

**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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**When guided by relational ethics, we find ourselves bending rules and considering a broader range of factors than the patient's autonomy and personhood, where our care and decisions are grounded, motivated, and justified by relational considerations.**

'Close encounters of the first kind: An interdisciplinary ethics of care approach mitigates moral injury and family division in the midst of COVID-19' (p.12), in *Journal of Pain & Symptom Management*.

## U.S.A.

### **The pandemic's next effect: A giant wave of disabling grief**

*SCIENTIFIC AMERICAN* | Online – 19 May 2021 – The deaths of more than 586,000 people in the U.S. from COVID since the spring of 2020 have left many millions grieving. A sizable number of these bereaved individuals will find their anguish lasts an unusually long time, does not diminish and renders their life almost unbearable, mental health specialists say. People who sufferer this intense bereavement are frequently unable to keep their job, leave their home or care for other loved ones. Even those who are able to navigate some of everyday life describe their agonized existence as just waiting to die. Their continued high level of stress can damage the body, increasing inflammation and risks for associated illnesses such as heart disease. This condition, a psychiatric state called prolonged grief disorder, typically lasts for many months after a loss – one year in the U.S. or six months per international criteria. The condition is much worse than normal grieving... And the isolation surrounding so many pandemic deaths likely makes people more vulnerable to it. The number of people with prolonged grief in the near future and beyond could be substantial. Each U.S. COVID death, it estimated, leaves, on average, approximately nine close relatives bereaved.<sup>1</sup>  
<https://bit.ly/3hDBYKP>

1. 'Tracking the reach of COVID-19 kin loss with a bereavement multiplier applied to the U.S.,' *Proceedings of the National Academy of Sciences of the United States of America*, published online 10 July 2020. [Noted in Media Watch 13 July 2020 (#674, p.11)] Full text: <https://bit.ly/322myb8>

### **Ethics at the end of life: The first ethical issue is not who decides but who accompanies**

*BAPTIST NEWS* | Online – 17 May 2021 – Anyone with much hospital experience as patient, healthcare provider, or both, can easily attest to how imperfect are the processes for protecting patient autonomy and informed consent. Medical practice, ratified by law in many nations, has responded to these difficulties, in part, by offering procedures for declaring one's choices in advance. In the U.S., these first were called living

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wills and then advance directives (ADs). These have moved into the realm of standard documents that states provide, and hospitals, doctors or lawyers deploy, to help individuals make medical decisions in advance. These documents generally are framed today as offering a spectrum of choices concerning how aggressive people would want healthcare providers to be in sustaining their lives under such conditions as their severe brain damage or permanent dependence on a breathing machine. There are three fundamental problems with such documents. First, they assume a continuity of preference between, for example, a healthy 35-year-old person filling out some papers and a gravely ill 75-year-old in a medical crisis. Second, these documents are, and can only be, vague and generic, whereas medical situations are detailed and specific. Third, the whole advance directive paradigm fails to take account of the fact that when most people head to the hospital, they bring not just a document (if they even do that) but also loved ones who almost always will become the central decision-makers regardless of what a document says. This is why the move to supplement or replace ADs with a document that we call in the U.S. “durable power of attorney for healthcare” has been wise. <https://bit.ly/3tZVWBZ>

## Public opioid policy may interfere with hospice patients’ pain management

*HOSPICE NEWS* | Online – 17 May 2021 – Public policy intended to reduce opioid abuse and addiction appear to have the unintended consequence of limiting hospice patients’ access to these often necessary pain management drugs. Misapplication of current U.S. Centers for Disease Control & Prevention guidelines for opioid prescribing is a likely contributor to this problem. Research spearheaded by the Oregon State University College of Pharmacy examined the medical records of 2,500 hospital patients who were discharged to hospice between 2010 and 2018.<sup>1</sup> Findings indicate that opioid prescriptions for hospice patients are on a

downward trend (a 12% decline), while the use of less powerful, non-opioid medications is rising. Researchers expressed concern that these trends mean that many hospice patients are being under-treated for pain. <https://bit.ly/33WdjJj>

### Specialist Publications

‘Assessment tools for problematic opioid use in palliative care: A scoping review’ (p.11), in *Palliative Medicine*.

1. ‘Decreasing trends in opioid prescribing on discharge to hospice care,’ *Journal of Pain & Symptom Management*, published online 10 April 2021. **Abstract (w. references):** <https://bit.ly/3fpmfMw>

Noted in Media Watch 1 March 2021 (#706, p.9):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 February 2021 – ‘**A national survey of challenges faced by hospices during the opioid crisis: Estimates of pain medication shortages, missing medications, and opioids left in the home post-death.**’ No national data exist on hospice medication shortages, the frequency that opioid medications go missing, and drug disposal practices. A national survey of 600 randomly selected hospices stratified by state and profit status was undertaken. Participants reported their knowledge and perceptions about medication shortages, frequency that opioid medications go missing, and the proportion of hospice deaths in which opioids are left in the home. **Abstract (w. references):** <https://bit.ly/3uEXOld>

Noted in Media Watch 23 May 2020 (#658, p.7):

- *CURRENT ONCOLOGY REPORTS* | Online – 13 March 2020 – ‘**Stringent control of opioids: Sound public health measures, but a step too far in palliative care?**’ Opioids are the only class of drug with the proven ability to control severe pain. The introduction of stringent opioid prescribing restrictions has inevitably impacted upon the ability of those prescribing opioids for advanced life-limited disease to practice as previously and could limit the supply of adequate pain relief to patients with cancer. This review considers the evidence that symptom management of patients with advanced cancer contributes to the “opioid problem” and whether there is adequate recognition of the risks involved. **Abstract (w. references):** <http://bit.ly/2w7Ltwj>

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Noted in Media Watch 30 December 2019 (#646, p.11):

