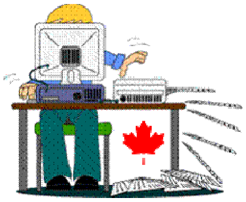
# *Media Watch...*

*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.*

**29 October 2018 Edition | Issue #587**



**Compiled & Annotated by Barry R. Ashpole**

**Best practice: Scroll down to Specialist Publications and 'What does it take to deliver brilliant home-based palliative care? Using positive organisational scholarship and video reflexive ethnography to explore the complexities of palliative care at home' (p.12), in *Palliative Medicine*.**

## Canada

### How cancer coaches help patients navigate an overwhelming diagnosis

ONTARIO | CBC ('White Coat, Black Art') – 26 October 2018 – Popular in Australia and England, cancer coaching is just starting to gain a toehold in Canada. The Ottawa Regional Cancer Foundation is the country's only cancer facility that employs paid cancer coaches, according to its CEO and president, Linda Eagen. But patients do not pay out-of-pocket. Cancer coaching is highly specialized to each patient. They get five hours of time with a coach, where they work to identify supports that will help them through the cancer journey. Needs differ from patient to patient, said Eagen. "Things such as I don't know how to tell my children that I have cancer; should I be eating this or eating that; I can't sleep; I'm always tired. What can I do for myself?" Other clients ask for assistance in creating medication plans or even managing their finances. Eagen's goal is to have cancer coaches in hospitals right across Canada. Her sales pitch is based on both compassion and economics. She said that studies have shown that coaching patients reduces health-care costs and leads to fewer hospital admissions. https://goo.gl/mtebJg

Noted in Media Watch 6 February 2017 (#498, p.10):

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 30 January 2017 – **'Promoting end-of-life discussions in advanced cancer: Effects of patient coaching and question prompt lists.'** Most patients with advanced cancer say they want honest, sensitive communication about end-of-life issues. These conversations help patients and their families prepare, make informed decisions, and avoid potentially burdensome aggressive medical treatments near death. Yet, patients are often misinformed about cancer survival and curability, and those with over-optimistic prognosis estimates are more likely to die in a hospital and receive burdensome aggressive care. **Full text:** https://goo.gl/cM068b

Noted in Media Watch 9 May 2016 (#461, p.13)

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2016;12(1-2):63-81. **'Coaching family caregivers to become better problem solvers when caring for persons with advanced cancer.'** Formal problem-solving training approaches have been developed over the past several decades to assist individuals with managing problems faced in daily life. Several of these problem-solving principles and techniques were incorporated into ENABLE (Educate, Nurture, Advise, Before Life End), an "early" palliative care telehealth intervention for individuals diagnosed with advanced cancer and their family caregivers. **Abstract (w. link to references):** http://goo.gl/aATOcR

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALBERTA | CBC News (Edmonton) – 23 October 2018 – **'Unassisted death.'** Covenant Health's policy on medical assistance in dying (MAiD) is not unique. Like many Catholic health-care providers across Canada, the publicly funded organization refuses to facilitate MAiD procedures, citing ethical and moral objections that make participating in such an act unconscionable. The Alberta government, which controls how MAiD is administered in the province, has exempted Covenant Health from having to do so. But Covenant Health cannot obstruct a patient's right to seek a procedure that the federal government legalized more than two years ago. It must give patients who request MAiD access to resources available through the province's health authority, Alberta Health Services. Except in limited circumstances, Covenant Health requires its patients to be transferred from its facilities for the assessments required to determine if they meet the legal requirements for a medically assisted death. Patients are always transferred for the procedure itself. https://goo.gl/7yRQQB

    **N.B.** CBC News reports that neither Covenant Health nor Alberta Health Services tracks exactly how many patients have been forced to leave Covenant's health facilities for MAiD assessments, and for the procedure itself. New federal rules that take effect 1 November will require all doctors and nurse practitioners to report that information directly to Alberta Health Minister Sarah Hoffman, who will then forward it to Health Canada. https://goo.gl/4dwhse

    Noted in Media Watch 25 June 2018 (#569, p.2):

    - ALBERTA | *The Edmonton Journal* – 18 June 2018 – **'Covenant Health walks ethical tightrope between Canadian, canon law on assisted death.'** In policy and in public, Covenant Health maintains a hard line against medical aid in dying (MAiD), two years after a new Canadian law on assisted suicide came into force. Alberta's Catholic health provider requires patients to leave its hospitals, nursing homes and hospice beds to receive the service, or even be assessed for eligibility. Yet behind the scenes, internal communications obtained by Postmedia show a health organization that has wrestled with dissension, doubt and sensitivity to criticism as it tries to walk an ethical tightrope between federal and canon law, and the needs of patients. https://goo.gl/csKo3h

**N.B.** Additional articles, reports, etc., on faith-based hospitals *vis-à-vis* MAiD noted in 15 January 2018 issue of Media Watch (#546, pp.1-2).

