

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.

3 May 2021 Edition | Issue #715



Compilation of Media Watch 2008-2021 ©

Compiled & Annotated by Barry R. Ashpole

Acknowledging the last stage of life as a real and important life stage, and decoupling end-of-life conversations from the cessation of curative treatment and a prognosis of death, ensures communication and planning around values and preferences begin.

'A question worth asking: What matters most at end of life?' (p.11), in *Medical Journal of Australia*.

Canada

Problems in Ontario's long-term care homes were neglected for decades, with deadly consequences: Report

ONTARIO | *The National* (Toronto) – 30 April 2021 – Ontario's neglected long-term care (LTC) sector needs sweeping reforms to protect its vulnerable residents, an independent commission has found, pointing the finger in a scathing report at governments past and present for thousands of COVID-19 deaths at the province's nursing homes.¹ Despite numerous past reviews, commissions and inquiries recommending improvements, the sector was completely unprepared for the pandemic... "Many of the challenges that had festered in the LTC sector for decades – chronic underfunding, severe staffing shortages, outdated infrastructure and poor oversight – contributed to deadly consequences for Ontario's most vulnerable citizens during the pandemic," the commissioners wrote. Now is the time to revisit the delivery model for LTC and adopt a better way to provide care for Ontario's seniors," the report said. Nearly 4,000 LTC residents and 11 staff have died of COVID-19 since the pandemic hit. The province failed to learn from the SARS

epidemic in 2003 and should heed expert advice this time around, they said. <https://bit.ly/3t8OkN1>

Extract from Ontario's Long-Term Care COVID-19 Commission report

The reality of LTC is that it is the last home for the majority of residents. As such, it would seem obvious that palliative care (PC), which aims to relieve suffering and improve quality of life, should be a critical aspect of the care provided to residents. Shockingly, the Commission heard that residents who died in LTC in 2016 and 2017, only 6% were recorded as having received PC in the last year of life. While the actual number of residents receiving "informal" PC (i.e., PC that was not recorded) may be higher, the finding that most LTC residents with less than six months to live did not have a record of PC is concerning. This lack of PC suggests that homes are often not equipped to provide their residents with timely, equitable access to palliative services that meet their needs.

1. 'Ontario's Long-Term Care COVID-19 Commission: Final Report,' 30 April 2021. **Download/view at:** <https://bit.ly/3gSLmK1>

Cont.

Noted in Media Watch 20 July 2020 (#675, p.1):

- **POLICY OPTIONS** | Online – 16 July 2020 – ‘**Palliative care has been lacking for decades in long-term care.**’ As Canada discusses reforming nursing homes in the wake of COVID-19, it is important that we recognize the need for early, integrated palliative care (PC). What this means is that suffering is monitored and then addressed in a timely fashion when required, not just in the last days or weeks. It means that we attend to the physical and emotional well-being of patients and their families while continuing to learn about what quality of life means for them. This care happens while patients are being treated for their underlying illnesses and continues after they or their doctors decide that treatment is no longer helpful, desirable or necessary. PC does not hasten death... <https://bit.ly/2B5GAXb>

Noted in Media Watch 22 June 2020 (#671, p.1):

- **HEALTHY DEBATE** | Online – 16 June 2020 – ‘**Not scared of dying but of dying scared.**’ COVID-19 has shone a bright light on a flawed system in need of dramatic reform, and on a workforce that must be better supported and empowered to provide meaningful end-of-life (EoL) care. This is not to place blame at the feet of our underpaid and undervalued care workers. These workers are cycling in and out of and in-between long-term care (LTC) settings without proper resources, training and educational supports. This workforce, much like the residents that they care for in an ageist society, has been largely ignored. While COVID-19 has brought this issue into focus, the lack of EoL support in LTC has been an ongoing injustice. <https://bit.ly/37F4bJS>

N.B. A special issue of *Nurse Leadership* published in 2019, and noted in Media Watch 25 November 2019 (#641 (p.13), focused on the quality of care in LTC in Canada. **Journal contents page:** <http://bit.ly/2CZ44KM>

Ontario paramedics to offer in-home palliative care to free up hospital capacity: Pilot to launch in 33 municipalities

ONTARIO | *The Brampton Guardian* – 26 April 2021 – Ontario is launching a new pilot program that will allow paramedics in 33 communities to treat palliative care (PC) patients for symptoms at home rather than in hospitals. Currently, paramedics are obligated to bring 9-1-1 patients to hospital emergency departments despite the availability of other care and treatment options in the community. Under the new pilot program, eligible PC patients and those experiencing mental health and addiction challenges can receive care from the paramedic directly or in the community, though a patient can ask at any time to be taken to a hospital. The program consists of two care models. In the first “alternate destination” model, specially trained paramedics assess the patient’s condition on-scene, following the established patient assessment standards, then transports the patient either to a local hospice for PC patients, or to a local crisis centre for patients experiencing mental health and addiction challenges. In the second “treat and refer” model, specially trained paramedics treat PC patients on-site in their home, which can include administering medication for pain, shortness of breath, hallucinations, agitation, terminal congested breathing and nausea or vomiting. Once a patient has been treated, paramedics directly co-ordinate follow-up care with a local hospice or the patient’s primary PC team to provide longer-term treatment options. <https://bit.ly/3dSgPKm>

Noted in Media Watch 26 April 2021 (#714, p.11):

- **PROGRESS IN PALLIATIVE CARE** | Online – 23 April 2021 – ‘**Community paramedicine to support palliative care.**’ Community-based models of care are essential in alleviating health systems burden by reducing emergency department visits and over-reliance on primary care. A rapid review was conducted to determine current scope of practice and geographical coverage of community paramedicine programming, as well as a broader literature search describing current roles. Pilot community paramedicine palliative care (PC) programs in Canada – in Alberta, Nova Scotia and Prince Edward Island – have demonstrated the benefits of community paramedics providing PC through reduced emergency department visits and improved patient satisfaction. **Abstract:** <https://bit.ly/3tOQbaZ>

N.B. Search back issues of Media Watch for additional articles on the potential role of “paramedics” in in-home PC at: <http://bit.ly/2ThijkC>



Share this issue of Media Watch with a colleague

U.S.A.