- **PALLIATIVE MEDICINE** | Online – 23 December 2019 – ‘**The perception of barriers concerning opioid medicines: A survey examining differences between policymakers, healthcare professionals and other stakeholders.**’ There are significant differences in the perception of barriers between policymakers and healthcare professionals working in the field of harm reduction, pain management and palliative care... The aspects that were most frequently perceived as a major barrier or as having major impact were lack of training, lack of financial resources, and physicians’ reluctance to prescribe opioids. The responses to the knowledge and attitude questions mirror familiarity with specific professional discourses in the diverse stakeholder groups. **Full text:** <http://bit.ly/34RxB4A>

### **Palliative care update: Delivery gaps, machine learning, and time-limited trials**

**MEDSCAPE** | Online – 17 May 2021 – Three recent studies report important advances in our understanding of palliative care (PC) delivery. The first study,<sup>1</sup> an analysis of differences in PC delivery patterns across different diagnoses, found that adults with non-cancer diagnoses are less likely to receive PC early and less likely to receive high-quality PC. In the second study,<sup>2</sup> the authors used a machine learning algorithm to predict mortality risk in patients with serious illness and provide behavioral prompts to clinicians to initiate serious illness conversations in those patients with the highest risk. Such interventions can ultimately lead to improved care delivery, including early PC initiation for patients with serious illness. The third study was conducted in the intensive care unit setting and explored the use of time-limited trials<sup>3</sup> – a shared decision-making strategy in which life-sustaining treatments are implemented for a predefined period to determine how the patient responds – as an approach to delivering care that respects patients’ and caregivers’ wishes while reducing non-beneficial treatments in patients with advanced medical illnesses and poor prognoses. These three studies highlight gaps in PC delivery, build evidence for strategies that can lead to earlier care planning for patients with serious illness, and suggest a clinical approach for managing critically ill patients with a poor prognosis. <https://wb.md/33QrwXZ>

1. ‘Comparison of palliative care delivery in the last year of life between adults with terminal non-cancer illness or cancer,’ *JAMA Network Open*, published online 4 March 2021. [Noted in Media Watch 8 March 2021 (#707, p.9)]. **Full text:** <http://bit.ly/2NXvpGy>
2. ‘Effect of integrating machine learning mortality estimates with behavioral nudges to increase serious illness conversions among patients with cancer: A stepped-wedge cluster randomized trial,’ *Journal of Clinical Oncology*, published online 20 May 2020. **Abstract:** <https://bit.ly/2T01tf1>
3. ‘Evaluation of time-limited trials among critically ill patients with advanced medical illnesses and reduction of non-beneficial ICU treatments,’ *JAMA Internal Medicine*, published online 12 April 2021. **Abstract:** <https://bit.ly/3oepXe>

## **International**

### **Comprehensive indigenous healthcare in prisons requires federal funding of community-controlled services**

AUSTRALIA | *The Conversation* – 20 May 2021 – The Royal Commission into Aboriginal Deaths in Custody Report made over 200 directives about improving the health of people in prisons in its 339 recommendations in 1991.<sup>1</sup> One of these recommendations included additional funding to provide better health services for Aboriginal and Torres Strait Islander people in prison. Aboriginal and Torres Strait Islander people are over-represented in prisons. They are 15.6 times more like-

#### **National Palliative Care in Prison Project**

The numbers of older people in prison is increasing, reflective of a trend in historical offence sentencing and societal reluctance for compassionate release. This has driven a need for the delivery of palliative care (PC) in prisons. The National Palliative Care in Prison Project addresses this need by partnering with justice and correctional health services to co-design a national PC framework for Australian prisons. <https://bit.ly/2QzXbdj>

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ly to be incarcerated than non-indigenous Australians. Yet, there are virtually no staff skilled in engaging with cultural protocols in health services in prisons. And current policies and procedures do little to extend cultural care to families when the death of an Aboriginal or Torres Strait Islander person in prison has occurred. The royal commission and the United Nations recommend people in prisons have access to healthcare equivalent to what is available in the community. However, the system is still strained, as the multiple deaths of Aboriginal people in custody in recent months, inquests revealing gaps in health care... Palliative care (PC) specialists and nurses with PC training are almost entirely missing [see sidebar]. <https://bit.ly/3ypW0hA>

1. 'Royal Commission into Aboriginal Deaths in Custody: Final report,' Australasian Legal Information Institute, April 1991. **Download/view at:** <https://bit.ly/3yr4Bkb>

**N.B.** End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report, last updated 1 May 2021, can be downloaded at the Palliative Care Network website at: <http://bit.ly/2RdegnL>

### Study highlights experiences of health and social care professionals during pandemic

U.K. | *MedicalXPress* – 19 May 2021 – The first paper to give voice to health and social care professionals providing end-of-life care (EoLC) during the COVID-19 pandemic has been published in *Palliative Medicine*,<sup>1</sup> led by researchers at the Universities of Oxford, Liverpool and Sheffield. The paper describes how providing EoLC during the pandemic has had a profound impact on health and social care professionals. They described struggling with the deaths of colleagues or their own family members and the risk of passing COVID-19 on to their loved-ones. Professionals had to take on the responsibility of being with patients in their final moments of life, as some families did not make it in time to “say goodbye.” The paper’s authors state that the long-term impact of these experiences for healthcare workers must not be overlooked. The study makes important recommendations for health and social care services when providing EoLC during a pandemic... Adopting these recommendations is important as research shows that when psychological skills are taught and promoted within clinical teams, professionals report better job satisfaction, stress levels, general health, and produc-

tivity, with an overall reduction in burnout. Furthermore, relatives who are involved in the end-of-life experience report better psychological outcomes after bereavement. <https://bit.ly/2RxZZrV>

#### Specialist Publications

**'Evaluation of a large scale advance care planning co-design education program for Chinese-speaking people in Australia'** (p.12), in *American Journal of Hospice & Palliative Medicine*.

**'Priorities and opportunities for palliative and end-of-life care in U.K. health policies: A national documentary analysis'** (p.6), in *BMC Palliative Care*.