## U.S.A.

### Nearly half of hospice providers uncertain they would survive an audit

*HOME HEALTH CARE NEWS* | Online – 23 October 2018 – As demand for end-of-life services has grown, governmental watchdogs sniffing out fraud, waste and abuse have turned their attention to U.S. hospice providers of all shapes and sizes. But the industry may not be ready to face that heightened scrutiny. Optima Healthcare Solutions ... asked hospice providers about their confidence in surviving federal audits and compliance obligations...[1] More than 170 hospice agencies across the country participated in the survey... Overall, nearly half of all hospice providers that participated in the Optima survey reported being uncertain they would financially survive an audit. Likewise, more than 40% of surveyed hospices expressed a lack of full confidence in their ability to successfully respond to Additional Documentation Requests, which are used by federal auditors to review hospice claims. https://goo.gl/Xzg9iH

### Specialist Publications

**'Dying on hospice in the midst of an opioid crisis: What should we do now?'** (p.6), in *American Journal of Hospice & Palliative Medicine*.

**'Does the term *intensive care unit* promote aggressive treatment?'** (p.6), in *JAMA Internal Medicine*.

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1. '2018 Report: Hospice Agency Challenges,' Optima Healthcare Solutions, October 2018. **Download/view at:** https://goo.gl/1Sbufg

## International

### Indigenous end-of-life portal guides carers, policy makers

AUSTRALIA | *Community Care Review* – 25 October 2018 – A new resource has been launched to guide health professionals and policy makers involved in providing end-of-life (EoL) care for Aboriginal and Torres Strait Islander people. The Palliative Care & End-of-Life Care portal on the Australian Indigenous HealthInfoNet website stresses that indigenous people often have unique customary practices surrounding EoL, death and bereavement which may be sacred and not widely discussed in the community. For example, directly referring to "death" and "dying" may make people uncomfortable and it may be preferable to use terms like "finished up" or "passed on." The portal includes sections on culturally appropriate care, grief and bereavement and planning ahead with links to relevant publications, resources, organisations, policies and programs. It includes workforce information including training, events and jobs. Australian Indigenous HealthInfoNet, which launched the resource portal in collaboration with Palliative Care Australia, says it will put clinicians and policy makers in touch with research and projects relating to EoL care for indigenous Australians. https://goo.gl/k686Nb

> **N.B.** Selected articles on palliative and end-of-life care for Indigenous peoples in Australia, Canada, New Zealand and the U.S. noted in the 7 May 2018 issue of Media Watch (#562, pp.8,12) and 10 July 2017 issue of the weekly report (#520, p.13). Australian Indigenous HealthInfoNet: https://goo.gl/96LbSU

### 6,000 elderly people waiting to receive home care support, report says

IRELAND | *The Irish Examiner* (Dublin) – 23 October 2018 – A new report says around 6,000 elderly people are on waiting lists to receive home care support.[1] Care Alliance Ireland says families usually have to wait more than three months to get a carer. It also estimates there is an 18% gap between the care hours that are needed and what people actually get. The group says there is still under-investment in the service, and it is more difficult to get home care now than it was ten years ago. "There really doesn't appear to be a consistent approach by the Health Services Executive, particularly in assessing unmet needs and by that we mean the level of homecare that people are assessed as needing and the support they actually get," said Liam O'Sullivan from Care Alliance Ireland and author of the report. "We estimate this level of unmet needs at approximately 18% of current provision or in the region of about four million homecare hours per year." The group is calling for an extra investment of €110 million over the next 3-4 years. "What it means is if there is a family continuing to care for a family member who they love dearly but they do need extra support, it can be the difference between keeping someone at home and someone entering a nursing home." https://goo.gl/XYYyDQ

Care Alliance Ireland

**Extract from Care Alliance Ireland report**

Discrepancies in prioritisation: Whilst we know that at least some regions operate a prioritisation system, this process remains unclear in the majority of regions. It appears that some regions use a 1, 2, 3 prioritisation system, others a 1, 2, 3, 4 system, whilst some also appear to offer immediate home care for those at end of life.

[1] 'Public Provision of Home Care in Ireland – Update 2018,' Briefing paper 2, Care Alliance Ireland. **Download/view at:** https://goo.gl/8VRLG4

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### Let down by "agonising" end-of-life care

U.K. (England) | BBC News (London) – 23 October 2018 – Staff shortages and inadequate training mean that end-of-life (EoL) care for elderly people is often unacceptable, a leading expert has warned. Andrea Sutcliffe, of the Care Quality Commission, told the BBC every nursing home needed to be capable of supporting people at the end of their lives. Her call follows complaints from some relatives that their loved ones are dying distressing and painful deaths. There is no legal requirement for EoL training for care home staff. There are voluntary frameworks that care homes can sign up to, but many do not do so. Ms. Sutcliffe, who is the chief inspector of adult social care for the regulatory commission said: "Nursing homes are where we see the greatest struggles in adult social care, largely because of the difficulty in recruiting and retaining skilled nursing staff. It's not acceptable that we cannot support people at the end of their life in the way that we want to. Some people can do it but it's not happening everywhere and we need to get that sorted." https://goo.gl/xhkt68

### "Death doulas" seek national accreditation

AUSTRALIA | *Community Care Review* – 22 October 2018 – Australia's "death doulas" are taking the first steps towards becoming an incorporated national body and hope to gain accreditation over the next year, as they seek an established role in the palliative care process. A recent Australian report ... found that the death doula is emerging as a new role in the end-of-life care space.[1] The death doula has been described as an "eldest daughter," or a "paraprofessional" who can fill a gap in the often highly medicalised palliative process as a guide, support, companion and advocate for the dying person and their carers. Current health and social care systems don't always meet the needs of the dying in their communities, the researchers found, and as a result "patients and families are choosing to place their trust in those who can advocate for them or fill the gaps in care." However the research team, led by Deborah Rawlings of the College of Nursing and Health Services Flinders University, found a lack of information when it came to issues like specific services provided by doulas, funding, training, licensing and where they fit in with health services. Rawlings says at present death doulas may represent a new direction for personalised care, an adjunct to existing services or an unregulated form of care provision that's able to operate without oversight. https://goo.gl/MeL8jz