New reform measures target fraud, kickbacks in California's end-of-life care industry

CALIFORNIA | *The Los Angeles Times* – 30 April 2021 – Widespread fraud, kickbacks and other abuses in an industry meant to provide comforting care for the dying are the focus of reform proposals that call for a temporary halt to new licenses and a crackdown on patient-recruiting schemes in California's booming hospice business. A bill working its way through the state Senate would impose a one-year moratorium on new hospice licenses. A related measure in the Assembly would prohibit hospices from paying recruiters or other "referral sources" for new patients, an area that has been ripe for fraud. Senate Bill 664 is aimed at "the proliferation of shysters who are making tons of money off both public and private sources" at the expense of vulnerable patients. The bill, which was largely spurred by a *Los Angeles Times* investigation published in December,^{1,2,3} is contingent on the state auditor taking up his request to examine the industry and report its findings. The *Times*' investigation found that an exponential boom in hospice providers has transformed end-of-life care that was

once the realm of charities and religious groups into a multibillion-dollar business dominated by profit-driven operators. <https://lat.ms/3gSzZla>

Specialist Publications

'Examining barriers and facilitators to palliative care access in rural areas: A scoping review' (p.6), in *American Journal of Hospice & Palliative Medicine*.

'Reluctance to accept palliative care and recommendations for improvement: Findings from semi-structured interviews with patients and caregivers' (p.7), in *American Journal of Hospice & Palliative Medicine*.

'Palliative care for persons with dementia' (p.9), in *Journal of the American Geriatrics Society*.

'Asian American Medicare beneficiaries disproportionately receive invasive mechanical ventilation when hospitalized at the end of life' (p.10), in *Journal of General Internal Medicine*.

1. 'End-of-life care has boomed in California. So has fraud targeting older Americans,' *The Los Angeles Times*, 9 November 2020. [Noted in Media Watch 14 December 2020 (#696, p.2)] <https://lat.ms/3m0qsOH>
2. 'Dying Californians suffer harm and neglect from an industry meant to comfort them,' *The Los Angeles Times*, 9 November 2020. [Noted in Media Watch 14 December 2020 (#696, p.3)] <https://lat.ms/2KaWtbfF>
3. 'What you need to know if you or a loved one requires end-of-life care,' *The Los Angeles Times*, 9 November, 2020. [Noted in Media Watch 14 December 2020 (#696, p.3)] <https://lat.ms/37NvCSr>

Providers face challenges and opportunities as need for pediatric hospice grows

HOSPICE NEWS | Online – 30 April 2021 – Youth-specific hospice patients are among the most underserved demographics, and they face a variety of end-of-life care needs that are unique from those of adults. The majority of children with serious illness are cared for exclusively by primary care or subspecialty clinicians, according to research by the American Academy of Pediatrics.¹ Like their adult counterparts, children are often subjected to intensive and expensive treatments that may be unlikely to improve their condition or relieve their symptoms. While every person should be afforded the right to choose high-acuity care if that is their preference, more families also need to understand the full spectrum of services that are available to them. Children with serious illness comprise less than 10% of the U.S. population but account for at least 50% of hospital resources for youth patients, according to the AAP study. This research indicated that childhood disease trajectories are often less predictable than those of adults, challenging the ability of physicians to predict the six-month prognosis typically involved in hospice care. This can lead to families avoiding hospice in favor of expensive and intensive medical interventions, though children are able to receive curative treatments concurrently. <https://bit.ly/3xGug80>

1. 'Improving home hospice and palliative care policies,' *Pediatrics*, published online 3 July 2019. [Noted in Media Watch 8 July 2019 (#621, p.12). Full text: <https://bit.ly/3u9OfK5>

Terminal toddler costing Texas \$24 million in life-support costs

TEXAS | WBAP News Talk (Fort Worth) – 29 April 2021 – Texas taxpayers are spending tens of millions of dollars to keep a toddler alive. Doctors have testified that Tinslee Lewis has no chance of recovery and every day she's kept alive is tortuous for her. Cook Children's Hospital is now pushing for a trial date to decide the matter. State Medicaid has spent more than \$24 million to keep Tinslee on a ventilator under heavy sedation. The toddler's mother says the girl deserves the right to live and her family should have the sole decision to take her off life support. The hospital and the girl's family are in a court battle over taking the toddler off life support. Doctors say the girl is terminal and is suffering by being kept alive, while her family believes she is getting better. Now, a Medicaid agency may enter the case as the cost of care for the toddler is approaching \$25 million. Although hospital officials don't cite financial reasons to make end-of-life decisions, Cook's attorneys are pushing the case to trial. The cost of Tinslee's care was never mentioned in previous court documents, but the hospital wants a court to decide immediately to end the girl's suffering. <https://bit.ly/330nVq9>

Noted in Media Watch 30 December 2019 (#646, p.4):

- TEXAS | *Kaiser Health News* – 23 December 2019 – **'Texas law highlights dilemma over care for patients with no hope of survival.'** While some physician groups prefer to talk about "potentially inappropriate" rather than futile care, the underlying quandary remains. What's the definition of "inappropriate," who can make that determination and how best to strike a balance between family members – if the patient is typically too ill or injured to weigh in – and the doctors and nurses who can become distressed providing care indefinitely without seeing any benefit? Texas is one of several states, including California and Virginia, that have enacted laws enabling doctors to withdraw life-sustaining treatment even if family members disagree... <http://bit.ly/2PQXM7a>

International

Freedom to speak up in hospices: Values in action

U.K. (England) | eHOSPICE – 28 April 2021 – Compassion and justice – the values of the hospice movement – are an integral element of creating a Freedom to Speak Up culture where everyone feels confident they will be listened to when they speak up, and action taken. It is a reflection of how psychologically safe people feel, that they are able to speak up, feedback, and work together to innovate and perform effectively. So, there is a strong case for encouraging a Speak Up culture and helping it to flourish. Hospices working towards a "one staff concept" – wanting to be inclusive of workers, whether they are staff or volunteers, will want to make sure that everyone is reassured that their voice is important. Speaking up and listening up is a dialogue between workers and their organisations. As values-led organisations, hospices have care at their very heart, and that extends to their care for workers. A supportive Speak Up, Listen Up, Follow Up Culture is one where all of us should be able to speak up about anything. Where we can share

Specialist Publications

'Challenges and opportunities for spiritual care practice in hospices in a middle-income country' (p.7), in *BMC Palliative Care*.