**'What is common and what is different: Recommendations from European scientific societies for triage in the first outbreak of COVID-19'** (p.8), in *Journal of Medical Ethics*.

**'Spanish and Portuguese Societies of Internal Medicine consensus guideline about best practice in end-of-life care'** (p.14), in *Revista Clinica Española*.

1. 'Health and social care professionals' experiences of providing end-of-life care during the COVID-19 pandemic: A qualitative study,' *Palliative Medicine*, published online 18 May 2021. **Full text:** <https://bit.ly/2QA6gKG>



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## Parents of children with a life-limiting condition left overwhelmed and isolated by pandemic

IRELAND | *The Irish Examiner* (Dublin) – 18 May 2021 – Over 60% of parents who are caring for a child with a life-limiting condition have reported feeling very isolated during the pandemic. There are approximately 3,840 children in Ireland living with a life-limiting condition, 1,900 of whom have palliative care needs, and COVID-19 has had a drastic impact on their lives and the lives of their families. A survey conducted by Irelands only childrens hospice, LauraLynn, has revealed some of the stark realities that these families have been faced with over the past 15 months. The majority of respondents revealed that they have been experiencing a great deal of isolation as many of their supports were impacted by the pandemic and restrictions. Over 85% of parents said they felt completely overwhelmed and totally exhausted as a result of providing care for their child with a life-limiting condition during the global pandemic. LauraLynn has remained open throughout the pandemic and strived to continue caring for and staying connected to these families. They are offering respite care, short breaks, crisis care and end-of-life care and supports to children and families. A virtual children's hospital was launched as a means of providing supports such as play therapy, music therapy, counselling and symptom management. <https://bit.ly/3bAzpp2>

## [Specialist Publications](#)

### Postponed withholding: Balanced decision-making at the margins of viability

*AMERICAN JOURNAL OF ETHICS* | Online – 17 May 2021 – Advances in neonatology have led to improved survival for periviable infants. Immaturity still carries a high risk of short- and long-term harms, and uncertainty turns provision of life support into an ethical dilemma. Shared decision-making with parents has gained ground. However, the need to start immediate life support and the ensuing difficulty of withdrawing treatment stands in tension with the possibility of a fair decision-making process. Both the parental “instinct of saving” and “withdrawal resistance” involved can preclude shared decision-making. To help healthcare personnel and empower parents, we propose a novel approach labeled “postponed withholding.” In the absence of a prenatal

advance directive, life support is started at birth, followed by planned redirection to palliative care after one week, unless parents, after a thorough counseling process, actively ask for continued life support. Despite the emotional challenges, this approach can facilitate ethically balanced decision-making processes in the gray zone. **Full text:** <https://bit.ly/33XTDo8>

### [Research Matters](#)

‘A time to act: Anti-racist paediatric research’ (p.14), in *Paediatrics & Child Health*.

**N.B.** Search back issues of Media Watch for additional articles on “neonatal” and “perinatal” palliative care at: <http://bit.ly/2ThijkC>

### Homecoming: Dignity through movement at the end of life: A qualitative interview study with healthcare professionals

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 18 May 2021 – Dignity is a multifaceted concept involving human value, a person's social position, ethical actions and personal identity within a larger group. Symptom distress, ability to preserve their core identity and roles as well as level of autonomy contribute to patients' perceptions of dignity at the end of life (EoL), in effect promoting courage to live despite existential pain. Palliative care has developed significantly during the past 30 years, resulting in a longer palliative phase of illness, and repeated periods of inpatient care. Without the possibility to be physically active while in hospital, there is a risk that patients will lose their independence. This study addressed the understanding of the experience of movement in a structured pathway for patients in a hospice context. The physical, psychological, social, and existential aspects of being the “lived body,” a person in a difficult situation, emerged in the results. Performing bodily movements in the EoL may support patients' identity and autonomy, thereby promoting their wellbeing and dignity. **Full text:** <https://bit.ly/3tYiltU>

## **Priorities and opportunities for palliative and end-of-life care in U.K. health policies: A national documentary analysis**

*BMC PALLIATIVE CARE* | In print – Accessed 18 May 2021 – Access to high-quality palliative care (PC) is inadequate for most people living and dying with serious illness. Policies aimed at optimising delivery of palliative and end-of-life care (EoLC) are an important mechanism to improve quality of care for the dying. The extent to which PC is included in national health policies is unknown. We aimed to identify priorities and opportunities for palliative and EoLC in national health policies in the U.K. Documentary analysis consisted of: 1) Summative content analysis to describe the extent to which palliative and EoLC is referred to and/or prioritised in national health and social care policies; and, 2) Thematic analysis to explore health policy priorities that are opportunities to widen access to palliative and EoLC for people with serious illness. Relevant national policy documents were identified through web searches of key government and other organisations, and through expert consultation. Documents included were U.K.-wide or devolved (i.e., England, Scotland, Northern Ireland, Wales), health and social care government strategies published from 2010 onwards. Fifteen policy documents were included in the final analysis. Twelve referred to palliative or EoLC, but details about what should improve, or mechanisms to achieve this, were sparse. Policy priorities that are opportunities to widen palliative and EoLC access comprised three inter-related themes: 1) Integrated care – conceptualised as reorganisation of services as a way to enable improvement; 2) Personalised care – conceptualised as allowing people to shape and manage their own care; and, 3) Support for unpaid carers – conceptualised as enabling unpaid carers to live a more independent lifestyle and balance caring with their own needs. Although information on palliative and EoLC in the U.K. health and social care policies was sparse, improving PC may provide an evidence-based approach to achieve the stated policy priorities of integrated care, personalised care, and support for unpaid carers. Aligning existing evidence of the benefits of PC with the three priorities identified may be an effective mechanism to both strengthen policy and improve care for people who are dying. **Abstract:** <https://bit.ly/3frJrK3>



