

**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.

13 July 2020 Edition | Issue #674



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Compiled & Annotated by Barry R. Ashpole

**Developing care plans in advance is personal, complex, nuanced, and requires timely and skilful communication, often over several conversations, to be reliable and trustworthy.**

'Advance care plans – back to the future?' (p.7), in *British Medical Journal*.

## Canada

### Hearing likely still possible even in dying person's final moments, research suggests

BRITISH COLUMBIA | CTV News (Vancouver) – 9 July 2020 – New research ... suggests dying people might still be able to hear, even once they've become unresponsive in their final moments. The research, conducted at the University of British Columbia, is the first time human hearing has been investigated close to death.<sup>1</sup> All the patients were in palliative care (PC) at St. John Hospice in Vancouver. A device was used to measure their brain's electrical activity both when they were conscious and later when they were unconscious. The results of the research suggest hearing might be the last sense to go. However, researchers were unable to tell if the patients were able to identify voices or understand language. Dr. Romyne Gallagher, who used to be a PC physician at St. John Hospice, but has since retired, said that she's noticed positive reactions in people who

have been spoken to in their final moments. "This research gives credence to the fact that hospice nurses and physicians noticed that the sounds of loved ones helped comfort people when they were dying," Gallagher said. "To me, it adds significant meaning to the last days and hours of life and shows that being present, in person or by phone, is meaningful. It is a comfort to be able to say goodbye and express love." <https://bit.ly/320R70P>

### Specialist Publications

'Association between palliative care and healthcare outcomes among adults with terminal non-cancer illness: Population-based matched cohort study' (p.8), in *British Medical Journal*.

1. 'Electrophysiological evidence of preserved hearing at the end of life,' *Scientific Reports*, published online 25 June 2020. Full text: <https://go.nature.com/31Y8xen>



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## Palliating end-of-life suffering during a pandemic

*VARSI* (University of Cambridge, U.K.) | Online – 4 July 2020 – In a pandemic, palliative care (PC) teams must continue caring for those dying from causes unrelated to the pandemic virus while also handling the rapid progression of suffering for those dying from the virus. In the absence of system-wide plans for PC at the regional and national levels, some PC physicians have been publishing guidance for reference within the community and for those caring for terminal stage loved-ones at home. Dr. James Downar is the Head of the Division of Palliative Care at the University of Ottawa and an attending physician in critical and PC at The Ottawa Hospital. He co-authored an analysis of pandemic PC...<sup>1</sup> The study builds on the pandemic's early lessons and expands on a 2010 study he authored.<sup>2</sup> In addition to preparing for strains on “stuff, staff, space and systems,” provisions must be made for increased use of “sedation” to manage pain that defies the medications usually used for palliation. Mitigating additional suffering that arises from “separation” must also be a point of focus. Rapid symptom onset, resource scarcity, and the surge in cases make communication between health professionals and patients all the more crucial. Dr. Downar emphasises the need to address “systemic inequities” that affect access to PC, which have been exacerbated by **COVID-19**. <https://bit.ly/2YXLuhX>

1. ‘Pandemic palliative care: Beyond ventilators and saving lives,’ *Canadian Medical Association Journal*, published online 31 March 2020. [Noted in Media Watch 6 April 2020 (#660, p.9)] **Full text (click on pdf icon):** <https://bit.ly/3437WY7>
2. ‘Palliating a pandemic: “All patients must be cared for,”’ *Journal of Pain & Symptom Management*, 2010; 39(2):291-295. [Noted in Media Watch 15 February 2010 (#136, p.7)] **Full text:** <https://bit.ly/3cy7gww>

## [U.S.A.](#)

### Designing career paths aids hospice, palliative care staff shortages

*HOSPICE NEWS* | Online – 9 July 2020 – The hospice and palliative care (PC) workforce has been shrinking in recent years due to staff retirement, burnout and limited opportunities for specialty training. “Currently, the specialty workforce is just too small to meet demand,” said Brynn Bowman, of the Center to Advance Palliative Care. “The relationship between the supply and demand of palliative and end-of-life care teams is overwhelmingly short-staffed. We hear tons of reports of clinicians working ‘round the clock. We need and want to provide more training avenues so that people enter these specialties because there’s a workforce shortage.” Hospice leaders identified staffing shortages as their top concern moving into 2020...<sup>1</sup> More than 26% of 300 respondents anticipated staffing as their greatest challenge, outweighing concerns over increased competition in the hospice space

and new payment models. Shortages are expected to worsen during the next 25 years, with research indicating that supply of a hospice and PC specialized workforce will be exceeded by demand of a growing aging patient population. <https://bit.ly/2Cr3J6v>

#### [Specialist Publications](#)

‘Palliative care team involvement in patients with **COVID-19** in New York City’ (p.5), in *American Journal of Hospice & Palliative Medicine*.

‘Advance directives state requirements, center practices, and participant prevalence in adult day services centers: Findings from the 2016 National Study of Long-Term Care Providers’ (p.11), in *Journals of Gerontology*.

