

**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**

**Beyond geographical availability, equitable access to palliative and end-of-life care is likely to require changes to traditional models of care, how services are delivered, and to inter-professional working relationships.**

'Exploring socioeconomic inequities in access to palliative and end-of-life care in the U.K.: A narrative synthesis' (p.6), in *BMC Palliative Care*.

## Canada

**"They are denied access"**

ONTARIO | *The Record* (Kitchener) – 25 October 2021 – People in Waterloo Region who want medical assistance in dying, or MAiD, are routinely denied access to hospice care, say the team of doctors and nurse practitioners who provide medical assistance in dying in the region. Medical assistance in dying has been legal in Canada since June 2016. During that time, 134 people in Waterloo Region have received MAiD. To receive MAiD, a person must be an adult capable of making health care decisions, who has a serious and incurable disease or disability, and is in advanced decline. "If the hospices are aware of their MAiD request, they are denied access," says Martha Taylor, a doctor on the team. The five doctors and three or four nurse practitioners have all had the same experience, Taylor says. "They'll say, 'You can't get in because you're asking for MAiD.' It's happening." Four hospices serve Waterloo Region: Lisaard House in Cambridge and Innisfree House in Kitchener, which are jointly run and together have 16 beds; Hospice Waterloo Region, a 10-bed facility which opened near RIM Park in March 2021 and Hospice Wellington, with 10 beds in Guelph. Hospice Wellington and Hospice Waterloo Region are clear to anyone considering going into their facility: MAiD is not provided on-site. If you choose MAiD, you will have to leave. Lisaard and Innisfree is somewhat more flexible. "Residents who choose MAiD will not be compelled to leave our hospice; however, if they choose an alternate location, we will support them by making transportation arrangements," it says on its website. <https://bit.ly/3xze9K4>

Noted in Media Watch 19 April 2021 (#713, p.7):

- **BMC PALLIATIVE CARE** | Online – 12 April 2021 –**'Hospice care providers' experiences of grappling with medical assistance in dying in a hospice setting: A qualitative descriptive study.'** The introduction of medical assistance in dying (MAiD) in Canada represents a new and evolving choice for end-of-life care which has affected the dynamic of care within the hospice environment. The experience of navigating MAiD within a non-provider context challenged care providers to rethink and redefine their roles and left some uncertain about how best to support their patients and others. Care providers worked to navigate the unchartered territory of the MAiD trajectory within a non-provider hospice setting and sought to remedy the moral complexities... **Full text:** <https://bit.ly/3sgHEvP>

## Quebec long-term care homes “forgotten” in COVID-19 planning, ombudsman says

QUÉBEC | Canadian Press (Montreal) – 23 November 2021 – Long-term care homes were almost totally forgotten in Québec's early COVID-19 planning, the province's ombudswoman said in a report that called for widespread changes to “humanize” the senior care model in the province.<sup>1</sup> Government officials took a “hospital-centric” approach to preparing for the pandemic based on images of overwhelmed hospitals in Italy and elsewhere in Europe. The strategy neglected the danger posed to the vulnerable residents of long-term care homes, known in Québec as CHSLDs [Centre d'hébergement et de soins de longue durée, i.e., residential and long-term care centres], the report concluded. “While Québec's eyes were turned toward Italy, no risk analysis tailored to Québec's residential-resource model and its specific features was carried out in crafting the strategy in response to the pandemic,” she wrote. “This is how CHSLDs slipped through the cracks of any scenario.” This failure to prepare had devastating consequences on the care homes' ability to handle the first wave, the report found. In order to free up beds, patients were transferred from hospitals to care homes that had neither the staff, equipment nor the infection-control expertise to manage the health crisis that would engulf them. <https://bit.ly/3HM6qNk>



PROTECTEUR  
DU CITOYEN

1. ‘First wave of COVID-19 in CHSLDs: Québec Ombudsman's final report,’ Protecteur du citoyen, November 2021. **Download at:** <https://bit.ly/3oQTJbo>

Noted in Media Watch 31 May 2021 (#719, p.5):