## **Places of death and places of care for indigenous peoples in Ontario: A retrospective cohort study**

*CANADIAN JOURNAL OF PUBLIC HEALTH* | Online – 18 May 2021 – In this retrospective cohort study ... indigenous decedents were on average 8.8 years younger, had more chronic diseases, and lived in lower income neighbourhoods compared with their non-indigenous counterparts. They spent nearly 8 more days in acute care in the last year of life and more died in acute care... When controlling for covariates, indigenous decedents received 1.9 fewer home care nursing hours and 5 fewer personal support worker hours and showed decreased odds of receiving a palliative physician visit in the last 90 days of life; a palliative physician visit lowered odds of dying in acute care by 50% and total days in acute care by 18%. Without continued efforts to address challenges that perpetuate health inequalities, many indigenous people will continue to die in acute care away from their people, families, and culturally relevant supports. **Abstract (w. references):** <https://bit.ly/3fw4aMQ>

**N.B.** Selected articles on palliative and end-of-life care for the indigenous peoples of Canada noted in Media Watch 1 June 2020 (#668, p.12) & 11 November 2019 (#639, pp.1-2).

## **Project ECHO: Enhancing palliative care for primary care occupational therapists and physiotherapists in Ireland**

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 15 May 2021 – Given projected demographic changes, more people with life-limiting conditions will live in the community, requiring a palliative approach to their care. As Project ECHO (Extension for Community Healthcare Outcomes) addresses disparities in access to care and slow dissemination of best practices within existing resources, it offers potential to expand capacity in resource constrained contexts. Overall, results from this study support the use of Project

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ECHO for healthcare professionals palliative care (PC) education in primary care. The utility of this format was confirmed as an effective and accessible model. Findings demonstrate positive impact on confidence in self-rated knowledge and skills and on establishing a network of practice between specialist services and primary care, across disciplines and geographical areas. Future developments to nurture local relationships formed to ensure sustainable practice change were highlighted to ensure Project ECHO directly impacts service delivery and improves the capacity of quality PC provision. **Full text:** <https://bit.ly/3hvdVgM>

Noted in Media Watch 15 February 2021 (#704, p.7):

- *JCO GLOBAL ONCOLOGY* | Online – 8 February 2021 – ‘**Using virtual learning to build pediatric palliative care capacity in South Asia: Experiences of implementing a teleteaching and mentorship program...**’ Project ECHO consists of biweekly videoconference sessions with didactic teaching and case-based discussions, engaging participants in meaningful learning by focusing on opportunities for participant interaction through teachings and case discussions. Key modifications to the model included course-specific leadership team, developing learning plans to address specific learning needs of participants, focusing on ensuring learner participation, and using social media and electronic resources to create opportunities for further learning outside of Project ECHO sessions. **Full text:** <http://bit.ly/3cVnSSt>

Noted in Media Watch 21 December 2020 (#697, p.7):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 December 2020 – ‘**A virtual community of practice to improve palliative care knowledge and self-efficacy among interprofessional healthcare providers.**’ Project ECHO has demonstrated feasibility and acceptability among community healthcare professionals across Canada and was successful in achieving perceived changes in knowledge and self-efficacy. Additional research is needed to determine the long-term impacts of Project ECHO. Future studies will report on self-assessed knowledge, self-efficacy, and practice impact after 12 months of participation in the program. The Project ECHO model is conducive for the delivery of continuing professional education to geographically dispersed HCPs providing pediatric PC. **Full text:** <https://bit.ly/2WqK3ql>

Noted in Media Watch 4 May 2020 (#664, p.13):

- *NURSING OLDER PEOPLE* | Online – 29 April 2020 – ‘**Evaluating a palliative care education programme for domiciliary care workers.**’ Many domiciliary care (DC) workers report low confidence and isolation when delivering end-of-life care in patients’ homes. This study tested the acceptability of Project ECHO by DC workers as a means of increasing their knowledge of, and confidence in, delivering palliative care (PC), and its effectiveness in reducing their isolation by developing a community of practice. PC education for DC staff using Project ECHO methodology was well received, relevant and accessible and may have the potential to improve self-assessed knowledge and confidence. However, finding an ideal time for as many staff to attend as possible may be challenging. **Abstract:** <https://bit.ly/2yUWnGM>

### **Delivering hospice care during the COVID-19 pandemic: Meeting nursing home residents’ needs**

*JOURNAL OF HOSPICE & PALLIATIVE NURSING* | Online – 17 May 2021 – This article provides an overview of the expectations of hospice care, explains the differences in delivering hospice care during the COVID-19 pandemic, examines social isolation and emotional loneliness and the role of familial caregivers, and describes policy changes related to the COVID-19 affecting hospice care delivery in nursing homes. This article answers the following questions: 1) How did residents receiving hospice care have their needs met during the COVID-19 pandemic; and, 2) What areas of nursing home care need to be improved through governmental policy and restructuring. This article also summarized the lessons learned as a result of the COVID-19 pandemic and provided practical implications for nursing, specific to changes in hospice care deliveries for nursing home residents. **Abstract:** <https://bit.ly/3fDKNSi>

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#### Related:

- *INTERNAL MEDICINE JOURNAL* | Online – 19 May 2021 – ‘**Healthcare-providers experiences with advance care planning and goals of patient care medical treatment orders in residential aged care facilities: An explanatory descriptive study.**’ Although barriers exist in completion and activation of plans, healthcare providers described them as progressing resident-centred care. Willingness to follow advance care planning (ACP) instructions was reported to be reduced by lack of trust by clinicians. Families were also reported to change their views from those documented in family-completed ACP, attributed to poor understanding of their purpose. Goals of patient care led to clearer documentation of residents’ medical treatment-plans than relying on ACP documents alone. **Abstract:** <https://bit.ly/3f40va3>
- *PALLIATIVE MEDICINE* | Online – 21 May 2021 – ‘**Advance care planning in residential aged care through multidisciplinary case conferences: A qualitative interview study exploring the experiences of families, staff and health professionals.**’ Advance care planning was like navigating an emotional landscape while facing the looming loss of a loved one. This emotional burden was exacerbated for substitute decision-makers, but made easier if the resident had capacity to be involved or had previously made their wishes clearly known. The “conversation” was not a simple task... Multidisciplinary case conferences facilitated informed decision-making and shared responsibility. Opportunity to consider all care options provided families with clarity, control and a sense of comfort. **Full text:** <https://bit.ly/3bEF2m3>