1. ‘The growing demand for hospice and palliative medicine physicians: Will the supply keep up?’ *Journal of Pain & Symptom Management*, published online 2 February 2018. [Noted in Media Watch 9 March 2020 (#656, p.4)] **Full text:** <http://bit.ly/2CRjxwO>

**N.B.** Selected articles on the status of the PC workforce in the U.S. noted in Media Watch 13 April 2020 (#661, p.13).

## **A call for North Carolina to surround the seriously ill and caregivers with interprofessional collaborative teams**

*NORTH CAROLINA MEDICAL JOURNAL*, 2020;81(4):249-253. This commentary is a call to action for North Carolina to grow its specialty palliative care and hospice workforce by: 1) Developing and enhancing palliative and hospice interprofessional collaborative care teams through purposeful designs of proofs of concept in various transitional models of care (e.g., acute care, community, hospice); 2) Recruiting and building a sustainable palliative specialist workforce that can lead, train, and prepare interprofessional collaborative team practices to enhance engagement with serious illness patients and families to meet their goals-of-care; and, 3) Pursuing legislative and grant funding for the development of a sustainable serious illness workforce and further research on the evaluation of serious illness workforce capacity and impacts. **Full text:** <https://bit.ly/2AH9IsT>

**N.B.** The current issue of the *North Carolina Medical Journal* includes several articles on care of the seriously ill. **Journal contents page:** <https://bit.ly/3glFSyq>

## **COVID-19 sheds light on hospice, palliative patients non-medical health needs**

*HOSPICE NEWS* | Online – 7 July 2020 – The COVID-19 pandemic has exposed gaps in hospice and serious illness care that impact providers and patients alike, illustrating the need for change in care models to expand and address various social determinants of health. Some stakeholders in the hospice and palliative care (PC) space have called for updated public policies to close these gaps and provide stronger support of patients' aging in place. Aging in place has been a priority for patients and families, and it has been increasingly important in keeping high-risk hospice and PC populations safe and healthy during the novel Coronavirus pandemic. While critical in continuing to reach patients and families during a national health emergency, providing home hospice and PC has been challenged by roadblocks resulting from the outbreak. <https://bit.ly/38EedMc>

## **Lack of caregiver support adversely impacts hospice utilization**

*HOSPICE NEWS* | Online – 6 July 2020 – A lack of sufficient family caregiver support can have a negative impact on whether or not a patient receives hospice care. New research shows that patients who are faced with end-of-life (EoL) decisions may be less likely to choose hospice unless they have a network of friends or family who can serve as home caregivers.<sup>1</sup> The study examined the records of more than 1,800 Medicare decedents who had a primary diagnosis of dementia or cancer using data from the National Health & Aging Trends Study from the years between 2011 and 2017. The trends study data is linked to Medicare claims. <https://bit.ly/2BODw1Z>

1. 'Family caregiving at the end of life and hospice use: A national study of Medicare beneficiaries,' *Journal of the American Geriatric Society*, published 30 June 2020. [Noted in Media Watch 6 July 2020 (#673, p.8)] **Abstract:** <https://bit.ly/3iluj1C>



### **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>

## International

### Woman succeeds in High Court challenge to definition of “terminal illness”

U.K. (Northern Ireland) | *Irish Legal News* – 8 July 2020 – A terminally ill woman who was denied fast-track access to certain benefits has succeeded in a High Court challenge to the definition of “terminal illness” in Northern Ireland. Mr. Justice Gerry McAlinden said the requirement for terminally ill claimants to demonstrate that their death can reasonably be expected within six months is “manifestly without reasonable foundation.” Lorraine Cox was diagnosed with motor neurone disease. “It is hard to imagine a more devastating diagnosis for a single mother of three young children,” Mr. Justice McAlinden wrote in his judgement. “This illness is a progressive neurological condition for which there is no effective treatment or cure. The progression of the illness is unpredictable, but it would seem that 50% of those individuals diagnosed with the condition die within three years of diagnosis.” He added: “I can find nothing to justify or indeed explain why those individuals who have a terminal diagnosis but are not expected to die within six months and those individuals with a terminal

diagnosis and who are reasonably expected to die within six months but who survive beyond that six month period are treated differently.” The judge ruled that the difference in treatment is without reasonable justification and is therefore in breach of Article 14 of the European Convention on Human Rights... <https://bit.ly/38FmLCt>

### Welcome to Mongolia: A great place to die

MONGOLIA | *Highbrow Magazine* – 7 July 2020 – Mongolia is punching above its weight in palliative care (PC), the branch of medicine that supports people with terminal or complex illnesses. PC takes a magpie approach, borrowing from other medical disciplines and addressing a whole range of issues at once, ranging from pain and other symptoms to spiritual, social and psychological support. In a 2015 survey of global PC, the U.K. comes top, Australia second and the U.S. ninth.<sup>1</sup> And while the richest Western nations lead the pack, Mongolia appears notably high up, especially considering that it's well down the economic rankings. It comes 28th in the PC survey but ranks 141st for gross national income per capita. When it comes to PC, Mongolia is performing far better than any comparable economy ahead of several European states with much more developed healthcare systems and greater spending power, including Greece, Hungary and Lithuania. It eclipses several big economies, including its two giant neighbors, Russia and China. <https://bit.ly/3e7yv1m>

### Specialist Publications

**‘Milestones: A mixed methods study of an educational intervention to improve care of the dying’** (p.6), in *BMJ Supportive & Palliative Care*.