1. 'What role do death doulas play in end-of-life care? A systematic review,' *Health & Social Care in the Community*, published online 26 September 2018 [Noted in the 1 October 2018 issue of Media Watch (#583, p.13)] **Full text**: https://goo.gl/DbPkPg

**N.B.** Selected articles on death doulas in 30 July 2018 issue of Media Watch (#574, p.3).

### Dying children face "postcode lottery" with inconsistent quality of end-of-life care, MPs warn

U.K. (England, Northern Ireland & Wales) | *The Independent* (London) – 22 October 2018 – Dying children face "unjustified health inequality" in palliative care (PC) due to inconsistency in the quality of services, MPs warn. Around 40,000 babies, children and young people in England have chronic illnesses but the quality of care has been criticised as "patchy," according to an All-Party Parliamentary Group. The group's report warned end-of-life care depended on a postcode lottery and called on the government to meet its commitment to providing personalised care for vulnerable children.[1] "The reality is that the quality of PC that children and families can access is patchy and depends on where in England they live," the report stated. "This is limiting the choices they can make about the PC they need. It is also unfair and represents a wholly unjustified health inequality." https://goo.gl/oC8B5k

**Specialist Publications**

**'Symptoms and concerns among children and young people with life-limiting and life-threatening conditions: A systematic review highlighting meaningful health outcomes'** (p.13), in *The Patient – Patient-Centered Outcomes Research*.

Cont.

1. ‘End of life care: Strengthening choice,’ An inquiry report by the All-Party Parliamentary Group for Children Who Need Palliative Care,’ October 2018. **Download/view at:** https://goo.gl/Bz84gt

**Related**

- U.K. (England) | ITV News (London) – 22 October 2018 – **‘Children’s hospice forced to turn people away.’** A children’s hospice is warning it’s having to turn young people away because it can’t cope with demand. Claire House was set up in Wirral 20 years ago to give vital care to children with life threatening illnesses. But bosses say they’re running out of space and will be at full capacity unless something is done soon. https://goo.gl/5cMRak

Noted in Media Watch 1 October 2018 (#583, p.6):

- U.K. | Together for Short Lives – 25 September 2018 – **‘New guide to commissioning and delivering children’s palliative care.’** The national charity launched its new guide to commissioning, planning and delivering children’s palliative care.[1] The guide is endorsed by the National Institute for Health & Care Excellence (NICE), the Royal College of Paediatrics & Child Heath, the International Children’s Palliative Care Network, and the European Association for Palliative Care. It aligns with the NICE guideline on end-of-life care for children.[1] **Download/view ‘A Guide to Children’s Palliative Care’ at:** https://goo.gl/fRmnMr

    1. ‘End-of-Life Care for Infants, Children & Young People,’ National Institute for Health & Excellence, September 2017. [Draft issued during a consultation process noted in 24 April 2017 issue of Media Watch (#509, p.14)] **Download/view at:** https://goo.gl/f1dFiv

Noted in Media Watch 29 January 2018 (#548, p.4):

- U.K. (England) | *The Daily Mail* (London) – 26 January 2018 – **‘Charities call to improve end-of-life care for seriously ill children.’** Too many seriously ill children and their families are still unable to access decent end-of-life (EoL) care, with a “cruel postcode lottery” meaning many cannot decide where they die. Despite a government commitment, good EoL support, planning and care based on choice is not available to all families, a coalition of charities said. 5,000 babies, children and young people in the U.K. under the age of 19 die every year, a significant number living with life-limiting or life-threatening conditions who need. https://goo.gl/YXW2Uz

## Specialist Publications

### Findings from a thematic synthesis of key messages from a palliative care research network: The KINDLE Project

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 25 October 2018 – Effective palliative care (PC) requires a strong evidence base to advance clinical practice and policy-making. Calls for more collaborative and strategic approaches to research have resulted in the development of research networks at national and wider regional levels. The authors’ was to synthesize the learning arising from the activities of the Palliative Care Research Network from the island of Ireland, in order to identify the overarching messages from these activities. The ultimate aim is to promote the communication of these messages to practice. The synthesis of 142 dissemination products, sourced from 22 associated projects, including peer-reviewed publications, conference presentations, reports, and web/social media posts, identified 4 key themes relating to PC research and practice: 1) Addressing the needs of patients while recognizing the caregiver role; 2) Equal access to connected services; 3) General and specific needs in PC research; and, 4) Challenges in PC research. The key themes identified relate to challenges in both practice and research, highlighting the complexity of PC provision that aims to support both patients and carers, and research in this area. However, an important implication is the need for a broader approach to dissemination (beyond traditional academic activities) to ensure that research in PC is well placed to inform both practice and policy. **Abstract:** https://goo.gl/1EdQjf

