professionals are coordinated to help develop and implement new educational programmes within oncology and PC. To succeed, effective integration must be anchored in management and policy at all levels of health care, and an integrated approach must be reflected in both international and national cancer control plans to help develop new models of care, educational and research programmes, adequate resource allocation, and sufficient investment. Hopefully, by bringing the need of PC into the limelight, not only does the Commission

challenge the traditional, dualistic perspective of treating either the tumour or the host, it also encourages a combined approach that places the patient's perspective at the centre of their care.

**Executive summary:** <https://goo.gl/ZfTU9g>

### THE LANCET COMMISSION

A step towards dignity in life and death

Oncology and palliative care: Patients need a seamless service

Integrating palliative and oncology care: Paediatric considerations

Integration of oncology and palliative care: Less-mentioned issues and a Japanese perspective

Integrating palliative care into health systems is essential to achieve Universal Health Coverage

**Download/view articles at:** <https://goo.gl/XGRGft>

**N.B.** Additional articles on the integration of oncology and palliative care noted in the 21 May and 1 October 2018 issues of *Media Watch* (#564, pp.7-8 and #583, pp.13-14, respectively).

#### Related

- *ILLNESS, CRISIS & LOSS* | Online – 18 October 2018 – ‘**Utilizing an autoethnographic case study approach to explore patient-centered care and its principles in an oncology and palliative care setting.**’ The aim of this article is to use the first author's lived experience to explore the pertinence of maintaining the patient's centrality in care planning. It is also argued that patient-centered care is the rhetoric within contemporary funding models rather than the reality of practice. Henceforth, recommendations for healthcare professionals are also provided. Each of the [established] eight principles is discussed in accordance with the first author's perspective, as she lives each day with advanced cancer which will ultimately claim her life. **Abstract:** <https://goo.gl/LJE938>

## Forecasting life expectancy, years of life lost, and all-cause and cause-specific mortality for 250 causes of death: Reference and alternative scenarios for 2016-2040 for 195 countries and territories

*THE LANCET* | Online – 16 October 2018 – The authors provide a robust, flexible forecasting platform from which reference forecasts and alternative health scenarios can be explored in relation to a wide range of independent drivers of health. Their reference forecast points to overall improvements through 2040 in most countries, yet the range found across better and worse health scenarios renders a precarious vision of the future – a world with accelerating progress from technical innovation but with the potential for worsening health outcomes in the absence of deliberate policy action. For some causes of years of lives lost, large differences between the reference forecast and alternative scenarios reflect the opportu-

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ity to accelerate gains if countries move their trajectories toward better health scenarios – or alarming challenges if countries fall behind their reference forecasts. Generally, decision makers should plan for the likely continued shift toward non-communicable diseases and target resources toward the modifiable risks that drive substantial premature mortality. If such modifiable risks are prioritised today, there is opportunity to reduce avoidable mortality in the future. However, communicable, maternal, neonatal and nutritional causes and related risks will remain the predominant health priority among lower-income countries. Based on the authors' 2040 worse health scenario, there is a real risk of HIV mortality rebounding if countries lose momentum against the HIV epidemic, jeopardising decades of progress against the disease. **Full text:** <https://goo.gl/fwtqtU>

### **How can a mobile palliative medicine team help in two paediatrics neurology and paediatrics metabolism illness departments?**

*MÉDECINE PALLIATIVE* | Online – 16 October 2018 – Requests for palliative care (PC) interventions concerned 32 children. The request at the first call was a global assessment in 24 cases (75%), participation in ethical meetings in 12 cases (37%), and help for terminal palliative symptoms in nine cases (28%). The PC team was solicited for nine children, 28% terminally ill and all of whom died; among these, 6 or 67% were seen for the first time during the first terminal phase intervention. This is a concrete example of acculturation in palliative medicine. **Abstract:** <https://goo.gl/SZ1iXx>

#### **Related**

- *MÉDECINE PALLIATIVE* | Online – 17 October 2018 – ‘**Why would disabled children require palliative care?**’ To this provocative question, the authors answer from their own professional experience, as members of a French paediatric palliative care (PC) team. They deconstruct PC representations to work with uncertainty, a concept that seems particularly relevant to support children with multiple disabilities, their families and professional teams. They develop the idea that taming uncertainty allows being closer to the needs of children to the extent that it is constitutive of our status of being alive. Abstract: <https://goo.gl/5nHmku>