#### What is common and what is different: Recommendations from European scientific societies for triage in the first outbreak of COVID-19

*JOURNAL OF MEDICAL ETHICS* | Online – 12 May 2021 – The sort of crisis that triggers the need for resource allocation will result in many patients arriving in a continuous stream, with shortages of equipment and trained personal. This emphasises the need for a suitable framework to allow health professionals to anticipate and adapt to the coming complexities and challenges. In most of the recommendations, when scarcity cannot be averted, the utilitarian criterion prevails, putting all efforts into trying to save as many lives as possible or saving the most life years possible. The clinical criterion will always remain fundamental, but for practical necessity other decision systems will have to be ready. All the recommendations that were analysed represent important contributions made in a very challenging context. However, as we have seen throughout the text, and as is reinforced by the opinions of the national ethics councils of some of the countries, the ethical complexity of an orientation such as this must incorporate relevant values and principles, in addition to biological criteria, and, therefore, other interested parties, in addition to medical staff, should be involved. In addition, and in line with the recommendations on the European response to the coronavirus pandemic, it would be beneficial, in the authors’ opinion, for the European Union to provide criteria for allocating, within member states, limited resources essential to managing a pandemic and to mitigate the damage, taking due account of the moral equality of all people. This framework needs to be flexible and adaptable, possibly with different levels of scarcity predicted and be periodically reviewed as the situation evolves. **Full text:** <https://bit.ly/3fk307b>

**N.B.** Search back issues of Media Watch for additional articles on “triage” at: <http://bit.ly/2ThijkC>

#### Related:

- *ONKOLOGE* | Online – 12 May 2021 – ‘**General palliative care during the pandemic.**’ The German healthcare system is facing unprecedented challenges due to the COVID-19 pandemic. Palliative care (PC) for critically ill patients and their families was also severely compromised, especially during the first wave of the pandemic, in both inpatient and outpatient settings. This article is based on the authors’ experience in routine inpatient PC and partial results of a study conducted as part of the collaborative project, ‘National Strategy for Palliative Care in Pandemic Times (PallPan).’ Based on their experience from the inpatient care of patients suffering from severe or life-limiting disease, best-practice examples for improving or maintaining care in the on-going pandemic are described. **Full text:** <https://bit.ly/3eOrJ4g>

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



Would the *Journal of Medical Ethics* article be of interest to a colleague?

## Prognostic predictors relevant to end-of-life palliative care in Parkinson's disease and related disorders: A systematic review

*JOURNAL OF NEUROLOGY, NEUROSURGERY & PSYCHIATRY*, 2021;92(6):629-636. Parkinson's disease and related disorders (PDRD) are the second most common neurodegenerative disease and a leading cause of death. However, patients with PDRD receive less ... palliative care (PC) than other illnesses, including other neurologic illnesses. Identification of predictors of PDRD mortality may aid in increasing appropriate and timely referrals. The authors provide recommendations for providers on identifying patients with PDRD ... PC referral. These guidelines differ from current Medicare guidelines [in the U.S.] in that they are specifically targeted for PDRD and have expanded PC triggers to include falls with fractures, loss of efficacy of medications and cover both motor and non-motor symptoms. The authors have also added that rapid or accelerated decline should trigger consideration for PC in that their collective experience suggests that decline rarely follows a straight line and often accelerates as patients are nearing the end of life. Even when patients may not be appropriate for services which are limited by prognosis (e.g., hospice in the U.S.), these guidelines may be used as event triggers for goals-of-care discussions, anticipatory guidance for patients and families and suggest areas for clinical monitoring (e.g., nutrition) that are often not emphasised with current standards of care. It

is worthy of note that atypical parkinsonian conditions may merit earlier PC. However, there is currently no sufficient evidence to suggest that triggers for hospice would be different, and it is the authors' experience that patients with advanced PDRD have similar predictors of the terminal phase. **Full text:** <https://bit.ly/3wdcXd9>

### New hope for advancing neuropalliative care

*THE LANCET*, 2021;20(6):49. People with neurological disorders can have substantial palliative care (PC) needs, which differ from those of patients with other life-threatening conditions, but are often overlooked. The International Neuropalliative Care Society (INPCS) has just been launched to promote the integration of PC within neurological services, and has the mission "to raise standards of care for all people affected by neurologic illness." A growing body of evidence support these views. INPCS plans to build an interdisciplinary professional network, develop educational tools, help disseminate good practices, and galvanise research to fill knowledge gaps. These activities, in turn, should promote the acceptance of PC and advance its integration into standard neurological practice. By working in partnership with other organisations with long expertise in improving practices, such as European Academy of Neurology, INPCS has the opportunity to help spur a rapid change. **Full text:** <https://bit.ly/2SfRTnW>

### Related:

- *PALLIATIVE MEDICINE* | Online – 18 May 2021 – '**Lessons from the COVID-19 pandemic for improving outpatient neuropalliative care: A qualitative study of patient and caregiver perspectives.**' COVID-19 has impacted persons with serious illness, including those with chronic, neurodegenerative conditions. While there are several reports on COVID-19's impact on inpatient palliative care, literature is limited about the impact on outpatient care which may be more relevant for these patients. Four main themes emerged: 1) Disruptions to delivery of healthcare and other supportive services; 2) Increased symptomatic and psychosocial needs; 3) Increased caregiver burden; and, 4) Limitations of telecommunications when compared to in-person contact. **Abstract (w. references):** <https://bit.ly/33USduK>