- **BMC GERIATRICS** | Online – 22 May 2021 – ‘**Multi-disciplinary supportive end-of-life care in long-term care: An integrative approach to improving end of life.**’ This Canadian study identified three key recommendations. The first is to establish knowledge and training expectations and resources for long-term care (LTC) staff and physicians, which focuses on a palliative approach, mentorship, communication and collaboration in LTC. The second is to build connections between all those involved in providing end-of-life care (EoL) care, including family members. The third is to create policies and provide funds needed to meet comfort care needs at EoL. Considering the identified priorities, the authors developed a 5-point strategy to providing supportive EoL care within LTC. **Full text:** <https://bit.ly/3fcD6mO>

## International

### End-of-life care: Worry over support for those dying at home

U.K. (Wales) | BBC News (Cardiff) – 25 November 2021 – People dying at home or in care homes might not be receiving the care and support they need, a charity has warned. Marie Curie said it was particularly concerned that some have not had proper pain relief at the end of their lives. It comes as figures show a rise in the number of people dying at home in all but three Welsh local authority areas. The Welsh government said it had increased funding to support end-of-life care at home. But Marie Curie's Lowri Griffiths said there were “real concerns” around the increase in people dying at home, and the inevitable pressure on those supporting them. Figures from the Nuffield Trust show every area in Wales except Anglesey, Bridgend and Torfaen saw an increase in the numbers of people dying at home in 2021, compared with the 5-year average for 2014-2019.<sup>1</sup> Studies estimate that by 2040 the total number of deaths in Wales and England will rise by a quarter to 628,659 a year.<sup>2</sup> If the recent increase continues, then 160,000 more people in Wales and England will need palliative care by 2040 – 42% more than in 2014. <https://bbc.in/3nS2MK2>

1. ‘Chart of the week: In which areas of England and Wales are more people dying at home?’ Nuffield Trust, October 2021. <https://bit.ly/3p1lul>
2. ‘How many people will need palliative care in 2040? Past trends, future projections and implications for services,’ *BMC Medicine*, published online 18 May 2017. [Noted in Media Watch 22 May 2017 (#513, p.11)] **Full text:** <http://bit.ly/2IHcYCi>



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## **Dying and Death in Ireland: What Do We Routinely Measure, How Can We Improve?**

IRELAND | Irish Hospice Foundation (Dublin) – 24 November 2021 – The Foundation's report contains findings from a study conducted by researchers in Trinity College Dublin about how and where people died in Ireland between 2013 and 2018. It also reports on the type and quality of data on death and dying that are available in Ireland. Cancer and heart-related disease are the leading causes of death in Ireland. In 2018, 31% of people died of cancer and 29% of heart-related conditions. Diseases of the respiratory system were the third most common cause of death (13%). The study also found an increase in deaths due to mental and behavioural disorders between 2013 and 2018. This increase was driven by higher rates of deaths due to dementia over that time. The report also found that hospitals were the most common place where people died between 2013 and 2018 in Ireland. Over 2 in 5 (44%) people died in Ireland's hospitals each year, followed by deaths at home (23%) and deaths in long stay residential care (23%) A further 8% of people died in specialist inpatient palliative units (hospices). **Download at:** <https://bit.ly/3CO1KTv>



Noted in Media Watch 27 September 2021 (#736, p.3):

- IRELAND | *The Independent* (Dublin) – 18 September 2021 – ‘**As our population ages, palliative care will become increasingly important.**’ Palliative care (PC) in Ireland is well developed in comparison to many European countries, but significant gaps remain. Filling these will require expansion of services where they are already in place, and developing new services in areas that have been less well served. However, the bigger challenge will be to meet the growing needs for PC that will result from population ageing. It is now very important to plan for a major expansion and strengthening of PC in Ireland. A recent study estimated the current and future numbers of people living in Ireland who have diseases associated with a need for PC.<sup>1</sup> <https://bit.ly/3hNurll>
  1. ‘Population-based palliative care planning in Ireland: How many people will live and die with serious illness to 2046?’ *HRB Open Research*, published online 13 February 2020. [Noted in Media Watch 10 February 2020 (#652, p.7)] **Full text:** <http://bit.ly/2OzrhJJ>

Noted in Media Watch 20 September 2021 (#735, p.3):