**N.B.** French language articles.

### **Multi-dimensional approach to end-of-life care: The Welfare Model**

*NURSING ETHICS* | Online – 14 October 2018 – Appropriate and balanced decision-making is sentinel to goal setting and the provision of appropriate clinical care that are attuned to preserving the best interests of the patient. Current family-led decision-making in family-centric societies such as those in Singapore and other countries in East Asia are believed to compromise these objectives in favor of protecting familial interests. Redressing these skewed clinical practices employing autonomy-based patient-centric approaches however have been found wanting in their failure to contend with wider socio-cultural considerations that impact care determinations. Evaluation of a number of alternative decision-making frameworks set out to address the shortcomings of prevailing atomistic and family-centric decision-making models within the confines of end-of-life care (EoLC) prove these alternative frameworks to be little better at protecting the best interests of vulnerable patients. As a result, the authors propose the Welfare Model that they believe is attentive to the relevant socio-culturally significant considerations of a particular case and better meets the needs of EoLC goals of preserving the welfare of patients. Employing a multi-professional team evaluation guided by regnant psychosocial, legal, and clinical standards and the prevailing practical and clinical realities of the particular patient's setting the Welfare Model provides a clinically relevant, culturally sensitive, transparent, and evidence-based approach to care determinations. **Abstract:** <https://goo.gl/YCvG9D>



**National Cancer  
Centre Singapore**  
SingHealth

## **Emotional labour in palliative and end-of-life care communication: A qualitative study with generalist palliative care providers**

*PATIENT EDUCATION & COUNSELING* | Online – 17 October 2018 – Semi-structured interviews conducted with generalist staff – those providing “primary” or “general” palliative care (PC), not PC specialists – who had attended a communication workshop. Five themes emerged: 1) Emotions experienced; 2) Emotion “display rules”; 3) Emotion management; 4) Support needs; and, 5) Perceived impact of emotional labour. Participants reported balancing “human” and “professional” expressions of emotion. Support needs included time for emotion management, workplace cultures that normalise emotional experiences, formal emotional support, and palliative and end-of-life care (EoLC) skills training. Diverse strategies to support the emotional needs of generalist staff are crucial to ensure high-quality EoLC and communication, and to support staff wellbeing. **Abstract (w. link to references):** <https://goo.gl/uVDw8w>

## **How I approach expressing condolences and longitudinal remembering to a family after the death of a child**

*PEDIATRIC BLOOD & CANCER* | Online – 14 October 2018 – Bereaved families fear their child being forgotten by those who knew their loved child, including their child’s oncology team. Thoughtfully timed, family-centric condolences shared by pediatric oncology team members have the potential to extend our compassion and kindness toward a family during the darkness of grief. Well-intended medical teams sometimes feel “at a loss” in terms of what to say to a grieving family and how or when to say it. The authors provide a tangible overview of written or verbal condolence communication in a format that can be personalized to the provider and the patient’s family. **Abstract:** <https://goo.gl/euPy8i>

Noted in Media Watch 4 September 2018 (#528, p.7):

- *CRITICAL CARE MEDICINE* | Online – 28 August 2017 – “**It was the only thing I could hold onto, But...**”: **Receiving a letter of condolence after loss of a loved one in the ICU...**’ The objective of the study was to understand bereaved family members’ experience of receiving a letter of condolence. Six themes emerged: 1) A feeling of support; 2) Humanization of the medical system; 3) An opportunity for reflection; 4) An opportunity to describe their loved one; 5) Continuity and closure; and, 6) Doubts and ambivalence. **Abstract:** <https://goo.gl/3ikF4n>

## **Palliative medicine for patients with advanced heart failure: New evidence**

*REVISTA CLÍNICA ESPAÑOLA* | Online – 11 October 2018 – Although heart failure is one of the most common clinical syndromes in medicine and has a high mortality rate, few patients have access to adequate palliative care for their clinical situation. Several trials have recently been published on the usefulness of starting palliative treatment along with cardiac treatment for patients with advanced heart failure. In this review, the authors analyse the aspects of diagnosing and controlling the symptoms of patients with advanced heart failure and provide a collection of clinical trials that have analysed the efficacy of a palliative intervention in this patient group. Physicians need to be equipped with strategies for recognizing the need for this type of intervention without it resulting in neglecting the active treatment of the patient’s heart failure. **Abstract:** <https://goo.gl/yFXX9F>