Noted in Media Watch 5 April 2021 (#711, p.8):

- *NEUROLOGY TODAY* | Online – 1 April 2021 – '**An expanding pool of neuropalliative care specialists drive the founding of a new society for neuropalliative care.**' The interest in neuropalliative medicine is growing. That interest has fueled the establishment of the International Neuropalliative Care Society, which will begin accepting members this spring. Only a tiny fraction of neurologists are trained in palliative care (PC); few PC physicians are trained in neurology; few occupational therapists and other allied health professionals have expertise in neurodegenerative illnesses. The new society is one of several signs that neuropalliative care is growing and maturing as a subspecialty. As neuropalliative care programs proliferate, so does the variety of practice models. **Full text:** <https://bit.ly/3cFsJqs>

**N.B.** Search back issues of Media Watch for additional articles on PC and people living with "Parkinson's" disease and "neuropalliative" care at: <http://bit.ly/2ThijkC>

## Suffering and the end of life

*JOURNAL OF PAEDIATRICS & CHILD HEALTH* | Online – 17 May 2021 – Relief of suffering is an important goal of medicine and aligns with the professional maxim of “do no harm” and the bioethical principle of non-maleficence. Capturing what individuals experience or third-parties sense in terms of suffering is difficult, made harder in the patient who is too young or not able to tell us. This article builds on the thoughts and experience of Isaacs and Preisz who open a discussion on suffering at the end of life (EoL). The discussion is extended by Tobin who recommends the use of goals of care to try to align clinician and parent expectations of what suffering might mean at the EoL. A further article by Brancatisano makes a comment that family resource and parental suffering might inappropriately guide parental decision-making at the EoL in cases where suffering is apparent. The author of this article adds his concerns that physicians can write their own narrative about suffering which can compete against the parent’s view. Furthermore, suffering can be used as a weapon for physicians to pressure parents towards the medical view. The article by Isaacs and Preisz<sup>1</sup> the follow-up commentaries by Tobin<sup>2</sup> and Brancatisano<sup>3</sup> are an opportunity to open the further discourse about suffering and EoL decision-making. **Full text:** <https://bit.ly/3tWOozY>



1. ‘Suffering and end-of-life decision-making,’ *Journal of Paediatrics & Child Health*, published online 15 February 2021. **Full text:** <https://bit.ly/33T720V>
2. ‘Suffering and end-of-life decision-making,’ *Journal of Paediatrics & Child Health*, published online 10 March 2021. **Full text:** <https://bit.ly/3wsZY7F>
3. ‘Suffering and end-of-life decision-making,’ *Journal of Paediatrics & Child Health*, published online 24 March 2021. **Full text:** <https://bit.ly/3otAVhD>

### Related:

- *WESTERN JOURNAL OF NURSING RESEARCH* | Online – 17 May 2021 – ‘**Pediatric end-of-life care: Impact of Islamic faith.**’ The purpose of this study was to explore the perceptions of Muslim women caring for a child at end of life (EoL). Using a qualitative approach, interviews were conducted with 24 female primary caregivers caring for a child at EoL. Thematic analysis was used to analyze the data. The researchers found that Islamic beliefs and practices had a positive influence on primary caregivers’ experiences. Islamic beliefs and practices helped support participants through their child’s EoL experience. Results have implications for healthcare education, practice, policy, and future research on EoL in Saudi Arabia other Muslim countries. **Abstract (w. references):** <https://bit.ly/3or6mt2>

## Responding to the fear of dying alone during COVID-19 pandemic

*JOURNAL OF PUBLIC HEALTH* | Online – 13 May 2021 – If people are unable to say goodbye in the traditional way, then “creative rituals” of mourning and of remembrance will need to be created. One way may be via the online environment (Zoom, Skype, Facetime) or social media (Facebook and Messenger) where this has become a more familiar sight in recent years. Indeed, as we move further along in the post-COVID-19 world, it is necessary to periodically reassess and readjust our approach to best address the needs of people. Telehealth and virtual meetings have become “new normal.” In fact, doctors and nurses go the extra mile to care for their patients by providing telecommunication between isolated patients and their families. Such conversation sometimes takes place at the doors to the ICU, over the phone, or in front of the hospital, as families beg to see their loved ones before they die. A seemingly simple request, which in other times would be encouraged, has become an ethical and healthcare dilemma. Therefore, “providing safe and effective palliative care, including end-of-life (EoL) care, becomes especially vital and especially difficult.” There is an urgent need to address the fear of dying alone during and after the COVID-19 pandemic. Finding “creative spaces” of compassionate love and belongingness to patients could mean supporting meaningful companionship at the EoL. Alleviation of all forms of suffering should be one of the immediate responses of all. We have to be aware that while COVID-19 will come to an end because of the vaccines, the effects could be longer term. **Full text:** <https://bit.ly/2RfhvkM>

Cont.

## Related:

- *PALLIATIVE MEDICINE* | Online – 21 May 2021 – ‘**Sadness, despair and anger when a patient dies alone from COVID-19: A thematic content analysis of Twitter data from bereaved family members and friends.**’ Twitter users expressed sadness, despair, hopelessness and anger about their experience and loss. Saying goodbye via video-conferencing technology was viewed ambivalently. Clinicians’ presence during a death was little consolation. Anger, frustration and blame were directed at governments’ inaction/policies or the public. The sadness of not being able to say goodbye as wished was compounded by lack of social support and disrupted after-death rituals. Users expressed a sense of political neglect/mistreatment alongside calls for action.. **Full text:** <https://bit.ly/341hZ0q>

Noted in Media Watch 17 May 2021 (#717, p.11):