**‘Conflicts of interest in the context of end-of-life care for potential organ donors in Australia’** (p.9), in *Journal of Critical Care*.

**‘The Compassionate Communities Connectors model for end-of-life care: A community and health service partnership in Western Australia’** (p.12), in *Palliative Care & Social Practice*.

### Palliative care development in Mongolia

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 7 July 2017 – Mongolia began palliative care (PC) development in 2000 with the creation of the Mongolian Palliative Care Society and the Palliative Care Department. PC is included in the Mongolia's Health Law, Health Insurance Law, Social Welfare Law, National Cancer Control Program, and the National Program for Non-Communicable Diseases, and has approved Palliative Care Standards & Pain Management Guidelines. PC education is included in the undergraduate and postgraduate curriculum in all medical universities. Six hospice units in Ulaanbaatar have 50 beds; each of the nine districts and all 21 provinces have up to four to five palliative beds, and there are 36 PC units, for a total 190 beds for three million people. In 2014, a pediatric PC inpatient unit was established with five beds. Essential drugs for PC have been available in Mongolia since 2015. The pharmaceutical company IVCO produces morphine, codeine, pethidine, and oxycodone in Ulaanbaatar. **Full text:** <https://bit.ly/3f5fbU4>

**N.B.** *Journal of Pain & Symptom Management* article noted in Media Watch 14 August 2017 (#525, p.14).

Cont.

1. '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit (commissioned by the Lien Foundation of Singapore), October 2015. [Noted in Media Watch 12 October 2015 (#431, p.6)] **Download/view at:** <http://bit.ly/30YoDkl>

## Specialist Publications

### **Palliative care team involvement in patients with COVID-19 in New York City**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 July 2020 – With the highest number of cases in the world as of 13 April 2020, New York City (NYC) became the epicenter of the global Coronavirus disease 2019 (COVID-19) pandemic. The data regarding palliative team involvement in patients with COVID-19, however, remains scarce. The authors aimed to investigate outcomes of palliative team involvement for the patients with COVID-19 in NYC. Consecutive 225 patients with confirmed COVID-19 requiring hospitalization in the authors' urban academic medical center in NYC were analyzed. They were divided into two groups, those with a palliative care (PC) consult ... versus those with no PC consult... The palliative group was older and had more comorbidities. During the hospital course, the palliative group had more intensive care unit stays, rapid response team activations, and more use of vaso-pressors... Patients with PC had higher rates of invasive mechanical ventilation than those without... Cardiopulmonary resuscitation was performed in 12 patients .. and death rate was 100% in both subsets. Notably, initial code status was not different between the two groups, however, code status at discharge was significantly different between them... The rate of full code decreased by 70% in the palliative group and by 47.5% in the no palliative care group from admission to the time of death. Critically ill patients hospitalized for COVID-19 benefit from palliative team consults by helping to clarify advanced directives and minimize futile resuscitative efforts. **Abstract (w. list of references):** <https://bit.ly/2DjZn1z>

Noted in Media Watch 15 June 2020 (#670, p.4):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 June 2020 – '**The role of palliative care in caring for the families of patients with COVID-19.**' The authors' New York City-based palliative care team has found that caring for patients' loved ones has proven to be an even more important aspect of the care they have provided during the COVID-19 epidemic. In this article, the authors describe the multi-component interdisciplinary interventions they have implemented to enhance the ability to create a therapeutic alliance with family members and facilitate the provision of goal concordant care to patients with COVID-19 during this extremely difficult time. **Abstract (w. list of references):** <https://bit.ly/2XlreQL>

Noted in Media Watch 8 June 2020 (#669, p.12):

- *NEJM CATALYST* | Online – 12 May 2020 – '**A beacon for dark times: Palliative care support during the Coronavirus pandemic.**' Palliative care (PC) physicians can provide critical expertise in communication and symptom management to help seriously ill patients in the Coronavirus disease 2019 pandemic. However, with an existing shortage of PC specialists, the surge of COVID-19 cases in New York City required rapid expansion of PC services... In response to these needs, the Icahn School of Medicine at Mount Sinai developed and adapted a 24-7 PALLiAtive Care Help line which focused in-person ED supports to serve 873 of the sickest patients with COVID-19 over 4 weeks... The authors describe key principles and lessons learned from this process. **Full text:** <https://bit.ly/2MtFBSC>

Noted in Media Watch 1 June 2020 (#668, p.17):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 29 May 2020 – '**National outreach of telepalliative medicine volunteers for a New York City safety net system COVID-19 pandemic response.**' The authors successfully implemented a telepalliative medicine response within a large safety-net system without a pre-existing telehealth infrastructure. Within just 72 hours of the initial outreach, over 400 volunteers enlisted, reflecting a rapid and robust response. To the authors' knowledge, this is the first model to leverage external telepalliative medicine volunteers from across the country for an institutional COVID-19 pandemic response. Several concepts resonated through our process, which may aid other institutions in future efforts. **Full text:** <https://bit.ly/3qtEUXn>