All Ireland Institute of
**Hospice and Palliative Care**

**N.B.** The KINDLE project website: https://goo.gl/8GNfXs

**Dying on hospice in the midst of an opioid crisis: What should we do now?**

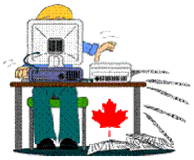
*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 23 October 2018 – The current opioid crisis in the U.S. is a major problem facing health-care providers, even at the end of life (EoL). Opioids continue to be the mainstay treatment for pain at the EoL, with the prevalence of pain reported in up to 80% of patients and tends to increase as one gets closer toward the EoL. In the past year, 20.2 million Americans had a substance use disorder (SUD) and SUDs are disabling disorders that largely go untreated. In addition, the co-existence of both a mental health and SUD is very common with the use of opioids often as a means of chemical coping. Most hospice programs do not have standardized SUD policies/guidelines in place despite the increasing concerns about substance abuse within the U.S. The goal of this article is to review the literature on this topic and offer strategies on how to manage pain in patients who have active SUD or who are at risk for developing SUD in those dying on hospice. **Abstract:** https://goo.gl/GtUE1Q

**Accepting the avoidable death: The philosophy of limiting intensive care**

*BIOETHICS* | Online – 20 October 2018 – Limiting intensive care is paid increasing attention. In the echoing call for physicians' ethical self-restriction, it is easily overlooked, however, that ethics needs a critical epistemological analysis before it can suffice as an emergency brake to futile treatment. The authors suggest that the difficulties of resolving moral dilemmas related to limiting intensive care may just be due to the unclarified epistemological status of moral claims. Even if normative ethics cannot prescribe right decisions, but only draw conclusions from defined premises, the premises may or may not be true. Their intertwined descriptive and normative evidence is endorsed in an academic and political discourse. There will necessarily be various demands for rationality in prudent decisions between physicians, their patients and society. These demands are formulated dialogically through critical questions and justified answers. A good argument is the convincing one that, finally and ideally, leads to the absence of open objections. Thus, in the end the rightness of a given decision does not depend on axiomatic moral principles, but is comparative and conditional, as it is given in an omnilateral argument. Neither is it the democratic process of shared decision making that we should evaluate, but rather the argumentative state itself, when we judge the morality of health politics and clinical practice. **Abstract:** https://goo.gl/zK8P9M

**Related**

- *JAMA INTERNAL MEDICINE* | Online – 22 October 2018 – **'Does the term *intensive care unit* promote aggressive treatment?'** Six million Americans are admitted to an intensive care unit (ICU) each year. Many receive aggressive efforts to return them to health that are appropriate and consistent with their values. Others are treated aggressively, despite a poor prognosis, even though many people indicate that they would not want burdensome treatment in such a situation. The term *intensive care unit* and its abbreviation, ICU, may contribute to this discrepancy by implying a default option of aggressive life-sustaining therapy. **Abstract:** https://goo.gl/UNKpm8



**Barry R. Ashpole**

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

### Access to palliative care for homeless people: Complex lives, complex care

*BMC PALLIATIVE CARE* | Online – 24 October 2018 - People experiencing homelessness often encounter progressive incurable somatic diseases in combination with psychiatric and psychosocial problems, and many need palliative care (PC) at the end of their lives. Little is known about how PC for this group can be started in good time and provided optimally. Three key themes [emerged in this study]: "late access," "capricious trajectory," and "complex care." The first key theme refers to the often delayed start of PC, because of the difficulties in recognizing the need for PC, the ambivalence of people experiencing homelessness about accepting PC, and the lack of facilities with specific expertise in PC for them. The second key theme refers to the illness trajectory, which is often capricious because of the challenging behaviour of people experiencing homelessness, an unpredictable disease process, and a system not being able to accommodate or meet their needs. The third key theme refers to the complexity of their care with regard to pain and symptom control, psychosocial and spiritual aspects, and the social network. The care for in the palliative phase does not satisfy the core requirements of PC since there are bottlenecks regarding timely identification, the social network, and the assessment and management of physical symptoms and psychosocial and spiritual care needs. **Full text:** https://goo.gl/jQNBHj


European Journal of

Palliative Care

A JOURNAL OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE

The homeless: a vulnerable population with poor access to palliative care

■ In his regular column, **Barry Ashpole** presents a selection of abstracts that highlight new findings and trends in the diverse and rapidly expanding body of research in the field of palliative and end-of-life care.

See March/April 2018 issue of the *European Journal of Palliative Care* (p.89). **Contents page (and access options):** https://goo.gl/7w8HS9

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

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

### Stressors and resources related to medication management: Associations with spousal caregivers' role overload

*THE GERONTOLOGIST* | Online – 24 October 2018 – Managing medications can be stressful for spousal caregivers, but little is known about particular aspects of medication management that are most consequential for caregiving outcomes. The authors examined care stressors and resources related to medication management, their associations with role overload among spousal caregivers, and whether these links vary by care recipients' number of chronic health conditions and dementia status. This cross-sectional study included 377 spousal caregivers of adults aged 65 and older from the 2011 National Health & Aging Trends Study and National Study of Caregiving. Caregivers who administered injections reported more role overload, whereas those who worked with care recipients to jointly manage medications reported less role overload. Keeping track of medications was linked to caregivers' greater role overload when care recipients had 5 or more chronic health conditions. Finally, care recipients' use of medication reminder systems was linked to less role overload for caregivers of a partner with dementia. Devising strategies to assist spousal caregivers in the more onerous components of medication management and promote resources that mitigate medication-related stress may improve caregiver well-being. **Abstract:** https://goo.gl/1K2367

Cont.