- IRELAND | *The Independent* (Dublin) – 13 September 2021 – ‘**One in four think they only have days to live if their doctor talked to them about palliative care: Survey.**’ Four in five people living with a serious illness would like their doctor to talk to them about palliative care (PC) if it could help them. The finding was from a new survey of the public’s perceptions of PC commissioned by the All-Ireland Institute of Hospice & Palliative Care. The survey of 1,000 people also highlighted some of the misconceptions that exist about PC. One in four people would think they only have days to live if their doctor or healthcare professional talked to them about PC, whereas PC may be appropriate for several years, not just for weeks and days at a person’s end of life. <https://bit.ly/3nuagTA>

**N.B.** All Ireland Institute of Hospice & Palliative Care press release: <https://bit.ly/2XlebY3>

Noted in Media Watch 10 February 2020 (#652, p.7):

- *HRB OPEN RESEARCH* | Online – 3 December 2019 – ‘**Population-based palliative care planning in Ireland: How many people will live and die with serious illness to 2046?**’ The number of people in Ireland dying from a disease associated with palliative care (PC) need is estimated to increase 68% between 2016 and 2046 if levels of need stay constant. Under assumptions of changing need, increases are estimated in the range 78-84% depending on projection method employed. The equivalent estimates for England & Wales between 2015 and 2040 are 25% with constant needs and up to 47% with changing needs.<sup>1</sup> The number of people living with a disease associated with PC need outnumber those in the last year of life with a relevant diagnosis. **Full text:** <http://bit.ly/2OzrhJJ>
  1. ‘How many people will need palliative care in 2040? Past trends, future projections and implications for services,’ *BMC Medicine*, published online 18 May 2017. [Noted in Media Watch 22 May 2017 (#513, p.11)] **Full text:** <http://bit.ly/2IHcYCi>

## **Residents of care homes “dying alone amid dangerously low staffing levels”**

U.K. (England, Northern Ireland & Wales) | Wales Online (Cardiff) – 24 November 2021 – Care home residents are dying alone and their everyday needs are being “neglected” due to staffing levels being at such a “dangerously low” level, according to new research by [the public service union] Unison. People in residential care are therefore being denied a dignified end to their lives as there are not enough staff to sit with them during their final hours, according to the survey. The union found that almost a third (31%) of care workers said that staffing levels are dangerously low, getting worse and negatively affecting care quality, leaving carers feeling “exhausted, angry and upset.” Around two thirds (67%), meanwhile, are considering leaving the sector, which Unison described as “disastrous, but inevitable” consequence of years of low wages and morale, and underfunding. As part of the research, Unison surveyed 1,637 employees in England, Wales and Northern Ireland who work in care homes, or help people at home or in supported living. <https://bit.ly/3CITxjf>

**N.B.** Unison press release: <https://bit.ly/3cGPJEI>

Noted in Media Watch 1 November 2021 (#741, p.4):

- U.K. | *The Independent* (London) – 26 October 2021 – ‘**Nurse shortages leave people dying in pain, charity warns.**’ One in three nurses, responding to a survey by the charity Marie Curie and *Nursing Standard*, say a lack of staff is the main challenge providing quality care to dying people.<sup>1</sup> More than half of the nurses said they feel the standard of care has deteriorated during the coronavirus pandemic. They raise concerns about the increased number of people dying at home and insufficient numbers of community nurses to support these people and their families. There have been more than 74,000 excess deaths in private homes in England and Wales since the start of the pandemic, according to the Office for National Statistics.<sup>2</sup> <https://bit.ly/3BpTNTW>
  1. ‘Dying at home: Not enough community staff to support a good death, nurses say,’ *Nursing Standard*, Royal College of Nursing, 27 October 2021. <https://bit.ly/3EjIU8R>
  2. ‘Care home resident deaths registered in England and Wales...,’ Office for National Statistics, 28 September 2021. [Noted in Media Watch 4 October 2021 (#737, p.3)] <https://bit.ly/39ODSDe>

## **Specialist Publications**

### **A missed opportunity in the emergency department: Palliative care consult delays during inpatient admission**

*AMERICAN JOURNAL OF EMERGENCY MEDICINE*, 2022;51(1):325-330. The importance of integrating palliative care (PC) into standard practice is underscored by the data that many patients qualify for PC but are not utilizing this aspect of medicine. The authors undertook an examination of patients who had died while an inpatient to identify whether they were appropriately receiving PC consults. The final study sample included 428 patients who died in hospital between January 2015 and December 2018. The analysis used a PC screening tool to determine which patients would have qualified for PC. Sixty-six percent of patients qualified for PC, whereas only 27% received it. **Abstract:** <https://bit.ly/3kX1CLc>

### **Research Matters**

‘A genetic researcher’s devil’s dilemma: Warn relatives about their genetic risk or respect confidentiality agreements with research participants?’ (p.9), in *BMC Medical Ethics*.