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

### **Related**

- *HEART, LUNG & CIRCULATION* | Online – 16 October 2018 – ‘**The perspectives of healthcare professionals on providing end-of-life care and palliative care for patients with chronic heart failure: An integrative review.**’ Twenty-six articles were selected that explored health care professionals’ perspectives towards end of life (EoL) care and palliative care (PC). The categories that emerged were grouped into patient, provider and system issues. Most health care professionals involved in providing care to heart failure patients have misperceptions of PC, often confusing it with EoL and hospice care. **Abstract (w. link to references):** <https://goo.gl/54f2a2>

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Noted in Media Watch 15 October 2018 (#585, p.14):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 11 October 2018 – ‘**Top ten tips for palliative care clinicians caring for heart failure patients.**’ To address challenges faced by palliative care clinicians, the journal assembled a team of experts to provide high-yield tips for the management of these patients. Management in hospice remains challenging, with a significant risk for readmission to the hospital. Almost a quarter of heart failure patients discharged to hospice from the hospital die in less than three days. **Abstract:** <https://goo.gl/Rdn6XK>

**N.B.** Selected articles on palliative care for heart failure patients noted in 1 October 2018 issue of Media Watch (#583, pp.11-12).

### **Neuropalliative care: A practical guide for the neurologist**

*SEMINARS IN NEUROLOGY*, 2018;38(05):569-575. Neuropalliative care is a new and growing field within neurology that focuses on improving the quality of life of patients with serious neurologic illnesses. While specialty-level palliative care (PC) training is available to interested neurologists, all neurologists can strive to provide primary PC for their patients. The authors describe the scope of neuropalliative care, define patient populations who may benefit from PC, and explore the communication and symptom management skills essential to PC delivery. **Abstract:** <https://goo.gl/mjj32k>

#### **Related**

- *FRONTIERS IN NEUROLOGY* | Online – 24 September 2018 – ‘**The “surprise question” in neuro-rehabilitation – prognosis estimation by neurologist and palliative care physician: A longitudinal, prospective, observational study.**’ Implementing an assessment tool into the care of neurological patients ... the 12-months “surprise” question with palliative care (PC) and neurological items might improve predictive performance of survival and thus identify an appropriate, sufficient time to initiate the PC approach and services if needed. **Full text:** <https://goo.gl/mXjv8C>

**N.B.** Additional articles on the role of palliative care in neurology noted in 19 February 2018 issue of Media Watch (#551, p.8). For additional articles specific to multiple sclerosis, Parkinson’s disease and amyotrophic lateral sclerosis see the following back issues of the weekly report: respectively, 30 July 2018 (#574, p.11), 17 September 2018 (#581, p.13), and 27 August 2018 (#578, p.8).

### **Futility and patients who insist on medically ineffective therapy**

*SEMINARS IN NEUROLOGY*, 2018;38(05):561-568. As physicians’ decisions come under greater scrutiny and society demands increasing transparency of care, it is likely that more opportunities for conflicts will arise. Some of the straightforward un-negotiated cases may shift into the gray zone leading to additional topics of debate. It is important to recognize how the beliefs of what is considered medically futile are shaped and acknowledge the limitations of modern medicine. Clinicians should be forthcoming with the uncertainty of prognostication while also articulating disease severity. Detecting sources of disagreement among clinicians is equally imperative. This step helps present a unified treatment team and facilitate a trusting relationship with the patient. Identifying patient values and goals early on in the hospital course can also increase this trust. Respectful and frequent communication between clinicians and patients is essential in limiting conflicts in end-of-life (EoL) decision making. Even when appropriate measures are taken, disagreements are inevitable in our shared decision-making healthcare model. The seven-step model offers procedural recommendations to aid in handling these difficult situations. However, these guidelines are not all-encompassing and may not apply to individual situations. Ultimately, clinicians need further training in ethics, experience in leading EoL discussions, and conflict resolution strategies to optimally handle these circumstances. **Full text:** <https://goo.gl/jw2NYS>



## Contentious ethical and legal aspects of determination of brain death

*SEMINARS IN NEUROLOGY*, 2018;38(05):576-582. Although the concept of death by neurologic criteria is accepted throughout much of the world and death can legally be determined by neurologic criteria throughout the United States, the process is fraught with contentious ethical and legal controversies. I explore historic and contemporary ethical and legal disputes about determination of death by neurologic criteria including the need for consent from patients' surrogates prior to determination of death, the role of religion in determination of death, management of objections to determination of death by neurologic criteria, the approach to patients who are dead by neurologic criteria but are pregnant, and gamete retrieval after determination of death. **Full text:** <https://goo.gl/cpTwnJ>