'Palliative care in advanced dementia: Comparison of strategies in three countries' (p.9), in *Geriatrics*.

'Difficulties in navigating the intersection of generalist and specialist palliative care services: A cross-sectional study of bereaved family's experiences of care at home in New Zealand' (p.9), in *Health & Social Care in the Community*.

'Evaluation of a commissioned end-of-life care service in Australian aged care facilities' (p.13), in *Progress in Palliative Care*.

'Children's palliative care education and training: Developing an education standard framework and audit' (p.13), posted on Research Square.

Cont.

Where we can share ideas, seek support, offer feedback, challenge decisions or speak up without fear of repercussions. The Freedom to Speak Up means we can ask questions where we might be uncertain and share positive practices that can be cascaded elsewhere in the organisation. Freedom to Speak Up Guardians are helping to lead changes in the systems, processes and policies in their organisations to ensure that when workers speak up they are heard and the right actions are taken. Their insights can not only protect staff and patients, but also the integrity and reputations of the organisations in which they work. <https://bit.ly/3gLHKJN>

N.B. 'Freedom to Speak Up Guardians in England,' National Guardian's Office: <https://bit.ly/3aNk8AF>

Palliative care is core business in aged care

AUSTRALIA | Palliative Care Australia – 26 April 2021 – Last month the Association welcomed the recommendations of the Royal Commission into Aged Care, Quality & Safety as an important first step towards reforming the aged care system and improving older Australians' quality of life.¹ In response, the Association has released a new report, 'Palliative care is core business for aged care,' summarising the Commission's recommendations against the Association's original Palli-8 eight-point plan for PC in aged care. The report highlights the alignment between the Commission's recommendations and the Association's recommendations as expressed in Palli-8. **Download PCA report at:** <https://bit.ly/3eJwACL>

1. 'Care, Dignity & Respect,' The Royal Commission into Aged Care Quality & Safety, March 2021. [Noted in Media Watch 8 March 2021 (#707, pp.2-3)] **Download/view report at:** <http://bit.ly/3r50V3J>

N.B. Selected articles on PC in Australia noted in Media Watch 8 March 2021 (#707, pp.2-3).

Dying Behind Bars: How can we better support people in prison at the end of life?

U.K. | Hospice UK – 26 April 2021 – Of the estimated 400,000 people a year across the U.K. who require palliative and end-of-life care (EoLC), a quarter do not have their needs met. Research consistently indicates that access to hospice and EoLC is unequal. This report demonstrates that for the prison population, this inequality of access can be particularly acute. It is a critical time to focus on imprisoned people. The number of over-60s in the prison population has more than tripled in the past two decades, and in the past ten years alone deaths in prison due to natural causes have increased by 77%, with older people accounting for over half of all deaths in custody. 90% of the older prison population have at least one moderate or severe health condition. This significant rise in deaths, together with an increasingly sick and older prison population, has led to a corresponding rise in the need for EoLC, a need that this report demonstrates is not being adequately met. Among the challenges this report identifies are the widespread inappropriate use of restraints, delayed or absent consideration of compassionate release, and care that did not make use of the skills and specialisms available from the health and social care sectors. **Download Hospice UK report at:** <https://bit.ly/3nzbECA>

“He wanted to die in prison ... his home”

U.K. | Politics.co.uk – 27 April 2021 – For those facing their last days in prison Society continues to fail them, with palliative and end-of-life care needs consistently unmet by the justice system. Today, the prison system is the nation's largest provider of residential care for frail, older men. Increasingly, more people are dying behind bars as a consequence of the number of incarcerated people aged over 60 tripling in the past two decades. Indeed, in the 12 months to June 2020, there were 218 deaths in prison due to natural causes, which is an increase of 77% compared to a decade prior. This trend is the consequence of harsher, longer sentences; the rise in the number of convictions for sexual offences (including historical cases); and the absence of timely and transparent compassionate release processes when terminally ill people in prison approach death. Despite people in prisons being legally entitled to the same healthcare and treatment as those on the outside, older incarcerated people's experiences are much worse in comparison to those of the same age in the general population. <https://bit.ly/32RfuNH>

N.B. EoLC 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 can be downloaded at the Palliative Care Network website: <http://bit.ly/2RdegnL>

Assembly’s “deafening silence” on end-of-life strategy criticised

U.K. (Northern Ireland) | *The Belfast Telegraph* – 26 April 2021 – Dying people in Northern Ireland are being failed by a lack of strategy from Stormont, a charity warns today. Marie Curie has urged the Executive to prioritise end-of-life care (EoLC) in its Programme for Government and criticised “deafening silence” on the issue ahead of a Northern Ireland Assembly debate tomorrow. More than 10,400 people in Northern Ireland have so far signed a petition from Marie Curie demanding issues around death and bereavement are prioritised. Nearly 19,000 people have died from all causes in Northern Ireland since the COVID-19 pandemic began, marking a 14% increase on the five-year average, the charity said. Joan McEwan of Marie Curie Northern Ireland said: “The Programme for Government is supposed to identify the biggest challenges facing Society, but there is a deafening silence on EoLC and bereavement. When you consider the enormous levels of bereavement and deaths under the cruelest of circumstances over the past year, the rising demand for palliative care and the growing number of local people dying with chronic diseases like cancer and dementia – the failure to not mention EoLC in Stormont’s most important strategy document is shocking.” <https://bit.ly/2PnUhYx>

Specialist Publications

Examining barriers and facilitators to palliative care access in rural areas: A scoping review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 28 April 2021 – Despite the growth of palliative care (PC), access to PC remains challenging for rural Americans living with chronic diseases. Given the demand and benefits of PC, a comprehensive view of PC access would inform policymakers in developing PC services in rural areas. Twenty-eight studies met inclusion criteria. Barriers to PC access in rural areas mostly arose in structural issues: 1) The inadequate knowledge and awareness of PC among both service users and providers; and, 2) The poorly structured PC system. Other barriers included communication gaps/challenges between providers and patients/families and cultural barriers. The facilitators mainly originated in patients/families’ connectedness with local providers and with other social networks such as friends. These findings highlight the need for funding support to increase provider competency, service availability and accessibility, and the public knowledge and awareness of PC in rural areas. A holistic and tailored PC model that standardizes care delivery, referral and coordination,

including family caregiver support programs, can improve care access. Future practice and research are warranted to implement and evaluate innovative approaches, such as a coordinated community-based approach, to the successful integration of PC in rural communities. **Abstract (w. references):** <https://bit.ly/2R0dsIp>

Research Matters

‘**Methodological challenges for epidemiologic studies of deprescribing at the end of life**’ (p.14), in *Current Epidemiology Reports*.