- *PALLIATIVE MEDICINE* | In print – Accessed 10 May 2021 – “‘**Saying goodbye” during the COVID-19 pandemic: A document analysis of online newspapers with implications for end-of-life care.**’ The act of “saying goodbye” (before, during and after death) was central to media representations of COVID-19 bereavement, represented as inherently important and profoundly disrupted. Bedside access was portrayed as restricted, variable and uncertain, with families begging or bargaining for contact. Video-link goodbyes were described with ambivalence. Patients were portrayed as “dying alone” regardless of clinician presence. Funerals were portrayed as travesties and grieving alone as unnatural. Articles focused on what was forbidden and offered little practical guidance. **Abstract:** <https://bit.ly/3uBe5a5>

Noted in Media Watch 7 December 2020 (#695, p.10):

- *JOURNAL OF AGING STUDIES*, 2020;55(12). ‘**Dying alone and lonely dying: Media discourse and pandemic conditions.**’ The authors of this article address the historically-situated concept of a “good death” and a “bad death” and suggests why dying alone, whether completely alone or without significant others physically present, may be considered a bad death. Contemporary dying involves conditions for which we are unprepared as a society. We seldom address our civic obligations to each other. Few people have discussed their wishes about their preferences in dying and whether and how they want to be accompanied at their death, if possible. This is an invisible constraint of modern healthcare. **Full text:** <https://bit.ly/3mHIUWW>

## Assessment tools for problematic opioid use in palliative care: A scoping review

*PALLIATIVE MEDICINE* | Online – 17 May 2021 – To the authors’ knowledge, this study is the first scoping review that identifies tools that have been used to assess for the presence or risk of problematic opioid use in palliative care (PC). The authors retrieved mainly observational studies that adopted use of questionnaires that were originally developed in the chronic non-cancer pain population. No identified studies adequately assessed the psychometric properties of these questionnaires in PC, and none were identified that reported on tools developed specifically for PC populations. Despite the paucity of evidence, PC experts, and organizations are recommending the use of tools developed for chronic pain populations in response to increasing concerns about harms associated with opioids; the authors’ findings suggest that these recommendations are premature. Similarly, PC services are increasingly adopting the use of urine drug tests. However, the purpose, administration and impact of urine drug tests on patients receiving PC are not clear from the current evidence. This review highlights significant gaps in knowledge. The duration of PC involvement can now range from hours to years, given the increasing and earlier integration of PC in life-threatening non-malignant and malignant conditions. Therefore, patients receiving PC may be at risk of opioid-related harms that differ from those of chronic pain populations, and that may vary according to country, PC setting and stage of illness. The development and validation of tools to assess for problematic opioid use in PC are the first critical steps to measure the extent of this problem, and to inform prevention and management strategies in this diverse population. **Full text:** <https://bit.ly/3fnhOBU>



Closing the Gap Between  
Knowledge & Technology  
<http://bit.ly/2DANDFB>

**“It’s almost superstition: If I don’t think about it, it won’t happen”: Public knowledge and attitudes towards advance care planning: A sequential mixed methods study**

*PALLIATIVE MEDICINE* | Online – 17 May 2021 – This study provides empirical evidence on the knowledge and attitudes of one region of the U.K. public’s awareness regarding advance care planning (ACP) and offers strategic direction to increase awareness and engagement through education within a public health campaign. Despite being advocated in policy and embedded in initiatives worldwide, the public are still largely unaware of the term “advance care planning” and what it means, and have a reluctance to engage in discussions, associating it with death and the very end of life (EoL). Family members play a key role in influencing attitudes and engagement with ACP and should be central in future interventions to increase participation. By shifting the view of ACP as a “normal” conversation to have irrespective of health status, essential conversations can start earlier and ensure appropriate care reaches everyone who would benefit. A community action approach to enhance understanding and engagement is supported, however, a “one size fits all” approach will not work; rather bespoke targeting is required with educational and media messaging aligned. There is a need for public health campaigns to recognise the disparity in what palliative care (PC) is seen to offer (EoL care), and move forward by raising awareness, removing misconceptions and increasing openness to holistic PC. A consistent message from a trustworthy source, inclusive of the voice of the patient, carer and healthcare professional, and offering both general and tailored information to the needs of specific groups is advocated. Although the results from this study indicate that most people were not

interested in seeking out further information, a global shift in mindset resulting from COVID-19 may create a platform upon which to start conversations. **Full text:** <https://bit.ly/2RkiCzF>

**Close encounters of the first kind: An interdisciplinary ethics of care approach mitigates moral injury and family division in the midst of COVID-19**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 19 May 2021 – In this compelling personal narrative describing a case from the front lines of the COVID-19 pandemic, a palliative care (PC) physician harnesses the creative powers and strengths of the interdisciplinary team to provide compassionate care to a critically ill patient and his family. The author describes the process of identifying a surrogate decision-maker from among the patient’s many adult children – several of whom were estranged from him and each other – and facilitating weighty decisions about his end-of-life care. Over the course of this journey, the author grapples with her inner biases and struggles with the emotional trauma associated with bearing witness to extraordinary suffering and social isolation imposed by COVID-19. Not only does the ethics of care approach embodied here lead to the creation of enduring vibrant works of art for this patient and others, but it also affirms a guiding principle of PC in which interdisciplinary collaboration is marshalled in the service of cultivating relationships, upholding responsibilities, and intensifying empathy among persons tied together by a common narrative. **Full text:** <https://bit.ly/3v6pCyK>

**Related:**

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 17 May 2021 – ‘**Evaluation of a large scale advance care planning co-design education program for Chinese-speaking people in Australia.**’ Advance care planning (ACP) is important, however ethnic minorities have half the completion rates in the U.S. compared to Caucasian counterparts, and in Australia only 3.5% of advance directives were completed by those overseas-born. Of 519 attendees across 17 workshops, 325 (63%) completed an evaluation. The majority (63%) were previously unaware of ACP. Perception of receipt of useful information positively correlated with motivation to undertake ACP agreed to participate in structured telephone interviews. **Abstract (w. references):** <https://bit.ly/3eTib8l>