‘Defining rurality in hospice research: Evaluation of common measures’ (p.10), in *Journal of Health Care for the Poor & Underserved*.

### **Publishing Matters**

‘A survey of biomedical journals to detect editorial bias and nepotistic behavior’ (p.10), in *Plos Biology*.

Cont.

Noted in Media Watch 9 August 2021 (#729, p.5):

- **ANNALS OF EMERGENCY MEDICINE** | Online – 2 August 2021 – ‘**U.S. best practice guidelines for primary palliative care in the emergency department.**’ The growing palliative care (PC) needs of emergency department (ED) patients in the U.S. have motivated the development of ED primary PC principles. An expert panel was convened to develop best practice guidelines for ED primary PC to help guide front-line ED clinicians based on available evidence and also the consensus opinion of the panel. Results include recommendations for screening and assessment of PC needs, ED management of PC needs, goals-of-care conversations, PC and hospice consults, and transitions of care. **Abstract (w. references):** <https://bit.ly/3jrg7W9>

**N.B.** Additional articles on PC in the ED noted in Media Watch 2 August 2021 (#728, p.7).

**Related:**

- **PALLIATIVE MEDICINE REPORTS** | Online – 22 November 2021 – ‘**Registration attendants show poor readiness to handle advanced care planning discussions.**’ Preparedness for, and attempts of advance care planning discussions with patients in the emergency department vary by profession. Attending physicians and social workers tend to be the most prepared, and they report the most frequent attempts at discussions with patients. Despite the fact that registration attendants are frequently tasked with asking about patient advance directives (ADs), they show little confidence in asking about and discussing such matters. This study indicates that registration attendants feel unprepared to guide discussions of ADs and should not do so without additional training. **Full text:** <https://bit.ly/3r3FmU2>

**Evaluation of an online toolkit for carers of people with a life-limiting illness at the end of life: Health professionals' perspectives**

**AUSTRALIAN JOURNAL OF PRIMARY HEALTH** | Online – 22 November 2021 – Carers of people with a life-limiting illness report unmet information, practical, and emotional support needs, and are often unaware of services available to help improve preparedness, wellbeing, and reduce strain. CarerHelp is the first e-health toolkit that focuses on the information and support needs of carers of people with a life-limiting illness at the end of life, using a pathway approach. This study investigated the usefulness of CarerHelp, from the perspective of health professionals (HPs) who care for these people. Through a 10-minute online survey, HPs provided feedback about their user experience and perceived usefulness of the website. Their expert opinion was sought to ascertain whether CarerHelp could increase carers' preparedness and confidence to support the person for whom they are caring and thereby improve carers' own psychological wellbeing. HPs also evaluated whether CarerHelp adequately raised awareness of support services available. CarerHelp was perceived as a useful resource for increasing preparedness for the caring role, including physical tasks and emotional support. HPs reported that CarerHelp would increase carers' knowledge of services, confidence to care and ability for self-care. They endorsed CarerHelp as a useful information source, guide for support, and would promote CarerHelp to clients and their families. **Full text (click on pdf icon):** <https://bit.ly/3xfFJMi>



**N.B.** CarerHelp website: <https://bit.ly/3FB1Uk5>

**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>



## **Exploring socioeconomic inequities in access to palliative and end-of-life care in the U.K.: A narrative synthesis**