‘**Cancer, clinical trials, and Canada: Our contribution to worldwide randomized controlled trials**’ (p.14), in *Current Oncology*.

‘‘**It can be hard but it’s not bad**’’: Three questions to solicit caregiver perceptions of benefits and burdens to participating in pediatric palliative care research’ (p.15), in *Journal of Palliative Medicine*.

N.B. Selected articles on the provision and delivery of hospice and PC services in rural America noted in Media Watch 7 September 2020 (#682, p.4).



Palliative Care Network
Palliative Care for Everyone, Everywhere

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

Reluctance to accept palliative care and recommendations for improvement: Findings from semi-structured interviews with patients and caregivers

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 26 April 2021 – Despite some insurance plans now paying for home-based palliative care (PC), recent reports have suggested that insurance coverage for PC may be insufficient in expanding patient access to home-based PC. The authors conducted a qualitative study using semi-structured individual interviews with twenty-five participants (patients, proxies, and their caregivers)... Themes related to home-based PC referral barriers included reluctance to have home visits, enrollment timing, lack of PC knowledge, misconceptions about PC, and patients' self-perceived health condition. Themes related to recommendations for overcoming these obstacles included ensuring that PC referrals come from healthcare providers or insurance companies and presenting PC services more clearly. Findings of this study reinforce the need for additional PC education among patients with serious illness (and their caregivers) and the importance of delivering PC information and referrals from trusted sources. **Abstract (w. references):** <https://bit.ly/3vi9MR8>

Challenges and opportunities for spiritual care practice in hospices in a middle-income country

BMC PALLIATIVE CARE | Online – 22 April 2021 – Member organisations [listed on the national database of the Hospice Palliative Care Association of South Africa] recognise the importance of spiritual care as a key component of palliative care (PC), but are acutely aware of the barriers that hinder such a consolidated approach. It is clear that the international models for the development of training and services in the field of spiritual care have much to offer the development of the field conceptually in South Africa (SA) but that the local situation of a divided and diverse society, with considerable resource constraints, will necessitate a local, contextually relevant approach. In a number of fields of care in Africa, and in SA in particular, the judicious use of international guidelines tempered with local realities have been attempted. It is uncertain, however, what an ideal model of spiritual care will look like practically in the SA context. The authors believe that this dimension of care is important and should be documented with prominence, and not hidden in PC frameworks for Africa. **Full text:** <https://bit.ly/3tQW07O>

Related:

- *JOURNAL OF HEALTH CARE CHAPLAINCY* | Online – 28 April 2021 – ‘**Coordinating assessment of spiritual needs: A cross-walk of narrative and psychometric assessment tools used in palliative care.**’ For those who do not work closely with chaplains, this work provides a sense of what domains chaplains prioritize, from their professional and lived experience, in assessing the spiritual life of the patient. Addressing spiritual needs of patients in healthcare settings improves patient experiences and clinical outcomes; however, non-chaplain providers typically assess spiritual needs differently (quantitative psychometric) than healthcare chaplains (long form narrative) and thus there is little shared language or cross-disciplinary evaluation frameworks across disciplines. **Abstract:** <https://bit.ly/3dZQSBz>

The role of advance care planning in cancer patient and caregiver grief resolution: Helpful or harmful?

CANCERS | Online – 20 April 2021 – Cancer patients and their family caregivers (FCGs) experience various losses when patients become terminally ill, yet little is known about the grief experienced by patients and caregivers and factors that influence grief as patients approach death. Additionally, few, if any, studies have explored associations between advance care planning (ACP) and grief resolution among cancer patients and caregivers. This study examined changes in grief over time in patients and their FCGs and whether changes in patient grief are associated with changes in caregiver grief. The authors also sought to determine how grief changed following the completion of advance directives. Results suggest synchrony, whereby changes in patient grief were associated with changes in caregiver grief. The authors also found that patients who completed a living will experienced increases in grief, while caregivers of patients who completed a do-not-resuscitate order experienced reductions in grief, suggesting that ACP may prompt “grief work” in patients while promoting grief resolution in caregivers. **Full text:** <https://bit.ly/2R7UorM>

Cont.

Related:

- *BRITISH JOURNAL OF HOSPITAL MEDICINE* | Online – 27 April 2021 – ‘**Advance care planning for patients with COVID-19: A communication guide.**’ In view of the high morbidity and mortality associated with COVID-19, early and honest conversations with patients about goals-of-care are vital. Advance care planning in its traditional manner may be difficult to achieve given the unpredictability of the disease trajectory. Despite this, it is crucial that patients’ care wishes are explored as this will help prevent inappropriate admissions to hospital and to critical care, improve symptom control and advocate for patient choice. This article provides practical tips on how to translate decisions around treatment escalation plans into conversations ... in a sensitive and compassionate manner. **Abstract:** <https://bit.ly/3aRe6z6>

The impact of COVID-19 on palliative care for people with Parkinson’s and response to future pandemics