Noted in Media Watch 17 September 2018 (#581, p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 11 September 2018 – **'Managing medicines for patients dying at home: A review of family caregivers' experiences.'** This review highlights implications for practice alongside an underlying concern about whether family caregivers (FCGs) have any "choice," in practice, about whether or not they take on this caring role. There are a number of moral consequences for FCGs if they choose not to take on this role and practical implications for services if FCGs do not want to administer medications. **Full text:** https://goo.gl/X6S9KW

Noted in Media Watch 11 September 2017 (#529, p.10):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 6 September 2017 – **'Pain management concerns from the hospice family caregivers' perspective.'** The study provided an investigation on hospice family caregivers' difficulties in pain management. The results can inform healthcare providers and researchers of family caregivers' challenges and provide insights for future designs of educational tools targeting pain management strategies, so that family caregivers can perform pain management effectively at home. **Abstract:** https://goo.gl/EN14ZM

### Healthcare provider planned responses to patient misunderstandings about end-of-life care

*HEALTH COMMUNICATION* | Online – 19 October 2018 – This study examined health-care provider planned responses to patient misunderstandings about end-of-life care using a multiple goals framework. Plan topics and content alignment with task, identity, and relational goal types were coded. Findings suggested that content was predominately task-oriented and concerned implications of treatment options such as choice outcomes and efficacy rates. A substantial percentage of providers planned to refer further discussion about the misunderstanding to another team member or occupational resource. Despite the prompt of patient misunderstanding, little attention was given to literacy and/or avoidance of medical jargon. Implications for these findings are discussed. **Abstract:** https://goo.gl/aNXbuV

### Designing a population-based approach to integrated end-of-life care on a small island

*INTERNATIONAL JOURNAL OF INTEGRATED CARE* | Online – 23 October 2018 – The Isle of Man is a small island of 83,000 residents situated in the Irish Sea. The Island is a self-governing Crown Dependency of the U.K. Due to its geographic isolation, the Island provides a unique opportunity to re-design and co-create a model of care that incorporates private, public, third sector and community elements. Financially strained health services recognise that sustainability depends on integration across sectors in the community. Hospice Isle of Man, the only specialist provider of end-of-life (EoL) care on the Island, is working with the Department of Health & Social Care and the Council of Voluntary Organisations to develop the Isle of Man's Integrated Palliative & End-of-Life Care Strategy. In order to provide the right care, at the right time, in the right place, the Island-wide strategy requires a population-based approach and methods to match patients and services based on needs. Early stakeholder engagement ... identified the need for earlier identification of patients at the EoL in order to provide the most appropriate services. It was recognised that patient networks and resources must be taken into account in order for gaps to be adequately identified and to meet patient needs. Patient journey case studies with different diagnoses identified needs across the spectrum of care – including the third sector and patient networks. Age-based segmentation fails to recognize the contribution and potential capacity of those who would otherwise be considered "dependent" in traditional demographic analyses. Cross-sector integration of care raises additional questions and challenges. Who leads the process? What does person-centred care look like with cross-sector involvement? Who can function as a "key worker"? How will fragmented services organise? How do charitable organisations balance mission and goals with the requirements of an integrated network? What trade-offs are stakeholders willing to make? By combining findings obtained through focus groups, patient and carer journeys and cross-sector workshops the authors identify the non-medical determinants of need for community EoL support and propose strategies to meet them. These findings will form the basis for initiatives that will be piloted and evaluated prior to Island-wide implementation. **Abstract:** https://goo.gl/mX6msV

### Development and implementation of the Steps to Successful Palliative Care programme in residential care homes for people with a learning disability

*INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 25 October 2018 – For health and social care services to meet the needs of a growing and ageing population they need to respond appropriately. This response is only going to be possible if attention is paid to the individuals within it. This includes those people living with a learning disability (LD). A palliative care (PC) programme and resource folder was created following a literature review and meetings with LD and specialist PC experts, organisations and care home managers. This folder was further developed collaboratively throughout the programme's implementation. 39 homes were recruited and 86% completed the programme. This programme enabled the identification, assessment and management of the health and social care needs of people living and dying in a care home with a LD. **Abstract:** https://goo.gl/EJsSCE

### "Planting the seed": Perceived benefits of and strategies for discussing long-term prognosis with older adults

*JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 22 October 2018 – Perceived benefits of discussing long-term prognosis [in interviews with clinicians from home-based primary care practices, community-based clinics, and academic medical centers across San Francisco] included establishing realistic expectations for patients, encouraging conversations about future planning, and promoting shared decision-making through understanding of patient goals of care. Communication strategies included adapting discussions to individual patient preferences and engaging in multiple conversations over time. Clinicians preferred to communicate prognosis in words and with a visual aid, although most did not know of a suitable visual aid. Engaging in customized longitudinal discussions of long-term prognosis aids clinicians in anchoring conversations about future planning and preparing patients for the end of life. **Abstract:** https://goo.gl/oPRPDb

**Related**

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 25 October 2018 – **'Communication is more than just a conversation: Family members' satisfaction with end-of-life care.'** Four themes were identified [in this study] as contributing to favourable communication with health professionals in end-of-life care (EoLC): 1) Establishing a relationship; 2) Flow of information; 3) Environment; and, 4) Acceptance at the time of death. The context of communication in EoLC is more than just a conversation. It includes health professional's appearances, decision-making and respect. **Abstract:** https://goo.gl/61LUKZ