### **Enhancing existential thinking through death education: A qualitative study among high school students**

*BEHAVIOURAL SCIENCES* | Online – 7 July 2020 – This research work stands among the studies that confirm the relevance of death education in high schools, highlighting how adolescents can manage issues on death, their fears and doubts. Their texts highlighted how the course contributed to reducing the anxiety linked to these themes, improved the communication between peers and made it more authentic and empathic, providing different alternative perspectives on life and its sense. Indeed, the project offered the occasion to talk about something that is strongly heartfelt but so rarely faced. Even though someone said the time was not enough, almost all students appreciated the opportunity to have a special setting to express their fears, doubts and ideas. The study showed that coping with death-related issues is a potent means to transmit the interest in scrutinizing their existential concerns and to understand deeply what life meant to them. All this supports what is already shown in the literature, but we want to stress the focus on the interaction between the meanings of death and reflections about the afterlife, which needs much more discussion about religious topics. The authors found that listing several religious perspectives made the students feel more confident about the plurality of modalities that have been used in the various periods and cultures of human history to talk about the same topic, the redeeming subject of religion. **Full text:** <https://bit.ly/2ZdAbCw>

**N.B.** Selected articles on the topic of dying and death in the school curriculum noted Media Watch 14 October 2019 (#635, pp.5-6).

### **Introducing the Trajectory Touchpoint Technique: A systematic methodology for capturing the service experiences of palliative care patients and their families**

*BMC PALLIATIVE CARE* | Online – 10 July 2020 – Evaluation of palliative care (PC) services is crucial in order to ensure high quality care and to plan future services in light of growing demand. There is also an acknowledgement of the need to better understand patient experiences as part of the paradigm shift from paternalistic professional and passive patient to a more collaborative partnership. However, while clinical decision-making is well-developed, the science of the delivery of care is relatively novel for most clinicians. The Trajectory Touchpoint Technique overcomes several limitations of other PC evaluation methods, while being more comprehensive. The new technique incorporates physical, psychosocial, and spiritual aspects of PC, and is user-friendly for inpatients, outpatients, families, and the bereaved. The new technique has been tested with people who have a range of illnesses, in a variety of locations, among people with learning disabilities and low levels of literacy, and with children as well as adults. The Trajectory Touchpoint Technique has already uncovered many previously unrecognised opportunities for service improvement, demonstrating its ability to shape PC services to better meet the needs of patients and their families. **Full text:** <https://bit.ly/303KWq4>

### **Milestones: A mixed methods study of an educational intervention to improve care of the dying**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 6 July 2020 – Approximately 460,000 people die annually in England. Three-quarters of these deaths are expected. Health Education England is prioritising upskilling of clinical staff in response to reports of poor care quality in the last days of life in acute hospitals, where almost half of all deaths occur. This study explores the impact of an end-of-life care (EoLC) educational intervention, Milestones, in acute hospital trusts in Greater London. A statistically significant increase in learner confidence across all five priorities of care was sustained up to 8 months. Interviewees wanted to discuss wider challenges in EoLC related to the organisations and cultural contexts in which they worked. Concerns included balancing hope when decision-making, learning as a multidisciplinary team and emotional impact. The findings suggest that Milestones is a flexible, beneficial resource for teaching EoLC that facilitates enhanced learner engagement. Understanding generated about wider concerns can inform future educational material development, organisational process and research study design. **Abstract:** <https://bit.ly/2O41gBS>



## What is a good death? A critical discourse policy analysis

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 6 July 2020 – This article examines what English end-of-life care (EoLC) policy defines as a good death. Policy explicitly defines a good death as having the following attributes: being treated as an individual, with dignity and respect; being without pain and other symptoms; being in familiar surroundings and being in the company of close family and/or friends. Critical discourse analysis of 54 documents found that rather than just being an outcome or event, descriptions of what makes a death good also include many processes. A more extended definition includes: the person receives holistic EoLC; the dying person is treated with dignity and respect; the death is not sudden and unexpected; people are prepared and have ideally done some advance care planning; people are aware that someone is dying and openly discuss this; on knowing the dying person's preferences, all involved are to work towards achieving these; the place of death is important; the person's family are involved and the needs of the bereaved are considered. This analysis indicates the complex nature of the current discourses around good death in EoLC policy, which often focuses on care rather than death. Policy should focus on outlining what quality EoLC looks like, rather than assume "good death" is a suitable outcome statement. **Abstract:** <https://bit.ly/2BF2tNo>