**Media Watch: Access 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.15.

## Patient characteristics for palliative care referral and perception of palliative care service name

*PALLIATIVE MEDICINE REPORTS* | Online – 17 May 2021 – This exploratory cross-sectional study highlights practical barriers to integration of early palliative care (PC) with standard oncology care as recommended by current American Society of Clinical Oncology guidelines.<sup>1</sup> As part of a larger pilot project to embed a PC provider in a thoracic oncology clinic, this survey-based study explored logistical and attitudinal barriers influencing referral to a freestanding palliative clinic before opening of an embedded onco-palliative clinic model. At this institution, medical oncology providers and inpatient palliative consult teams are the primary gatekeepers to outpatient palliative clinic referral. By capturing perceptions of the overall referral base, this study explores perceived barriers in relation to a freestanding outpatient palliative clinic before piloting embedded palliative providers in oncology clinics. To assess nursing perception of outpatient PC, thoracic oncology nurses were included in this study to elicit baseline perspective in a targeted nursing cohort before embedding a palliative provider in the thoracic oncology clinic. Eliciting the perspective of referring providers and nursing staff was pertinent in exploring barriers to PC referral, acceptance of a new embedded palliative clinic model, and providing baseline data to explore how perceptions and barriers change with embedded outpatient onco-PC. **Full text:** <https://bit.ly/3uY176x>

1. 'Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline update,' *Journal of Clinical Oncology*, 2017;35(1):96-112. [Noted in Media Watch 31 October 2016 (#486, p.7)] **Full text:** <http://bit.ly/2utXVSB>

## Strong emotional reactions for doctors working in palliative care: Causes, management and impact. A qualitative study

*PSYCHO-ONCOLOGY* | Online – 17 May 2021 – Doctors working in palliative care (PC) services are exposed to challenging emotional environments almost daily. Strong-emotional reactions experienced in this setting have implications for patient care and doctor wellbeing. Existing research has not focused on doctors working in specialist PC. This study aimed to understand what strong emotional reactions are experienced by doctors working in specialist PC, the cause of these strong emotional reactions and the impact they have on the lives of PC doctors. Twenty doctors were recruited from a specialist PC service within a public health network in Melbourne, Australia, comprising of two inpatient units, a consult service and outpatient clinic. PC doctors experience a myriad of strong emotions in their line of work. Experiences found to elicit strong emotional reactions included patient, family and staff distress and organizational issues. Strong emotional reactions impacted clinical behaviours, patient care and doctors' personal lives. Strategies developed for managing strong emotional reactions included debrief, setting boundaries, avoidance and self-reflection, along with non-work strategies such as time with family. Whilst emotionally challenging experiences are unavoidable and necessary in a PC doctor's development, doctors need to be supported to avoid adversely impacting patient care or their own wellbeing. **Abstract:** <https://bit.ly/3ynxCNw>



### **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://bit.ly/2RPJy9b>

## Spanish and Portuguese Societies of Internal Medicine consensus guideline about best practice in end-of-life care

*REVISTA CLINICA ESPAÑOLA* (English Edition), 2012;221(1):33-44. A steering committee of 12 Spanish and Portuguese experts proposed 37 recommendations. A two rounds Delphi method was performed, with participation of 105 panelists including internists, other clinicians, nurses, patients, lawyers, bioethicians, health managers, politicians and journalists. The panel addressed seven specific areas for 37 recommendations spanning: identification of patients; knowledge of the disease, values and preferences of the patient; information; patient's needs; support and care; palliative sedation; and, after death care. The panel formulated and provided the rationale for recommendations on good clinical practice rules for caring end-of-life patients. **Abstract:** <https://bit.ly/3bCLQAv>

## Research Matters

### **A time to act: Anti-racist paediatric research**

*PAEDIATRICS & CHILD HEALTH* | Online – 22 May 2021 – Research offers the potential for new treatments, programs and services, and underlies decisions about funding that can have profound implications for people's lives. When racism in research is not addressed, children and their families will be unjustly impacted by systemic discrimination, exclusion, and inequity. With a growing acknowledgement that racism is a social determinant of health, and as COVID-19 reveals staggering racial disparities, the authors believe now is the time for intentional anti-racism initiatives throughout the research ecosystem to prevent further harms in patient care and the lives and futures of children. The authors aim to highlight this need for justice, and conclude with a series of practical recommendations, ranging from the collection and use of race-based data, to equity, diversity, and inclusion education, to mentorship opportunities. **Abstract:** <https://bit.ly/2Si-weey>

### 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.

Cont.

### 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.

### Media Watch: Access on Online

#### International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3ttHLVu>

[Scroll down to 'Media Watch']

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://bit.ly/2ThijkC>

PALLIATIVE CARE NETWORK: <http://bit.ly/2Ujdk2S>

PALLIMED: <http://bit.ly/2ResswM>

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at: <http://bit.ly/2MwRRAU> ]

#### Asia



Asia Pacific  
Hospice Palliative  
Care Network

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://bit.ly/2SWdYWP>

[Scroll down to 'Media Watch']

#### Australia

PALLIATIVE CARE RESEARCH NETWORK: <http://bit.ly/2E1e6LX>

[Click on e-News (November 2019); scroll down to 'Useful Resources in Palliative Care Research']

#### Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <http://bit.ly/2Dz9du3>

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

ONTARIO | Acclaim Health: <https://bit.ly/3g82uuS>

[Scroll down to 'General Resources' and 'Media Watch']

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <http://bit.ly/2TboKFX>

ONTARIO | Mississauga Halton Palliative Care Network: <https://bit.ly/3tby3b3>

#### Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <HTTP://BIT.LY/3EPKUAC>

HUNGARY | Magyar Hospice Alapítvány: <http://bit.ly/2RgTvYr>

U.K. | Omega, the National Association for End-of-Life Care: <http://bit.ly/2MxVir1>

#### South America

Academia Nacional de Cuidados Paliativos (Brazil): <http://bit.ly/2G2ISGr>