**N.B.** Additional articles on defining "brain death" noted in the 27 August 2018 issue of *Media Watch* (#578, p.13).

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BIOETHICS* | Online – 16 October 2018 – '**Institutional non-participation in assisted dying: Changing the conversation.**' Whether institutions and not just individual doctors have a right to not participate in medical assistance in dying (MAiD) is controversial, but there is a tendency to frame the issue of institutional non-participation in a particular way. Conscience is central to this framing. Non-participating health centres are assumed to be religious and full participation is expected unless a centre objects on conscience grounds. Institutional non-participation is plausibly not primarily, let alone exclusively, about conscience. The authors seek to reframe the issue by making two main points. First, institutional non-participation is primarily a matter of institutional self-governance. They suggest that institutions have a natural right of self-governance which, in the case of health centres such as hospitals or hospices, includes the right to choose whether or not to offer MAiD. Second, there are various legitimate reasons unrelated to conscience for which a health centre might not offer MAiD. These range from considerations such as institutional capacity and expertise to a potential contradiction with palliative care (PC) and a concern to not conflate PC and MAiD in public consciousness. It is a mistake to frame the conversation simply in terms of conscience-based opposition to MAiD or full participation. The authors goal is to open up new space in the conversation, for reasons unrelated to conscience as well as for non-religious health centres who might nonetheless have legitimate grounds for not participating in MAiD. **Abstract:** <https://goo.gl/9oEy1Z>
- *HEC FORUM* | Online – 17 October 2018 – '**Problematic ethics: Public opinion surveys in medico-legal disputes.**' Public opinion surveys and polls have a long history as tools for the reportage of public sentiment. Born in the "straw polls" of nineteenth century politics, their use expanded in the last century to include a range of commercial and social subjects. In recent decades, these have included issues of medico-legal uncertainty including, in a partial list, abortion, fetal tissue research, and the propriety of medical termination. Because public opinion surveys are assumed to be "scientific," and thus unbiased, there has been little discussion of either their suitability in areas of complex, medico-legal uncertainty or the ethics of their use in these areas. This paper reviews their general history and then their use in the debate over medical termination, often called "medical aid in dying." In this review, two problems are highlighted. First, there is the ambiguous nature of polls and the manner of their construction. Second, there is the manner in which they are deployed as simple and definitive statements in areas of complex medico-legal debate. The result calls for caution in their use by ethicists and a clear duty by both academics and journalists to understand the limits of the medium in areas of medico-legal debate and discussion. **Abstract (with list of references):** <https://goo.gl/mFhnJ9>
- *JOURNAL OF ADVANCED NURSING* | Online – 16 October 2018 – '**Nurses' use of conscientious objection and the implications for conscience.**' Conscience issues and conscientious objection (CO) are current, critical issues for nurses. For Canadian nurses this need has been recently heightened by the national legalization of euthanasia, known as medical assistance in dying (MAiD) in Canada. Ethics education, awareness, and respect for nurses' conscience are needed in Canada and across the profession to support nurses to address their issues of conscience in professional practice.

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Ethical meaning emerges for nurses in their lived experiences of encountering serious ethical issues that they need to professionally address, by way of conscience-based CO. This is the first study to explore what conscience means to nurses, as shared by nurses themselves and in the context of CO. Nurse participants expressed that support from leadership, regulatory bodies, and policy for nurses' conscience rights are indicated to address nurses' conscience issues in practice settings. **Abstract:** <https://goo.gl/ZFsyUg>