## Advance care plans – back to the future?

*BRITISH MEDICAL JOURNAL* | Online – 6 July 2020 – In the noughties, as an attempt to improve care for the dying across healthcare, there was a wholesale adoption and rollout of a pathway to systematise and quality assure care for the dying – the Liverpool Care Pathway (LCP). However, after press reports of poor end of life care associated with the LCP, and after the results of an independent review in 2013, the pathway was phased out of clinical practice.<sup>1</sup> In our laudable attempts to mitigate the real and present danger of a bad death from COVID-19, we risk abusing the principles of advance care planning (ACP) and sending it the same way. The bones of the LCP have been picked clean and we should have learned that fitting people to processes is misguided. The LCP was not to blame for its misuse. Much as a hammer, the tool in itself is morally neutral, the way that it is used or abused is not. The foundation of ACP ... is inherent to good healthcare. A capacitate person knows their own best interests and they are to be respected. The General Medical Council is clear that we are duty bound to understand our patients' views on treatments and seek consent, not just in the here and now, but where someone is at risk of losing capacity to seek views about the possible benefits, harms, and risks of future interventions and the limits they may wish to set. An advance care plan seeks to capture and record this. It is not a single entity, it is a blend of conversation between two people: the subject, who is their own expert and knows their beliefs, values, experiences and goals, and a clinician. It is not a proforma to be completed, nor an independent fait accompli in need of agreement. It is unique. Blanket approaches, or those advance care plans generated without appropriate attention to all these areas risk being impersonal and discriminatory. **Full text:** <https://bit.ly/38yWBkC>

1. 'Review of Liverpool Care Pathway for Dying Patients,' Department of Health, July 2013. [Noted in Media Watch 22 July 2013 (#315, p.6)] **Download/review at:** <http://bit.ly/2khETNO>

### Related:

- *JOURNAL OF PALLIATIVE CARE* | Online – 8 July 2020 – 'What is good advance care planning according to hospitalized palliative patients and their families? An explorative study.' Participants wanted communication about treatment and care throughout their disease and about different aspects: social, psychological, physical, practical and medical. Four important goals: establishing a trustful relationship with the physician, in which they feel the involvement of the physician; giving and receiving relevant information for the decision process, making a personal decision about which treatment and care are preferred; and finding consensus between the preferred decision of the physician, the patient and the family concerning treatment and care... **Abstract (w. list of references):** <https://bit.ly/31VF17L>



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

## Association between palliative care and healthcare outcomes among adults with terminal non-cancer illness: Population-based matched cohort study

*BRITISH MEDICAL JOURNAL* | Online – 6 July 2020 – Patients, caregivers, and healthcare systems struggle with the growing burden of medical complexity that is also associated with poor quality of life and high healthcare expenditure. End-of-life (EoL) care that involves hospital admission and intensive care unit admission is costly and potentially burdensome. This study supports the role palliative care (PC) has in providing high value EoL care to people dying from cancer and most non-cancer illness. The authors found PC might reduce healthcare use and potentially burdensome interventions near the EoL. They found an association between PC and an increased odds of dying at home, which is where most people would prefer to die and a recognised indicator of high quality EoL care. Their findings are consistent with previous litera-

ture on the association between home based PC and healthcare use outcomes, and with location of death in patients with cancer. This study adds to the knowledge about the associated effects in non-cancer illness across all care settings. **Full text:** <https://bit.ly/2O2Ds0Q>

### Extract from *British Medical Journal* article

Patients, caregivers and healthcare systems struggle with the growing burden of medical complexity that is also associated with poor quality of life and high healthcare expenditure. EoLC that involves hospital admission and intensive care unit admission is costly and potentially burdensome. This study supports the role PC has in providing high value EoLC to people dying from cancer and most non-cancer illness.

**N.B.** See ‘Palliative care in illness other than cancer,’ editorial by lead author of *British Medical Journal* article: <https://bit.ly/3gMkjgn>

Noted in Media Watch 20 January 2020 (#649, p.7):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 January 2020 – ‘**Palliative care for non-cancer conditions in primary care: A time trend analysis in the U.K. (2009-2014).**’ The authors examined whether the recording of a palliative care (PC) approach and the numbers of hospital deaths for deceased patients with heart failure, dementia, chronic obstructive pulmonary disease (COPD) and cancer have changed since the U.K. End-of-Life Care Strategy was introduced. From 2009 to 2014, proportions with a primary care record of PC increased for COPD from 13.6% to 21.2%; dementia from 20.9% to 40.7%; and heart failure from 12.6% to 21.2%; but, remained substantially lower than for cancer (57.6% to 61.9%). **Abstract:** <http://bit.ly/2Rj0xO3>

Noted in Media Watch 30 December 2019 (#646, p.9):

- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 27 December 2019 – ‘**Hospice utilization in the U.S.: A prospective cohort study comparing cancer and non-cancer deaths.**’ Hospice utilization rate was 52.4% for the patient population studied with 70.8% for cancer deaths and 45.4% for non-cancer deaths. Findings suggest hospice remains underutilized, especially among individuals with non-cancer illness. Extrapolating results to the U.S. population, the authors estimate that annually nearly a million individuals who are likely eligible for hospice die without its services. Most (84%) of these decedents have a non-cancer condition. Interventions are needed to increase appropriate hospice utilization, particularly in non-cancer care settings. **Abstract:** <http://bit.ly/378HU5Y>