*BMC PALLIATIVE CARE* | Online – 21 November 2021 – This study reiterates the finding that socioeconomically disadvantaged populations are more likely to receive hospital-based care at the end of life, and that there is a lack of evidence regarding access to and use of services that might be providing generalist palliative care (PC) in the community. The review findings did not suggest a consistent or clear narrative regarding the relationship between socioeconomic position and receipt of specialist PC in the U.K., with many studies finding no evidence of differences in receipt of care between socioeconomic groups. Finding an absence of evidence does not preclude there being socioeconomic inequities in access to PC in the U.K. However, it indicates there is currently very poor understanding within the U.K. of the extent to which these exist. While it is possible to draw on evidence from the U.S., Canada, and Australia, which suggests an overall trend towards individual socioeconomic disadvantage being associated with lower odds of using specialist PC, further research in U.K. should look to clarify where and when inequities in receipt of care occur. Ascertaining whether differences or similarities in receipt of PC are inequitable or equitable requires better understanding of the relationship between socioeconomic position and need for PC, particularly population level need. This issue has been identified in earlier studies and was reiterated again in the findings from this review. Building on this evidence base, the findings from this review point towards specific evidence gaps within the U.K. context concerning the relationship between socioeconomic position, how need – or “candidacy” – for PC is assessed, and the organisation of care. **Full text:** <https://bit.ly/30KmM8H>

Noted in Media Watch 15 February 2021 (/705, p.10):

- *THE LANCET: PUBLIC HEALTH* | Online – 8 February 2021 – ‘**Socioeconomic position and use of hospital-based care towards the end of life: A mediation analysis using the English Longitudinal Study of Ageing.**’ Many patients prefer to avoid hospital-based care towards the end of life (EoL), yet hospitalisation is common and more likely for people with low socioeconomic position. The reasons underlying this socioeconomic inequality are not well understood. This study investigated health, service access, and social support as potential mediating pathways between socioeconomic position and receipt of hospital-based care towards the EoL. Socioeconomically driven health differences might explain patterns of hospital admissions towards the EoL. **Full text:** <https://bit.ly/36YA699>

**N.B.** See ‘What mediates end-of-life care choices?’ a commentary on ‘Socioeconomic position and use of hospital-based care towards the end of life...,’ *The Lancet: Public Health*, published online 8 February 2021. **Full text:** <https://bit.ly/3tP8vRK>

## **Cultures that collide: An ethnographic study of the introduction of a palliative care consultation team on acute wards**

*BMC PALLIATIVE CARE* | Online – 21 November 2021 – Acute care and palliative care (PC) are described as different, incompatible organisational care cultures. Few studies have observed the actual meeting between these two cultures. The authors report part of ethnographic results from an intervention study where a PC consultation team used an integrative bedside education approach, trying to embed PC principles and interventions into daily practice in acute wards. Three themes were found: 1) Anticipations meets reality; 2) Valuation of time and prioritising; and, 3) The content and creation of PC. There are many differences in values and the way PC is provided in the acute care wards compared to what a PC consultation team expects. **Full text:** <https://bit.ly/3FlwmaZ>



### Media Watch: Access Online

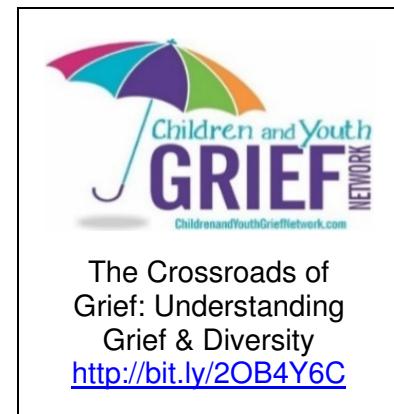
Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.11.

## Challenges of paediatric palliative care in Romania: A focus groups study

*BMC PALLIATIVE CARE* | Online – 18 November 2021 – Results of this study show that for many healthcare professionals (HCPs) the problem of understaffing and the associated issue of unhealthy work-life balance, was one of the biggest barriers to paediatric palliative care (PC) integration. One of the major challenges of the Romanian healthcare system, and paediatric healthcare system in particular, is the great shortages of staff due to huge outflows of medical personnel to western Europe. Hence it should not come as a surprise that also in the paediatric PC setting, shortage of staff is an important problem. Interestingly, according to the participants in this study, the lack of staff was not only due to a lack of financial resources, but also related to a kind of reluctance to specialize in paediatric oncology due to the emotional burden inherent to the profession. This finding is confirmed by other studies that show that paediatric oncology providers by caring for children with a life-threatening disease are at a heightened risk of burnout and compassion fatigue. At the same time, however, we should not ignore the possible persisting cultural stigma around the word “cancer” and “palliative care.” Unlike for cancer, the stigma surrounding PC seems to be a more global phenomenon, which has been frequently reported in previous studies. In the literature, different solutions have been suggested to deal with this stigma, such as replacing PC with a synonym such as “supportive care,” educating families and HCPs about the benefits of PC, investing in positive word-of-mouth by families, and making sure that PC is integrated at the beginning of diagnosis and not when curative treatment is no longer in place. **Full text:** <https://bit.ly/3kSstlb>