EXPERT REVIEW OF NEUROTHERAPEUTICS | Online – 26 April 2021 – Although in some countries, palliative care (PC) still remains poorly implemented, its importance throughout the course of Parkinson’s disease (PD) is increasingly being acknowledged. With an emergence of Severe Acute Respiratory Syndrome Coronavirus-2 (SARS-CoV-2) pandemic, growing emphasis has been placed on the palliative needs of people with Parkinson’s (PwP), particularly elderly, frail, and with comorbidities. The ongoing COVID-19 pandemic poses an enormous challenge on aspects of daily living in PwP and might interact negatively with a range of motor and non-motor symptoms (NMS), both directly and indirectly – as a consequence of pandemic-related social and healthcare restrictions. The authors outline some of the motor and NMS relevant to PC and propose a pragmatic and rapidly deployable, consensus-based PC approach for PwP during the ongoing COVID-19 pandemic, potentially relevant also for future pandemics. The ongoing COVID-19 pandemic poses a considerable impact on PwP and their caregivers, ranging from mental health issues to worsening of physical symptoms – both in the short and long term, and calls for specific personalized PC strategies relevant in a lockdown setting globally. Validated assessment tools should be applied remotely to flag particular motor or NMS that require special attention, both in short- and long-term. **Introduction:** <https://bit.ly/3vq5BD0>

Related:

- *MOVEMENT DISORDERS* | Online – 28 April 2021 – ‘**Preferences for communication about end-of-life care in atypical Parkinsonism.**’ Studies on preferences regarding discussions on end-of-life care (EoLC), advance care planning (ACP), medical assistance in dying (MAiD), and brain donation have not yet been conducted in patients with atypical Parkinsonism (AP). This study demonstrates that patients with AP have preferences regarding the timing of the discussion of the different themes surrounding EoLC and ACP. A needs-based approach in initiating and conducting timely discussions on these difficult but essential issues is proposed. A thorough explanation and recognition of a patient’s beliefs are recommended when initiating conversations about MAiD and brain donation. **Abstract:** <https://bit.ly/3t5tpdQ>

N.B. Search back issues of Media Watch for additional articles on PC for people living with “Parkinson’s” at: <http://bit.ly/2ThijkC>.



[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>

Difficulties in navigating the intersection of generalist and specialist palliative care services: A cross-sectional study of bereaved family's experiences of care at home in New Zealand

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 24 April 2021 – A cross-sectional postal survey was undertaken to explore bereaved family's experiences of generalist palliative care (PC) and its intersection with hospice services in the last three months of life. People who received support from hospice were more likely to receive support from multiple other services. Those who received no community services were less likely to feel supported by their general practitioner, less likely to spend the last two days of life or die at home. Feeling supported had a strong association with services working well together, being involved in decision-making and being aware of the poor prognosis. The provision of PC is complicated by a lack of integration with specialist PC and may be the basis of continuing inequities in the provision of community care at the end of life. The assumption at a policy level that "generalists" are willing and able to play a key role in PC provision needs to be further challenged. **Abstract:** <https://bit.ly/3dRpih8>

Palliative care for persons with dementia

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 24 April 2021 – The American Geriatrics Society identifies palliative care (PC) knowledge and skills as core entrustable activities for geriatricians, including the regular reassessment of goals-of-care, effective treatment of most pain and non-pain symptoms, and referral to palliative medicine specialists or hospice services "as needed." When medical, psychosocial, or spiritual needs or symptom management are more complex, secondary or tertiary levels of PC services may be sought. The growing need for PC is likely to exceed the availability of geriatricians and PC specialists, thus specific triggers may streamline care to those most in need and at the appropriate time. PC specialist consultation (secondary PC) may be accessible through PC consultation most commonly in hospital inpatient settings and increasingly is becoming available at home provided by hospice agencies or in community/academic medical center office-based settings. For the most complex cases, tertiary PC referral in an academic center with specialist clinical, educational, and research programs may provide a more comprehensive assessment and treatment plan. PC is a vital dimension of care for persons living with dementia and their families and should be a core component of dementia care from diagnosis. In anticipation of millions of more Americans diagnosed with and living with dementia, guidelines for consultation may efficiently allocate a scarce but valuable resource of specialist PC services. In the meantime, primary care providers, hospitalists, and geriatricians should all be working to recognize the need for and to deliver PC in every healthcare setting as an ongoing dimension of care for persons living with dementia. **Full text:** <https://bit.ly/3gGI2CK>

Related:

- *GERIATRICS* | Online – 22 April 2021 – '**Palliative care in advanced dementia: Comparison of strategies in three countries.**' Care in each country has some positive elements: hospice availability in the U.S., the use of a palliative approach in The Netherlands, and home care in Israel. Trends in the three different countries show shifts that might continue and trigger a reassessment of advanced dementia care. However, more research on palliative models of care for advanced dementia is needed. Research should also address the earlier stages on which ambiguity may be even greater, and different settings and different countries with different cultural context across the globe. In addition, there is a need for national datasets with standardized data collection. **Full text:** <https://bit.ly/3euXgak>

N.B. 'Palliative care for persons with dementia' is a commentary on 'Referral criteria to specialist palliative care for patients with dementia: A systematic review,' published online in the *Journal of the American Geriatric Society* 2 March 2021. **Abstract:** <https://bit.ly/3gC1Jul>. Search back issues of Media Watch for additional articles on PC for people living with "Alzheimer's" and "dementia" at: <http://bit.ly/2ThijkC>. Selected articles on the interface between geriatric medicine and PC noted in Media Watch 19 April 2021 (#713, p.4).

Continuous palliative sedation until death: The development of a practice protocol for nursing homes

JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION | Online – 27 April 2021 – Challenges inherent in the practice of continuous palliative sedation until death appear to be particularly pervasive in nursing homes. The authors aimed to develop a protocol to improve the quality of the practice in Belgian nursing homes. The final protocol was signed off by expert panels after two consultation rounds in which the remaining issues were ironed out. The protocol encompassed seven sequential steps and is primarily focused on clarification of the medical and social situation, communication with all care providers involved and with the resident and/or relatives, the organization of care, the actual performance of continuous sedation, and the supporting of relatives and care providers during and after the procedure. Although consistent with existing guidelines, the authors' protocol describes more comprehensively recommendations about coordination and collaboration practices in nursing homes as well as specific matters such as how to communicate with fellow residents and give them the opportunity to say goodbye in some way to the person who is dying. **Abstract (w. references):** <https://bit.ly/2RauJyF>

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

Asian American Medicare beneficiaries disproportionately receive invasive mechanical ventilation when hospitalized at the end of life