### Telehealth was gaining increasing attention before the COVID-19 pandemic, and has since gained more

A selection of articles from past issues of Media Watch on this topic are noted in the current issue of the newsletter of the International Association for Hospice & Palliative Care. **Download/view at:** <https://bit.ly/2ZO16DZ>

**N.B.** Scroll down to ‘Media Watch: Telehealth’.



## Conflicts of interest in the context of end-of-life care for potential organ donors in Australia

*JOURNAL OF CRITICAL CARE* | Online – 4 July 2020 – End-of-life (EoL) care has become an integral part of intensive care medicine and includes the exploration of possibilities for deceased organ and tissue donation. Donation physicians are specialist doctors with expertise in EoL processes encompassing organ and tissue donation, who contribute significantly to improvements in organ and tissue donation services in many countries around the world. Donation physicians are usually also intensive care physicians, and thus they may be faced with the dual obligation of caring for dying patients and their families in the intensive care unit (ICU), whilst at the same time ensuring organ and tissue donation is considered according to best practice. This dual obligation poses specific ethical challenges that need to be carefully understood by clinicians, institutions and healthcare networks. These obligations are complementary and provide a unique skillset to care for dying patients and their families in the ICU. The authors review current controversies around EoL care in the ICU, including the use of palliative analgesia and sedation specifically with regards to withdrawal of cardiorespiratory supports, the usefulness of the so-called doctrine of double effect to guide ethical decision-making, and the management of potential or perceived conflicts of interest in the context of dual professional roles. **Abstract:** <https://bit.ly/3eecvCo>

## Conflict before the courtroom: Challenging cognitive biases in critical decision-making

*JOURNAL OF MEDICAL ETHICS* | Online – 6 July 2020 – Conflict is an important consideration in the intensive care unit (ICU). In this setting, conflict most commonly occurs over the “best interests” of the incapacitated adult patient; for instance, when families seek aggressive life-sustaining treatments, which are thought by the medical team to be potentially inappropriate. Indeed, indecision on futility of treatment and the initiation of end-of-life discussions are recognised to be among the greatest challenges of working in the ICU, leading to emotional and psychological “burnout” in ICU teams. When these disagreements occur, they may be within the clinical team or among those close to the patient, or between the clinical team and those close to the patient. It is, therefore, crucial to have a theoretical understanding of decision-making itself, as unpicking misalignments in the family’s and clinical team’s decision-making processes may offer strategies to resolve conflict. The authors suggest that through the establishment of common ground, challenging of cognitive biases and formulation of mutually agreeable solutions, mediation may offer a pragmatic and cost-effective solution to conflict resolution. The litigation process is intrinsically adversarial and strains the doctor-patient-relative relationship. Thus an alternative external party should be considered, however mediation is not frequently used and more research is needed into its effectiveness in resolving conflicts in the ICU. **Full text:** <https://bit.ly/3falu8L>

Noted in Media Watch 18 May 2020 (#666, p.4):

- *REUTERS HEALTH* | Online – 5 May 2020 – ‘**Many lay people lack clear understanding of “futile treatment.”**’ “When patients are terminally ill, shared decision-making is often complicated by the public’s lack of understanding of what is meant by “futile” or “potentially inappropriate” treatment, coupled with the belief that the patient or family should have the final say, a focus-group study suggests.<sup>1</sup> “Although it is difficult to recommend the discontinuation of life-sustaining treatment, it is crucial that physicians communicate to families when treatments are non-beneficial, will not change patient outcomes, and potentially prolong suffering,” said Dr. Thanh H. Neville of David Geffen School of Medicine at University of California, Los Angeles. <https://wb.md/3brmqNiJ>

1. ‘The community perspective on potentially inappropriate treatment,’ *Annals of the American Thoracic Society*, published online 29 April 2020. [Noted in 4 May 2020 issue of Media Watch (#664, p.6)] **Abstract:** <https://bit.ly/2KUaA9u>



### 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 beginning p.13.

## Experience of caregivers supporting a patient through voluntarily stopping eating and drinking

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 July 2020 – Voluntarily stopping eating and drinking (VSED) is an ongoing voluntary choice to forego food and hydration in an effort to hasten death. Ongoing caregiving is necessary as patients become weak and lose focus as a result of dehydration, but little is known about the process of supporting a patient through VSED. Interviews with 24 U.S. caregivers for 20 individuals who had attempted VSED produced four themes: 1) Caregivers believe that VSED is the best death available to the patient; 2) Caregivers act as advocates and worry that the patient's goals will be challenged by healthcare professionals, the community, or legal authorities (obtaining support from a hospice is an important way to legitimize VSED); 3) Through the VSED process itself, caregivers carry the responsibility for the patient's success as the patient becomes weaker and loses focus; and, 4) Because there is no social script to guide the VSED process, caregivers choose what roles to play during VSED, such as focusing on physical care or being emotionally present as the patient's spouse or child. Caregivers face unique challenges in helping patients undertake VSED. Many are uncertain about whether they will receive support from clinicians or the community. Support from health professionals may improve caregiver confidence and reduce worry. **Abstract:** <https://bit.ly/3fcdPXz>