### Weakening the ethical distinction between euthanasia, palliative opioid use and palliative sedation

*JOURNAL OF MEDICAL ETHICS* | Online – 23 October 2018 – Opioid and sedative use are common "active" practices in the provision of mainstream palliative care services, and are typically distinguished from euthanasia on the basis that they do not shorten survival time. Even supposing that they did, it is often argued that they are justified and distinguished from euthanasia via appeal to Aquinas' doctrine of double effect. The author appraises the empirical evidence regarding opioid/sedative use and survival time, and argue for a position of agnosticism. He argues that the doctrine of double effect is a useful ethical tool but is ultimately not a sound ethical principle, and even if it were, it is unclear whether palliative opioid/sedative use satisfy its four criteria. Although this article does not establish any definitive proofs, it aims to provide reasons to doubt – and therefore weaken – the often-claimed ethical distinction between euthanasia and palliative opioid/sedative use. **Abstract:** https://goo.gl/qdFS92

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Noted in Media Watch 18 December 2017 (#543, p.20):

- *JOURNAL OF BIOETHICAL INQUIRY* | Online – 11 December 2017 – **'Knowing, anticipating, even facilitating but still not intending: Another challenge to double effect reasoning.'** Double effect reasoning has hitherto been used to legitimate treatments which may shorten life, but where the intent of treatment is pain relief. The situation reviewed by the Victorian tribunal went further, supporting actions where a doctor agrees to provide pentobarbitone to a patient at some time in the future if the patient feels at that time that his pain is unbearable and he wants to end his life. The offer to provide the drug was described as a palliative treatment in that it gave reassurance and comfort to the patient. Double effect reasoning was extended in this instance to encompass potentially facilitating a patient's death. This extension further muddies the murky double effect reasoning waters and creates another challenge to this concept. **Abstract:** https://goo.gl/EBkSdA

**N.B.** Selected articles on palliative sedation noted in 27 August 2018 issue of Media Watch (#578, p.5).

## Communication differences between oncologists and palliative care clinicians: A qualitative analysis of early, integrated palliative care in patients with advanced cancer

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 25 October 2018 – Growing evidence demonstrates the benefits of early, integrated palliative care (PC) for patients with advanced cancer and their caregivers. Yet, data are lacking on the communication patterns within this model of care. The goals of this study were to describe the content of patient-clinician discussions among patients receiving PC and to compare differences in discussion content between oncologists and PC clinicians. Although both oncology and PC clinicians discussed symptom management, medical understanding, and treatment decision making with patients at nearly all post-progression visits, PC clinicians tended to assess patient understanding of the treatment process and prognosis more often than oncologists. PC clinicians addressed patient coping, caregiver experiences and needs, and advance care planning more frequently than oncologists. **Abstract:** https://goo.gl/dzdMdb

Noted in Media Watch 1 January 2018 (#544, p.8):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 19 December 2017 – **'Bridging the cultural divide between oncology and palliative care sub-specialties: Clinicians' perceptions on team integration.'** The authors assessed oncologists' and palliative care (PC) clinicians' perceptions about integrating oncology and PC using a nurse delivering PC to patients newly diagnosed with lung cancer. They identified two main themes: 1) Tensions, differences, and mistrust between services occur in the least integrated teams; and, 2) Open communication, sharing common goals, and promoting oncology "buy in" build trust and foster collaboration between teams. **Abstract:** https://goo.gl/jTtck4

## Use of non-palliative medications following burdensome health care transitions in hospice patients: A matched cohort analysis

*MEDICAL CARE* | Online – 22 October 2018 – Limited benefit medications (LBMs), those medications with questionable benefit at the end of life, are often recommended for discontinuation in hospice patients. Transitions in care are associated with inappropriate prescribing in older and terminally ill populations. In total, 17.9% of 7,064 hospice patients [i.e., patient population studied] received at least 1 LBM following their first burdensome health care transition. Post-transition continuation of a medication class used before hospice admission was most common for antidementia medications (14.2%) and antihypertensives (11.2%). Transitions were associated with a 33% increase in the risk of receiving at least 1 LBM, increasing to 56% when evaluating only hospitalization transitions. Medication classes more likely to be dispensed after a transition included antihyperlipidemics, antihypertensives, and proton-pump inhibitors. Burdensome health care transitions were associated with the receipt of non-palliative medications in older hospice patients. **Abstract:** https://goo.gl/hRXGJd

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Noted in Media Watch 23 July 2018 (#573, p.9):

- *DRUGS & AGING* | Online – 14 July 2018 – **'International Group for Reducing Inappropriate Medication Use & Polypharmacy: Position statement and 10 recommendations for action.'** This article outlines current strategies to reduce inappropriate medication use, provides evidence for their effect, and then proposes recommendations for moving forward with 10 recommendations for action and 12 recommendations for research. The authors conclude that an urgent integrated effort to reduce inappropriate medi-cation use and polypharmacy should be a leading global target of the highest priority. **Full text:** https://goo.gl/zj4Q3Y

Noted in Media Watch 2 July 2018 (#570, p.8):

- *EUROPEAN JOURNAL OF CLINICAL PHARMACOLOGY* | Online – 23 June 2018 – **'Adequate, questionable, and inadequate drug prescribing for older adults at the end of life: A European expert consensus.'** The expert panel reached consensus on a set of 14 drug classes deemed as "often adequate," 28 drug classes deemed "questionable," and 10 drug classes deemed "often inadequate" for continuation during the last 3 months of life. The panel reached consensus on a set of 10 drug classes deemed "often adequate," 23 drug classes deemed "questionable," and 23 drug classes deemed "often inadequate." Consensus remained unachieved for some very commonly prescribed drug treatments... **Full text:** https://goo.gl/wtWTJ7