JOURNAL OF GENERAL INTERNAL MEDICINE | Online – 26 April 2021 – Achieving equitable and high-quality end-of-life (EoL) care for racial and ethnic minorities represents a national objective of the U.S. healthcare system. Despite prior evidence demonstrating that ethnic minorities experience disparate care at the EoL, little is known about the care Asian Americans receive. The authors' findings demonstrate that older Asian Americans disproportionately experience high-intensity care when hospitalized at the EoL. Specifically, when compared to White beneficiaries, Asian Medicare beneficiaries hospitalized at the EoL are more likely to receive IMV and have higher rates of ICU admissions, in-hospital deaths, and lower rates of hospice use. Confidence in these results is bolstered by the consistency of this study's findings across diagnoses, Medicare plans, and adjustment for within- and between-hospital effects. Although the findings likely raise more questions than answers, the striking differences in care suggest that older Asian adults may disproportionately receive burdensome care when hospitalized in the last month of life. **Full text:** <https://bit.ly/2R3Sskb>

Best practices for using telehealth in hospice and palliative care

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 27 March 2021 – Prior to the COVID-19, hospice and palliative care (PC) adopted telehealth slowly compared with other specialties, but its rapidly increasing utilization during the pandemic with long-term implications for access to primary and specialty PC, particularly for patients in rural communities and populations experiencing inequitable access to services. Telehealth also shows great promise for leveraging technology to provide care more effectively and efficiently. As more provider organizations become equipped with telehealth infrastructure, and as advocacy for broader reimbursement of these services grows, telehealth services for hospice and PC are expected to continue. This article highlights the work of expert clinicians from multiple hospice and PC organizations to develop best practices for conducting telehealth visits in inpatient and community settings. The authors propose that best practices be compiled and considered to ensure quality-driven, evidence-based clinical practice guidelines with interprofessional applicability. **Abstract:** <https://bit.ly/2S7EEW8>

N.B. Search back issues of Media Watch for additional articles on “telehealth” (and “telemedicine”) at: <http://bit.ly/2ThijkC>.



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.16.

A question worth asking: What matters most at end of life?

MEDICAL JOURNAL OF AUSTRALIA | Online – 26 April 2021 – Many Australians aren't having the end-of-life (EoL) experience they want or deserve. Seventy per cent of Australians would prefer to die at home or in a home-like setting. But the last generation where most people died at home was that of our grandparents. Today, about half of us will die in hospital. There is an urgent need to recognise, talk about, and prepare for the last stage of life. It is estimated that more than half of the 100,000 predictable deaths in Australia each year have regretful outcomes, when things don't go to plan, or there is no plan. Regretful outcomes at the EoL come at significant cost, and an even greater human one, often as a result of uncertainty, lack of planning and preparation, rushed decision-making and poor communication. Currently, only 15% of Australians have an advanced care plan. In the last 12 months of life, many hospitalisations are unwanted or unnecessary and, on average, a person spends 33 days in hospital. Family dynamics often drive non-beneficial treatments, noting that of all those in the last stage of life, 33-38% will receive non-

beneficial treatments. This is compounded by the increasing cost of moral distress and workforce burnout among those whose work is associated with the last stage of life. This gap between preferences and experience also has an impact on those we leave behind. Twenty percent of Australians are unable to "move on" after the death of a loved one. With annual deaths set to double by 2040, the time to tackle the issue of awareness, communication and preparation is now. **Full text:** <https://bit.ly/32MAN33>

Extract from *Insight* article

The shift from home to hospital brought with it a decline in community awareness of death and dying, creating a gap in communication and support through the last stage of life. A lack of dialogue around death and normal functional decline means families are often ill-prepared for the last stage of life, and the normal processes of dying.

Death Café, Bauman and striving for human connection in "liquid times"

MORTALITY | Online – 28 April 2021 – Death Café is the most popular and well-known of a "new wave" of social initiatives associated with the death awareness movement; a new social movement which began in America in the 1970s, chastising modernity's disenchantment with death. As this study shows, this social franchise ... has spread to upwards of 34 countries around the world in a relatively short space of time, and has gained a large amount of media attention. The authors offer the first critical analysis of Death Café by asking: "Why this form and why now?" Their interviews with Death Café organisers in a wide range of countries revealed striking similarities in the perception that Death Café was needed to encourage and elicit "death talk" not permissible in other public spaces... However, the analysis presented here also suggests that Death Café is in part a response to the profound loneliness experienced in liquid modernity. The authors argue that the form in which Death Café takes – pop-up, fluid spaces not requiring long-term commitment and with the possibility to "stage" atmospheres designed to promote instant identification and "sharing" – are a case of Baumanian "peg communities" and liquid modernity par excellence. The topic of conversation – death – imagined as secret and transgressive, and with its claims to authenticity, is a primary conductor for connection within the space of the café and gives rise to a particular liquid modern form of intimacy or "communion." Death Café also conforms to another feature of liquid modernity – inescapable individual responsabilisation whereby individuals are expected to find or make their own meaning, in death as in life. The "survival strategy" which Death Café and the death-positive movement more widely purport to offer is to remove people's death anxiety by normalising death-themed conversations and turn continuous engagement with death into a form of regular inoculation. As a social initiative which is ostensibly about death education and awareness-raising, Bauman's theories permit a different, more radical view of Death Café: as a form which exemplifies the specific condition and organisation of life in liquid modernity. **Full text:** <https://bit.ly/2R0Q8KB>



Norwegian University of
Science and Technology

Cont.