Noted in Media Watch 26 March 2018 (#556, p.9):

- *FRONTIERS IN PHARMACOLOGY* | Online – 14 March 2018 – ‘Ethical challenges for an understanding of suffering: Voluntary stopping of eating and drinking and the wish to hasten death in advanced patients.’ The authors analyze the data reported in some studies in relation to primary care patients who died as a result of voluntarily stopping eating and drinking (VSED) and examine their results in light of the qualitative findings of patients that expressed a wish to die. In their view, VSED can be understood as a response to physical/psychological/spiritual suffering, as an expression of a loss of self, a desire to live but not in this way, a way of ending suffering, and as a kind of control over one's life. **Full text:** <http://bit.ly/2HBf4mW>

**N.B.** Additional articles on the wish to hasten death noted in this issue of Media Watch.

## A tool for the evaluation of clinical needs and eligibility of pediatric palliative care: The validation of the ACCAPED Scale

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 8 July 2020 – Despite their importance, pediatric palliative care (PPC) services are still scantily diffused. In addition, eligibility criteria for PPC are quite complex. Consequently, clinicians require a tool that suggests how to refer patients with life-limiting diseases to the most appropriate service and how to properly allocate health care resources. Recently, the Accertamento dei bisogni Clinico-Assistenziali Complessi in PEDIatria (ACCAPED) scale has been developed by a group of experts in PPC to evaluate the specific clinical needs of pediatric patients with a life-limiting disease. This study presents the validation of the ACCAPED scale. Results show a very high concordance between the evaluation of the vignettes through the ACCAPED scale and the evaluation by the clinical experience for experts in PPC and pediatricians. A less favorable grade of concordance has been recorded for healthcare professionals not involved in PPC, suggesting that educational efforts to improve basic knowledge of PPC within the medical community are needed. **Abstract:** <https://bit.ly/321UjZV>

### “How long can I carry on?”

## The need for palliative care in Parkinson's disease: A qualitative study from the perspective of bereaved family caregivers

*JOURNAL OF PARKINSON'S DISEASE* | Online – 9 July 2020 – Family caregivers (FCGs) provide the majority of care for people with Parkinson's disease (PD) in the palliative care phase. For many this is a demanding experience, affecting their quality of life. The authors identified four main themes. 1) Feeling like a professional caregiver (while caring for a person with PD, the FCGs took over many roles and tasks of the person with PD); 2) Healthcare professionals (HCPs) do not always know what PD really means

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(most interviewees had negative experiences with knowledge and understanding of PD, especially nurses); 3) Being on your own (many respondents had felt highly responsible for their loved one's care and lacked time and space for themselves (grief and feelings of guilt were present during the caregiving period and after death); and, 4) Being behind the times (to provide PC in line with patients' preferences and to feel prepared for the PC phase of PD, proactive PC planning was considered important). These findings indicate that caring for a person with PD in the PC phase is a demanding experience for FCGs. They experience psychological problems for many years before and after the death of the person with PD. Increasing HCPs' awareness of family and bereaved caregivers' needs may mitigate these long-term detrimental effects. **Abstract:** <https://bit.ly/2ZjM4Xr>

**N.B.** selected articles on PC for patients living with PD noted in Media Watch 27 April 2020 (#663, p.13).

### **Advance directives state requirements, center practices, and participant prevalence in adult day services centers: Findings from the 2016 National Study of Long-Term Care Providers**

*JOURNALS OF GERONTOLOGY* | Online – 5 July 2020 –

This study examined the associations between advance directives (AD) prevalence and having a state requirement for adult day service centers (ADSCs) to provide AD information to participants; ADSC's awareness of state requirements; and, providing AD information. Despite the absence of a federal mandate and less than a quarter of ADSCs located in 9 states with a requirement, about 80% of ADSCs that documented ADs provided AD information and 41% of their participants had ADs. A state requirement was associated with prevalence of ADs; however, this association was mediated by awareness. ADSC directors/staff that think there is a state requirement (despite incorrect perceptions of requirements) and providing AD information were important independent drivers of the prevalence of ADs, regardless of actual state requirements. These findings suggest ADSCs may believe providing AD information is a useful practice for many reasons, it is encouraged by other entities, or have other AD-related state requirements. **Full text (click on pdf icon):** <https://bit.ly/3iyFy6M>



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### **Dividual identity in grief theories, palliative and bereavement care**

*PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 8 July 2020 – This article is exploratory in questioning ideas of personhood, and in assuming that they underlie approaches to both palliative care and bereavement care. The author has aligned these two concerns, considering them to share an extensive overlap of relationships, emotions and dynamics of healthcare. He has been alert to some assertions concerning theories of grief and is deeply aware of the potential for serious criticism in making blunt propositions without detailed study of their complexity. This is intentional as an extended reflection on personhood as a concept underlying both theoretical considerations and professional practice. This article offers a potential elaboration of and complement to the continuing bonds and narrative approach to grief, while not abandoning the theme of attachment and loss if given a dividual approach. It invites further theoretical critiques of assumptions underlying palliative and bereavement care as an ongoing process, not least within a journal devoted to these profoundly human and humane aspects of our dying and living. **Full text:** <https://bit.ly/2CdrYVQ>