## How best to provide help to bereaved adolescents: A Delphi consensus study

*BMC PSYCHIATRY* | Online – 23 November 2021 – Involving an expert panel consisting of bereaved adolescents, parents of bereaved adolescents, and helping professionals who work with such adolescents, this study developed consensus recommendations on how to help bereaved adolescents. Help should be offered on an ongoing basis, accessible as needed, and acknowledge the agency of the adolescent. In-person help was preferred to online help. Adequate support should be offered to parents of bereaved adolescents. The recommendations imply that training of helping professionals is paramount. These consensus recommendations provide a guide for helping professionals, and future implementation and evaluation studies can determine their usefulness in practice. It is anticipated that the recommendations will contribute to good practice in bereavement support as well as adolescent grief intervention studies. **Full text:** <https://bit.ly/30PRblv>



### European Association for Palliative Care Blog

‘Abstract Watch’ highlights selected articles, noted in past issues of Media Watch, on a wide range of issues specific to palliative and end-of-life care. Past postings, for example, focus on the **hospice and palliative care workforce**, **palliative and end-of-life care for patients living with intellectual and developmental disabilities**, **paediatric palliative care and transition to adult care**, **advance care planning and advance directives**, and **neuropalliative care**. Access at: <https://bit.ly/3wvL5RW>



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

## **Winners and losers in palliative care service delivery: Time for a public health approach to palliative and end-of-life care**

*HEALTHCARE* | Online – 23 November 2021 – This consumer survey provides a detailed exploration of experiences during the caregiving journey through to bereavement, identifying strategies that worked well and strategies that could have worked better. The survey also provides useful feedback to services as to where they are meeting the six priorities of the Strategy [see sidebar] and where there are still unmet needs as experienced by their consumers. It also provides some insight into those who die without accessing their services. It is admittedly stretching the point to characterise respondents to the survey as winners or losers, but clearly differences in quality of end-of-life (EoL) care emerged. The winners – those who received the best quality EoL care – were those who were aware of palliative care (PC) as an EoL care option; qualified for admission to, and were able to access, a specialist PC program; and were supported throughout their illness by family and a wider social network. They were for the most part people with a cancer diagnosis. The losers – those who received care at EoL that was adequate rather than best practice – were those who were unaware of PC as an EoL care option or did not qualify for or were un-

able to access specialist PC, and for the most part had a non-cancer diagnosis. They too were supported by family who responded to the survey. In the losers' category are also family carers not being supported during caregiving and during bereavement. A public health approach to palliative and EoL care is proposed to integrate tertiary, primary, and community services through active consumer engagement in the design and delivery of care. **Full text:** <https://bit.ly/3xrYOLb>

### **Priorities of the Western Australia End-of-Life Strategy:**

- Priority 1. Care is accessible to everyone, everywhere
- Priority 2. Care is person-centred
- Priority 3. Care is coordinated
- Priority 4. Families and carers are supported
- Priority 5. All staff are prepared to care
- Priority 6. The community is aware and able to care

**N.B.** 'Western Australia End-of-Life and Palliative Care Strategy 2018-2028,' Government of Western Australia (Department of Health). **Download at:** <https://bit.ly/30YJKsQ>

**N.B.** Selected articles on a public health approach to palliative and EoL care noted in Media Watch 28 September 2020 (#685, pp.14-15).