Noted in Media Watch 28 January 2019 (#599, p.11):

- *MEDICAL HUMANITIES* | Online – 19 January 2019 – ‘**Can Death Cafés resuscitate morale in hospitals?**’ There is a great need within the medical community for the kind of conversation that Death Cafés foster: open, unstructured, spontaneous, genuine and interdisciplinary dialogue. The authors introduce the concept of hospital-based Death Cafés as distinct from community-based Death Cafés. From their experience, hospital-based Death Cafés are easy to implement, inexpensive, require little planning and yet offer tremendous reward to participants. Should the phenomenon of Death Cafés take off in hospitals as it has in communities internationally, the authors propose that this intervention be studied for its effect on healthcare worker burnout. **Abstract:** <https://goo.gl/tVNMq8>

Why and how the work of motor neurone disease associations matters before and during bereavement: A consumer perspective

PALLIATIVE CARE & SOCIAL PRACTICE | Online – 22 April 2021 – By enacting the several improvements suggested by consumers, motor neurone disease associations have great potential to play a more effective role as an enabler in the public health approach to end-of-life (EoL) model of care and to be more relevant to the communities they serve at the national and international levels. This also applies to most third-sector organisations where their role needs to be bolstered alongside formal services. Currently, this potential is not achieved in Australia because of the lack of consistency of training and delivery of services across the states, primarily due to a lack of research investment in health and social care and service improvement, as distinct from basic science and clinical research. A national approach is needed that encompasses uniformity, continuum of care incorporating EoL care and bereavement support, consumer feedback and representation in designing services... A national approach is required to monitor consumer feedback as a basis for service planning, highlighting the gaps and providing meaningful policy advice to governments.

Full text: <https://bit.ly/32OhXZ7>

Noted in Media Watch 20 April 2020 (#662, p.8):

- *PALLIATIVE MEDICINE* | Online – 14 April 2020 – ‘**The experiences of, and need for, palliative care for people with motor neurone disease and their informal caregivers: A qualitative systematic review.**’ Despite being a terminal neurodegenerative disease, the role of palliative care (PC) is less recognised for motor neurone disease (MND) than for other life-limiting conditions. This review identified a considerable literature exploring the care needs of people with MND and their carers; however, descriptions of PC were associated with the last days of life. Across the disease trajectory, clear points were identified where PC input could enhance patient and carer experience of the disease, particularly at times of significant physical change. **Abstract (w. list of references):** <https://bit.ly/3ckntFB>

N.B. Additional articles on PC for patients living with MND noted in Media Watch 17 February 2020 (#653, p.16).

Prognostic tools or clinical predictions: Which are better in palliative care?

PLOS ONE | Online – 28 April 2021 – The results of a multi-centre, cohort validation study suggest that practitioners need to exercise caution before incorporating prognostic tools into clinical practice. The authors did not find evidence that the prognostic tools assessed were more accurate than clinical predictions of survival, nonetheless there are still reasons to believe that their routine use may be a valuable addition to clinical practice. Clinicians may value a prognostic tool even if it were no better than clinical predictions of survival (CPS) because it is likely to be more objective and reproducible and because it could be used as an educational, training or communication aid for less experienced staff. Clinicians find that prognosticating is an uncomfortable task and they are sometimes tempted to avoid discussing time scales, instead choosing to give only vague estimates or avoiding the issue altogether. Since they are more objective and reproducible than clinicians subjective assessments, prognostic tools may also have a role in defining entry criteria to clinical studies or in describing the case mix of clinical services. Future work should focus on evaluating the relative impact of prognostic tools or CPS on clinical care and decision-making and evaluating whether they have other attributes to recommend them (e.g., ease of understanding, reliability or objectivity) beyond their ability to prognosticate accurately. **Full Text:** <https://bit.ly/3dYIFVn>

Evaluation of a commissioned end-of-life care service in Australian aged care facilities

PROGRESS IN PALLIATIVE CARE | Online – 29 April 2021 – Residential aged care facilities (RACFs) face severe challenges in the provision of high-quality end-of-life (EoL) care. A pilot of a nurse-led EoL palliative care consultative service (CiMaS) supporting RACFs was conducted in three RACFs in the West Moreton Region of Queensland, Australia, from May 2018. The authors conducted a mixed method evaluation comprising: a chart audit of deaths in the 12 months before and after the intervention; focus groups with RACF staff; and, interviews with facility directors, primary family members and GPs. Quantitative and qualitative data were assessed separately with statistical and thematic analyses respectively. The RACFs cared for 277 residents. There were 24 pre-intervention deaths and 44 in the intervention period (28 (64%) referred to CiMaS). There was widespread support for the service. Families felt supported and knowledgeable about what was happening. Care plans were almost always recorded in health records. Patients' symptoms appeared to be better recognised and managed. Staff and Facility managers felt more support than previously, with more responsive and reliable out of hours support. There were significant care improvements in patients not referred to CiMaS, suggesting a learning effect. GPs observed improvements in nursing staff confidence and support to families. Transfers to hospitals fell by two-thirds for both referred and non-referred patients compared with the year before implementation. The program was both efficient and effective. **Abstract:** <https://bit.ly/3uaXKZy>

Children's palliative care education and training: Developing an education standard framework and audit

RESEARCH SQUARE | Online (Preprint) – 21 April 2021 – The need to align the range of guidance and competencies concerning children's palliative care (PC) and develop an education framework have been recommended by a U.K. All-Party Parliament Group and others.¹ In response to these recommendations the need for a revised children's



CHILDREN'S PALLIATIVE CARE
EDUCATION STANDARD FRAMEWORK
AND SELF AUDIT TOOL

PC competency framework was recognized. A Children's Palliative Care Education & Training Action Group was formed across the U.K. and Ireland in 2019 to take this work forward. Their aim was to agree core principles of practice in order to standardize children's PC education and training. The Action Group reviewed sources of evidence and guidance including PC competency documents and the U.K. and Ireland quality and qualification frameworks. Expected levels of developing knowledge and skills were agreed and identified competencies mapped to each level. The mapping process led to the development of learning outcomes, local indicative programme content and assessment exemplars. Four sections depicting developing levels of knowledge and skills were identified: 1) Public health; 2) Universal; 3) Core; and, 4) Specialist. Each level has four learning outcomes: 1) Communicating effectively; 2) Working with others in and across various settings; 3) Identifying and managing symptoms; and, 4) Sustaining self-care and supporting the well-being of others. An audit tool template was developed to facilitate quality assurance of programme delivery. The framework and audit tool repository is on the International Children's Palliative Care Network website for ease of international access.² The framework has received interest at the U.K., Ireland and International launches. While there are education programmes in children's PC this is the first international attempt to coordinate education, to address lay carer education and to include public health. **Full text:** <https://bit.ly/3dTz1TP>

1. 'End of life care: Strengthening choice,' An inquiry report by the All-Party Parliamentary Group for Children Who Need Palliative Care,' October 2018. [Noted in Media Watch 29 October 2018 (#587, p.4)] **Download/view at:** <https://bit.ly/39gFTJm>
2. 'Children's Palliative Care Education Standard Framework & Self Audit Tool,' International Children's Palliative Care Network: <https://bit.ly/3xlztSC>

N.B. This preprint is under consideration at *BMC Medical Education*. A preprint is a preliminary version of a manuscript that has not completed peer review at a journal.