- *JOURNAL OF THORACIC & CARDIOVASCULAR SURGERY* | Online – 5 September 2018 – **'Biting the dust with medical help: Should state law legitimize physician-assisted suicide?'** Physicians may be involved in the death of a patient in several different ways. Life support may be withdrawn from a critically ill patient in an intensive care unit at the request or agreement of the patient or a substitute decision maker; this is often referred to as passive euthanasia, but is legally and ethically acceptable because the patient is considered to have died of his disease. Active euthanasia is administering a substance or using other means to cause death; this act is illegal everywhere in the U.S., but may be acceptable in a few other countries. Physician-assisted suicide (PAS) occurs when a physician supplies a patient with lethal means, usually a medication, and the patient causes his own death. Public opinion has shifted regarding PAS. When Oregon adopted legislation permitting PAS in 1997, approval of the practice by the US public stood at 52% and, with some year-to-year variability, increased to 68% in 2015. This popular view has been reflected in state laws: since Oregon passed its statute, similar laws have been passed by Washington (2008), Vermont (2014), Colorado (2016), California (2016), and Hawaii (2018); it is legal also in the District of Columbia (2016) and in Montana (2009) by judicial findings. PAS is widely accepted in Europe; it is legal in The Netherlands, Belgium, Finland, Luxembourg, Switzerland, Germany, Albania, and Canada. Active euthanasia is legal under some circumstances in Belgium, Colombia, Luxembourg, and The Netherlands. The current trend in state laws seems clear, but PAS remains illegal by statute in 36 states and by common law in 3 states. Legalization is under consideration, however, in at least a dozen other states. **Full text:** <https://goo.gl/zVkJi5>

**N.B.** The focus of this article is on the pros and cons of physician-assisted suicide.

- *SEMINARS IN NEUROLOGY*, 2018;38(05):522-532 **'Physician-hastened-death in patients with progressive neurodegenerative or neuromuscular disorders.'** For physician participation in hastened-death to be considered a legally and ethically permissible act, both opponents and supporters would need to agree on the following considerations. Out of respect for both patient and physician autonomy, and in the spirit of shared decision making, hastened-death must represent a requested action of internally and externally uncoerced dying patients aligned with the conscience and judgment of their physicians. To that end, physicians considering requests for physician-hastened death should feel obligated to explore and address the underlying reasons for such requests and ensure palliative failure to the extent possible for both tangible and existential sources of distress. By doing so, patient trust in their physicians may be enhanced, and in some cases, interest in hastened-death averted. Physicians participating in hastened-death should be adequately trained to ensure that the peaceful and respectful death that patients seek can be effected without the harm created by potentially avoidable mistakes. Ideally, some compromise can be achieved to modify current regulations regarding physician-assisted suicide which are unfair to some patients, such as those with neurodegenerative diseases who may lack capacity or be unable to request or self-administer, without erosion of the safeguards and the public trust in the medical profession that these regulations provide. **Full text:** <https://goo.gl/pPgHd7>

## [Publishing Matters](#)

**Editorial by the Editor-in-Chief of *Palliative Medicine***

### **Clear, simple, precise, meaningful: A quick guide to writing for publication**

*INDIAN JOURNAL OF PALLIATIVE CARE*, 2018;24(4):391-392. Compare and contrast these words: kind, helpful, invaluable; rejection, disappointment, frustration. The first set are ones we are (hopefully) used to hearing as palliative care (PC) clinicians, gaining some satisfaction from caring for people toward

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the end of their lives. The second set, sadly, are those we often hear as PC researchers and writers, when (yet again) the article we have carefully crafted has been declined for publication. Unfortunately, I do not have a cure to help you cope with the disappointment of rejection, but perhaps, some of the guidance given here might help mean you are more likely to have your article accepted for publication. Remember though that many journals are only able to accept a small proportion of articles submitted, and that even the most eminent of researchers experience rejection. Writing is a skill, like any other, that has to be learned. Sadly, we can sometimes learn from those who believe they demonstrate their importance through overly complex, jargon-laden writing. Rather, learn from those who are excellent communicators, who are able to engage their audience and enable them to understand complex concepts and why they matter. I hope that the next email you open from a publisher is one saying “yes” to publication of your work. This is the first step to your work making a difference to patients and families, who we must never forget are the reason we conduct our research. **Full text:** <https://goo.gl/prke55>

### [Media Watch: Access on Online](#)

#### **International**



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/xGvt2A>

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

PALLIATIVE CARE NETWORK: <https://goo.gl/YBP2LZ>

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

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at <https://goo.gl/6vdk9v>]

#### **Asia**

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

[Scroll down to 'Resource Collection' and 'Media Watch Barry Ashpole']

#### **Canada**



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLqxy2>

[Scroll down to 'Are you aware of Media Watch?']

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

[Scroll down to 'Additional Resources']

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

#### **Europe**

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

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

#### **South America**



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

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Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

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

### 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.

[Search Back Issues of Media Watch @ http://goo.gl/frPgZ5](http://goo.gl/frPgZ5)

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