## The "five stages" in coping with dying and bereavement: Strengths, weaknesses and some alternatives

*MORTALITY* | Online – 23 October 2018 – This article offers a reflective analysis of one well-known psychological theory, the so-called "five stages" in coping with dying and coping with bereavement. Despite widespread acceptance among the general public and continued presence in some forms of professional education, it is argued that the "five stages" model is less attractive than it initially appears. Significant criticisms of the theory are set forth here, as well as notable strengths of its underlying foundations. Lessons to learn about this theory are offered in terms of both coping with dying and coping with bereavement. In addition, examples of alternative theories from the literature are presented in both spheres. Although the "five stages" model is important as a classical theory with constructive historical implications, it does not measure up to the standards of a sound theory in contemporary thinking, can actually do damage when misapplied to individuals or applied too rigidly, and should be set aside as an unreliable guide to both education and practice. **Abstract:** https://goo.gl/R8sMLF

**Related**

- *FAMILIES IN SOCIETY: THE JOURNAL OF CONTEMPORARY SOCIAL SERVICES* | Online – 18 October 2018 – **'The profession of social work and the legacy of Kübler-Ross.'** Social work is a practice-based profession. As such, it is important to understand our roots and the basis for our interventions, to assess continuing validity, and to determine if the assumptions and methodologies we use still fit. This article focuses on the tenets put forth by psychiatrist Elisabeth Kübler-Ross 50 years ago and describes how the profession of social work extended and expanded her pioneering work to define a robust area of social work practice in palliative and end-of-life care. Abstract: https://goo.gl/ZivFuT

Noted in Media Watch 25 May 2015, #411 (p.10):

- *ILLNESS, CRISIS & LOSS* | Online – 21 May 2015 – **'Let's stop "staging" persons who are coping with loss.'** This article offers a critical analysis of ... *On Grief & Grieving: Finding the Meaning of Grief Through the Five Stages of Loss*. Although the five stages of grief are described in the first chapter, they play little role thereafter. Further, readers are told these stages are neither universal nor linear. Consequently, it would be desirable to stop staging persons who are coping with loss or at least be extremely cautious in using this stage-based model in appreciating their unique journeys. **Abstract:** https://goo.gl/rlBjcG

### GPs pulling back from palliative care over opioid crackdown fears

*NEWSGP* | Online – 25 October 2018 – A number of GPs have written to Palliative Care Australia (PCA) stating they will no longer risk prescribing opioids for palliative care (PC) patients. One of those GPs, Adelaide's Dr. Peter Ford, told *newsGP* he had reduced his PC work in aged care facilities after receiving a letter from the Department of Health (DoH) earlier this year stating his rates of opioid prescribing were very high. The news underlines the Royal Australian College of General Practitioners' early concerns about a letter the DoH sent to almost 5,000 GPs around the country in June, warning them that their rates of opioid prescription were in the top 20% of all GPs in Australia. The letter stated that the DoH would monitor their opioid prescriptions over the following 12 months. A DoH spokeswoman previously told *newsGP* that a small number of GPs with very high rates could be asked for an interview as part of the Practitioner Review Program to understand the reasons for their prescribing. While the campaign may be well intentioned, the College has significant concerns for GPs who work in PC, aged care or rural hospitals, all of whom have legitimate reasons for high rates of opioid prescribing. According to PCA nurse practitioner clinical adviser, Kate Reed, a key factor in the issue is that oxycodone hydrochloride – a potent opioid – is not listed as a PC item on the Pharmaceutical Benefits Scheme. That could mean GPs working in PC have been sent the letters unnecessarily. **Full text:** https://goo.gl/kaMVoM

THE ROYAL AUSTRALIAN
COLLEGE OF
GENERAL PRACTITIONERS

### What does it take to deliver brilliant home-based palliative care? Using positive organisational scholarship and video reflexive ethnography to explore the complexities of palliative care at home

*PALLIATIVE MEDICINE* | Online – 26 October 2018 – Despite the increasing number of people requiring palliative care (PC) at home, there is limited evidence on how home-based PC is best practised. This study was inspired by the Brilliance Project – an initiative to explore how positive organisational scholarship in healthcare can be used to study brilliant health service management from the viewpoint of patients, families, and clinicians. Home-based specialist PC services across two Australian states participated in the study. Clinicians were able to take part in the study at different levels. Pending their preference, this could involve video-recording of PC, facilitating and/or participating in reflexive sessions to analyse and critique the recordings, identifying the characteristics that contribute to brilliant home-based PC, and/or sharing the findings with others. Brilliance in home-based PC is contingent on context and is conceptualised as a variety of actions, people, and processes. Care is more likely to be framed as brilliant when it is epitomised: anticipatory aptitude and action; a weave of commitment; flexible adaptability; and/or team capacity-building. This study is important because it verifies the characteristics of brilliant home-based PC. Furthermore, these characteristics can be adapted for use within other services. **Abstract:** https://goo.gl/DtB3Nv

### The conceptual models and mechanisms of action that underpin advance care planning for cancer patients: A systematic review of randomised controlled trials