Placing death and dying: Making place at the end of life

SOCIAL SCIENCE & MEDICINE | Online – 29 April 2021 – Over the last decade, policies in both the U.K. and many other countries have promoted the opportunity for patients at the end of life to (EoL) be able to choose where to die. Central to this is the expectation that in most instances people would prefer to die at home, where they are more likely to feel most comfortable and less medicalised. In so doing, recording the preferred place of death and reducing the number of hospital deaths have become common measures of the overall quality of EoL care. The authors argue that as a consequence, what constitutes a desired or appropriate place is routinely defined in a very simple and static “geographical” way, that is linked to conceptualising death as unambiguous and discrete event that happens at a precise moment in time in a specific location. In contrast, the authors draw on 18 months of ethnographic fieldwork with two inner-London palliative care (PC) teams to describe the continual work staff do to make places suitable and appropriate for the processes of dying, rather than for a singular event. In this way, instead of “place of death” merely defined in geographic terms, the PC staff attend to the much more dynamic relation between a patient and their location as they approach the end of their life. Central to this is an emphasis on dying as an open-ended process, and correspondingly place as a social space that reflects, and interacts with, living persons. The authors propose the term “placing work” to capture these ongoing efforts as a patient’s surroundings are continually altered and adjusted over time, and as a way to acknowledge this as a significant feature of the care given. **Abstract:** <https://bit.ly/3e6oPYw>

Research Matters

Methodological challenges for epidemiologic studies of deprescribing at the end of life

CURRENT EPIDEMIOLOGY REPORTS | Online – 23 April 2021 – This narrative review summarizes existing approaches to the measurement of deprescribing and key outcome variables for studies examining deprescribing at the end of life (EoL). For each measure, there are several approaches to consider. The selection of appropriate measure follows from the method and study design, and design follows from the research question and the investigators’ vision for the study goals. Some studies implemented randomized clinical trials, while others were observational pre-post studies. Of note is the small sample size of most of the available studies. As with all epidemiological studies, the final choices depend on the details and the perspective of the stakeholders who will utilize the study results. Since patients are central to all deprescribing studies, and the goal of deprescribing is to reduce medication burden and improve (or maintain) quality of life (QoL), the authors have summarized approaches to capturing these measures as they have been operationalized to date. Somewhat unique to EoL research is the perspective of both the patient and the caregiver. The authors have summarized measures including burden of medication administration and caregiver QoL, which rely on primary data collection. While costs are important to patients and caregivers, detailed costing methods are beyond the scope of this paper. Issues such as the distinction between out-of-pocket costs vs total costs and costs versus charges are important to consider in this domain. **Full text:** <https://bit.ly/2QyBV7N>

Cancer, clinical trials, and Canada: Our contribution to worldwide randomized controlled trials

CURRENT ONCOLOGY | 13 April 2021 – In this report, the authors provide an overview of oncology randomized controlled trials (RCTs) published during 2014-2017 with Canadian authors. Several important findings have emerged. First, Canadian investigators are co-authors on one-quarter of all oncology RCTs led by high-income countries (HICs). These trials are published in higher impact journals compared to RCTs without Canadian involvement. Second, the cancer RCTs that are led by Canadian authors do not match the burden of cancer in Canada. Third, most Canadian RCTs test new systemic therapies in the palliative setting and use surrogate outcomes ... as the primary endpoint. Fourth, the vast majority (85%) of Canadian RCTs have industry funding; this is a higher proportion than RCTs from outside Canada. Finally, one-third of “positive” Canadian oncology RCTs identify a new treatment with “substantial clinical benefit”. This transl-

Cont.

ates to only 13% of all Canadian clinical trials (the corresponding figure for non-Canadian RCTs is 12%). The authors' data suggest two fundamental threats to Canadian cancer trials: 1) The system is almost entirely reliant upon funding by industry (more so than other HICs); and, 2) Only a small minority of all Canadian RCTs identify a new treatment for patients that is associated with substantial clinical benefit. **Full text:** <https://bit.ly/2RdtJts>

“It can be hard but it's not bad”: Three questions to solicit caregiver perceptions of benefits and burdens to participating in pediatric palliative care research

JOURNAL OF PALLIATIVE MEDICINE | Online – 23 April 2021 – To allay uneasiness among clinicians and institutional review board members about pediatric palliative care (PC) research and to yield new knowledge relevant to study methods, documenting burdens and benefits of this research on children and their families is essential. English-speaking caregivers participating in palliative or end-of-life decisions for their child with incurable cancer or their seriously ill child in the intensive care unit participated. Thirty-seven caregivers of 33 children completed interviews; most were mothers, African American, and married. The most frequently reported themes were of positive personal impact: “Hoping to help others,” “Speaking about what is hard is important,” and “Being in the study was sometimes hard but not bad.” No caregiver described the study as burdensome. Some acknowledged that answering the questions could evoke sad memories, but highlighted benefits for self and others. Attrition somewhat tempers the emphasis on benefits. Documenting perceived benefits and burdens in a standardized manner may accurately convey impact of study participation and yield new knowledge. **Abstract:** <https://bit.ly/3tYYMrs>

Media Watch: Editorial Practice

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

Distribution

MEDIA WATCH IS DISTRIBUTED AT NO COST to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

IF YOU ARE AWARE OF A CURRENT REPORT, ARTICLE, ETC., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

Media Watch: Access on Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/2RsCRKZ>

[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



CSPCP
Canadian Society of
Palliative Care Physicians

SCMSP
Société canadienne des
médecins de soins palliatifs

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>

Barry R. Ashpole, Ontario CANADA

e-mail: BarryRAshpole@bell.net