## **Top ten tips palliative care clinicians should know about their work's intersection with clinical ethics**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 22 November 2021 – Palliative care (PC) sub-specialists and clinical ethics consultants often engage in parallel work, as both function primarily as interprofessional consultancy services called upon in complex clinical scenarios and challenging circumstances. Both practices utilize active listening, goals-based communication, conflict mediation or mitigation, and values explorations as care modalities. In this set of tips created by an interprofessional team of ethicists, intensivists, a surgeon, an attorney, and pediatric and adult PC nurses and physicians, the authors aim to describe some paradigmatic clinical challenges for which partnership may improve collaborative, comprehensive care. **Abstract:** <https://bit.ly/3qXteDU>

## **Theravada Buddhism and Roman Catholicism on the moral permissibility of palliative sedation: A blurred demarcation line**

*JOURNAL OF RELIGION & HEALTH* | Online – 20 November 2021 – Although Theravada Buddhism and Roman Catholicism agree on the moral justification for palliative sedation (PS), they differ on the premises underlying the justification. While Catholicism justifies PS on the ground of the principle of double effect, Buddhism does so on the basis of the Third Noble Truth. Despite their theological differences, Buddhism and Catholicism both value the moral significance of the physician's intent to reduce suffering and both respect the sanctity of life. This blurs the demarcation line between Buddhism and Catholicism regarding the moral justification of PS. **Abstract (w. references):** <https://bit.ly/3cz8ytB>

## **The panoramic view of amyotrophic lateral sclerosis: A fatal intricate neurological disorder**

*LIFE SCIENCES* | Online – 19 November 2021 – Amyotrophic lateral sclerosis (ALS) is a progressive and fatal neurological disease affecting both upper and lower motor neurons. In the U.S. alone, there are 16,000-20,000 established cases of ALS. The early disease diagnosis is challenging due to many overlapping pathophysiologies with other neurological diseases. The etiology of ALS is unknown; however, it is divided into two categories: familial ALS which occurs due to gene mutations & contributes to 5-10% of ALS, and sporadic ALS which is due to environmental factors & contributes to 90-95% of ALS. There is still no curative treatment for ALS: palliative care and symptomatic treatment are therefore essential components in the management of these patients. In this review, the authors provide a panoramic view of ALS, which includes epidemiology, risk factors, pathophysiologies, biomarkers, diagnosis, therapeutics (natural, synthetic, gene-based, pharmacological, stem cell, extracellular vesicles, and physical therapy), controversies (in the clinical trials of ALS), the scope of nanomedicine in ALS, and future perspectives. **Abstract:** <https://bit.ly/3oRIIGF>

## **The patient-centered emergency plan: Practical experiences**

*PRAXIS* | Online – 24 November 2021 – This practical report shows how the cooperation of family physicians and a specialized palliative care team as well as the application of an emergency plan individually adapted to the general goal-of-care and the basic illness of the patient can support the realization of this wish. Good coordination of advance care planning through an individualized patient-centered emergency plan as well as the joint implementation of this care by the interdisciplinary, multiprofessional treatment team and the organization of a good care network are essential components to avoid unwanted emergency hospitalizations at the end of life. **Abstract:** <https://bit.ly/3xioCJw>

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

### **The broad spectrum of palliative care**

The current issue of the German-language journal *Praxis* focuses in palliative and end-of-life care. **Journal contents page:** <https://bit.ly/3l6eD57>

## **Research Matters**

### **A genetic researcher's devil's dilemma: Warn relatives about their genetic risk or respect confidentiality agreements with research participants?**

*BMC MEDICAL ETHICS* | Online – 23 November 2021 – In research investigating the process and outcomes of family communication in the context of hereditary disease, researchers can be confronted with the dilemma of knowing about relatives who have not been informed about a serious health risk. By warning uninformed at-risk relatives, harm could be prevented, especially when prevention and treatment options are available. A researcher may consider warning at-risk relatives directly, or indirectly by informing the treating healthcare professional (HPs). However, while the information about genetic risk or about uninformed at-risk relatives would be valuable for, respectively, these relatives and the probands' HPs, we feel that the harm caused by breaking confidentiality outweighs the benefits of warning at-risk relatives because it potentially creates distrust between the researcher and study participant and possibly harms the proband and family relationships. In other words, the agreement between researcher and participant to keep all data collected confidential should, in principle, take precedence over the duty to warn relatives. One option to avoid dilemmas like this is to inform participants, prior to their signing the informed consent form, about the possibility that research findings with consequences for their relatives will be directly or indirectly communicated. This, however, is not considered appropriate in the context of research on family communication in hereditary disease as it would create significant bias in the patients who might be inclined to participate as well as in the data collected. This jeopardizes research integrity, which will be compromised by biased results. **Full text:** <https://bit.ly/3xfJAsA>

Cont.