#### **Related:**

- *PROCEEDINGS OF THE NATIONAL ACADEMY OF SCIENCES OF THE UNITED STATES OF AMERICA* | Online – 10 July 2020 – **'Tracking the reach of COVID-19 kin loss with a bereavement multiplier...'** The authors created the COVID-19 bereavement multiplier, an indicator that clarifies one downstream impact of COVID-19 mortality and can be applied to different epidemiological projections of death counts: How many people are at risk for losing a grandparent, parent, sibling, spouse, or child for each COVID-19 death. Every death from COVID-19 will leave approximately nine bereaved. Studying how acute mortality crises reverberate through a population in the form of bereavement multipliers expands understandings of the social impacts of health crises. **Full text:** <https://bit.ly/322myb8>

## The Compassionate Communities Connectors model for end-of-life care: A community and health service partnership in Western Australia

*PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 2 July 2020 – With the number of Australians dying annually expected to double in the next 25 years, the end-of life (EoL) sector and Australian communities are looking for alternative, sustainable options for supporting positive EoL experiences for dying people, their carers and society more broadly. Many Australians currently die in a way and a place that does not reflect their values or their choice, and their EoL journey is interrupted with preventable or unnecessary admissions to hospital. Compassionate Communities is an international strategy for implementing the public health palliative care (PC) approach to EoL care. It recognises that sickness and health, death and loss are a natural part of life, and that care is not only a task for health and social services but is a community responsibility. While professional services are part of the mix, they need to recognise that their role is to work in partnership with civic and personal networks to support social connections and co-design EoL support. Hence, there is an international drive towards increasing provision of community-led models of social, psychological and practical support for people living with advanced illness and their families. These models

differ in terms of duration of support, contact time, focus and range of activities, raising questions about their comparative effectiveness. There is limited but growing base of evidence concerning existing public health models in PC. **Full text:** <https://bit.ly/2ABmTGw>

### General practitioners' perceptions of compassionate communities: A qualitative study

*BMC PALLIATIVE CARE* | Online – 6 July 2020 – “Compassionate communities” is a relatively new palliative care (PC) initiative that is gaining traction. In this study, the majority of participants recognised services in their current practice related to the model, including social prescribing and the introduction of the Daffodil standards. However, they were not overly familiar with “compassionate communities” as a distinct term or approach to PC. This is a concern given the emphasis in the broader literature as to the central role that GPs have in the implementation of a public health PC approach. If the model is to be expanded, further engagement and training of GPs is an important consideration, to provide a clearer understanding of compassionate communities, their aims, and how this can be achieved in practice. **Full text:** <https://bit.ly/2O5fyBX>

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

- *DEATH STUDIES* | Online – 19 March 2020 – ‘**Grief literacy: A call to action for compassionate communities.**’ The compassionate communities movement challenges the notion that death and dying should be housed within clinical and institutional contexts, and works to normalize conversations about death and dying by promoting death literacy and dialogue in public spaces. Community-based practices and conversations about grief remain marginal in this agenda. The authors theorize how grief could be better conceptualized and operationalized within the compassionate communities movement. They develop the concept of *Grief Literacy* and present vignettes to illustrate a grief literate society. Grief literacy augments the concept of death literacy... **Abstract:** <http://bit.ly/2vyvsiN>

Noted in Media Watch 20 January 2020 (#649, p.10):

- *PROGRESS IN PALLIATIVE CARE* | Online – 12 January 2020 – ‘**Bereavement support: From the poor cousin of palliative care to a core asset of compassionate communities.**’ The negative consequences of bereavement and the disruption of social relationships put the impact of bereavement squarely into a public health perspective. Adopting and strengthening a compassionate communities approach is necessary, not only for end-of-life care for dying people but also for providing bereavement support. Many palliative care services continue to adopt an unhelpful standardised approach in offering bereavement support. So, who provides support to the bereaved? Who needs support and to what extent? **Abstract (w. link to references):** <http://bit.ly/2NktLLo>

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Would the articles above be of interest to a colleague?

Noted in Media Watch 23 December 2019 (#645, p.10):

- *PROGRESS IN PALLIATIVE CARE* | Online – 18 December 2019 – ‘**Compassionate cities: Global significance and meaning for palliative care.**’ Compassionate cities programs are civic efforts to contribute to the work of palliative care by providing a variety of supports – educational, interpersonal, policy-oriented – for the end-of-life care needs for people from all walks of life in the wider society. These programs are public health initiatives that trace their history to the WHO Healthy Cities movement of the 1980s. They are designed to understand and act upon the social determinants of health, work to promoting health and wellbeing, tackle morbidities and unnecessary mortality, and lead on community action, often in partnership with health services. **Abstract (w. link to references):** <http://bit.ly/35H2KJe>

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### [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.

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