Noted in Media Watch 27 September 2021 (#736, p.14):

- **SUPPORTIVE CARE IN CANCER** | Online – 22 September 2021 – ‘Views and experiences of palliative care clinicians in addressing genetics with individuals and families: A qualitative study.’ A proportion of people with palliative care (PC) needs unknowingly have a genetic predisposition to their disease, placing relatives at increased risk. As end-of-life nears, the opportunity to address genetics for the benefit of their family narrows. Clinicians face numerous barriers addressing genetic issues, but there is limited evidence from the PC clinician perspective. Themes identified: 1) Harms and benefits of raising genetics: a delicate balancing act; 2) Navigating genetic responsibility within the scope of PC; and, 3) Overcoming practice barriers: a multipronged approach. **Abstract (w. references):** <https://bit.ly/3IS72XF>

**N.B.** Additional articles on communication of genetic information in the PC context noted in this issue of Media Watch.

### **Defining rurality in hospice research: Evaluation of common measures**

*JOURNAL OF HEALTH CARE FOR THE POOR & UNDERSERVED*, 2021;32(4):2167-2180. Inconsistency in identifying rural hospices has biased research findings and policy analysis. The purpose of this study was to conduct a comprehensive evaluation of eight rural-urban classifications against the gold standard of the [U.S.] Office of Budget & Management (OMB) to determine the utility of alternative measures in hospice research. These classifications included: Urban-Rural Classification Scheme for Counties (URCSC), Urban Influence Codes (UIC), Rural-Urban Continuum Code (RUCC), Federal Office of Rural Health Policy (FORHP), Index of Relative Rurality (IRR), the U.S. Census Bureau, Rural-Urban Commuting Area codes (RUCA), and Frontier & Remote (FAR). The last and the U.S. Census Bureau classified the smallest number of hospices; URCSC, UIC, and RUCC were indistinguishable from the OMB; and RUCA, IRR, and FORHP classified as rural the largest number of hospices. The latter three classifications also had good agreement with the OMB and therefore can be recommended for use instead of the OMB. **First page view:** <https://bit.ly/3HPDSCs>

### **Publishing Matters**

#### **A survey of biomedical journals to detect editorial bias and nepotistic behavior**

*PLOS BIOLOGY* | Online – 23 November 2021 – Alongside the growing concerns regarding predatory journal growth, other questionable editorial practices have gained visibility recently. Among them, the authors explored the usefulness of the Percentage of Papers by the Most Prolific author (PPMP) and the Gini index (level of inequality in the distribution of authorship among authors) as tools to identify journals that may show favoritism in accepting articles by specific authors. They examined whether the PPMP, complemented by the Gini index, could be useful for identifying cases of potential editorial bias, using all articles in a sample of 5,468 biomedical journals indexed in the National Library of Medicine. For articles published between 2015 and 2019, the median PPMP was 2.9%, and 5% of journal exhibited a PPMP of 10.6% or more. Among the journals with the highest PPMP or Gini index values, where a few authors were responsible for a disproportionate number of publications, a random sample was manually examined, revealing that the most prolific author was part of the editorial board in 60 cases (61%). The papers by the most prolific authors were more likely to be accepted for publication within 3 weeks of their submission. Results of analysis on a subset of articles, excluding non-research articles, were consistent with those of the principal analysis. In most journals, publications are distributed across a large number of authors. Our results reveal a subset of journals where a few authors, often members of the editorial board, were responsible for a disproportionate number of publications. To enhance trust in their practices, journals need to be transparent about their editorial and peer review practices. **Full text:** <https://bit.ly/3CO2Cr2>

## 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.

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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.

## Media Watch: Access on Online

### **International**



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3CX3lr3>

[Scroll down to 'Media Watch: a Potpourri']

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: <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']

Cont.

## **Canada**



BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION <https://bit.ly/3two4xX>

[Grief & Bereavement & Mental Health Summit 2021 'Resource Page.' Scroll down to 'International Palliative Care Resource Center']



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): <https://bit.ly/3wvL5RW>

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

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

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