*PALLIATIVE MEDICINE* | Online – 26 October 2018 – No systematic review has focused on conceptual models underpinning advance care planning (ACP) for patients with advanced cancer and the mechanisms of action in relation to the intended outcomes. Nine randomised controlled trials were included, with only four articulated conceptual models. Mechanisms through which ACP improved outcomes comprised 1) Increasing patients' knowledge of end-of-life (EoL) care; 2) Strengthening patients' autonomous motivation; 3) Building patients' competence to undertake EoL discussions; and, 4) Enhancing shared decision-making in a trustful relationship. When used, conceptual models identify the individual behavioural change. Strengthening patients' motivation and competence in participating ACP discussions are key mechanisms of change. Understanding cultural feasibility of the logic model for different educational levels and ethnicities in non-Western countries should be a research priority. **Abstract:** https://goo.gl/T8ttjB

### Symptoms and concerns among children and young people with life-limiting and life-threatening conditions: A systematic review highlighting meaningful health outcomes

*THE PATIENT – PATIENT-CENTERED OUTCOMES RESEARCH* | Online – 26 October 2018 – Most of the 81 studies included were from high-income countries and focused on young people with cancer. A total of 3,236 young people, 2,103 family carers, 108 families, and 901 healthcare providers were included in the studies. Young people did not contribute to data in 30% of studies. Themes on priority concerns are presented by the following domains and health outcomes: 1) Physical, e.g., physical symptoms; 2) Psychological, e.g., worry; 3) Psychosocial, e.g., relationships; 4) Existential, e.g., existential loss; and, 5) "other," e.g., information access. Burdensome symptoms and concerns affect young people with malignant and non-malignant conditions and occur across the disease trajectory; pediatric palliative care should not be limited to the end-of-life phase. A child-family-centered framework of health outcomes, spanning the patient, family, and quality of service levels is proposed to inform service development. Future research should address gaps identified across the literature (i.e., the involvement of young people in research, evidence for developing countries, and a focus on non-malignant conditions**. Abstract (inc. list of references):** https://goo.gl/jmjXLT

### Assisted (or facilitated) death

Representative sample of recent journal articles:

- *JOURNAL OF ETHICS IN MENTAL HEALTH* | Online – Accessed 24 October 2018 – **'Euthanasia of Dutch patients with psychiatric disorders between 2015 and 2017.'** The Netherlands is one of the few countries in the world that allows euthanasia and assisted suicide (EAS) due to psychiatric suffering. The Dutch regional euthanasia review committees published 43 case summaries online between 2015 and 2017, of which 35 were analyzed (22% of all psychiatric EAS cases) on patient characteristics and physician involvement. 77% of patients were women. 51% of patients were between 50 and 70. Major depression disorder and personality disorders were present in almost half of the patients. All patients were considered mentally competent. The incidence of psychiatric EAS cases is rising, but the authors found no shift in patient characteristics. The division between psychiatric and somatic suffering may prove more complicated than expected. Patients dying from suicide differ on several characteristics from patients dying through assisted suicide. The fact that all patients are considered competent suggest that they are unjustly seen as vulnerable or that the competence assessment lacks due diligence.

  **N.B.** This article is included in a special theme issue of the *Journal of Ethics in Mental Health* focused on medical assistance in dying. The full text of this and each article in this issue of the McMaster University publication can be **downloaded/view at:** https://goo.gl/mvuqAT

## Publishing Matters

### Plan S aims to transform scholarly communication. Will publishers be ready?

*PUBLISHERS' WEEKLY* | Online – 25 October 2018 – The announcement in September of Plan S is sending shockwaves throughout the global scholarly research and publishing communities. A joint commitment launched by cOAlition S, an assembly of major European research funders, Plan S seeks to require immediate open access to the coalition's scientific publications by 2020, a potentially dramatic change to the scholarly communication landscape. How will today's publishers adapt? Liz Ferguson, Vice President of Editorial Development at Wiley, sees Plan S as a bid to change both publisher business models and author behavior. And after years of moving slowly toward open access, the key challenge now, Ferguson says, will be speed. There are just 14 months before the plan's requirements are scheduled to take effect. "You could argue that publishers have had prior warning from the European Union Competiveness Council's announcement in 2016,"[1] Ferguson says, "but the reality is that few institutions,

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funders, and governments had shown much formal commitment to those goals until recently." Among the 10 principles set out in Plan S are some game-changers for the scientific publishing, including: authors must retain their copyrights; article publication charges must be capped; and strong support for gold open access over subscription and hybrid journals, which currently account for some 85% of the total. **Full text:** https://goo.gl/92dwxC

1. 'In dramatic statement, European leaders call for "immediate" open access to all scientific papers by 2020,' *Science*, 27 May 2016. https://goo.gl/4NiehY

**N.B.** cOAlition S website: https://goo.gl/JgwwrB

### How to read and learn from scientific literature, even if you're not an expert

*THE CONVERSATION* | Online – 24 October 2018 – Reading scientific literature is not for the faint-hearted. It's dense, and very often full of foreign terms and ideas. It also assumes a basic understanding of the discipline in question. I can't imagine that many people outside the world of theoretical physics are reading journal articles on the subject. That makes sense: research has found that scientific literature across disciplines is getting more complicated. But as more and more journals embrace the principles of open access, and more information becomes freely available online, curious readers are probably more likely to start engaging with scientific literature. That's a good thing. Research shouldn't be regarded as a closely kept secret for a small number of people. In a world full of half truths, simplistic and misleading summaries, and outright "fake news," being able to read and engage with scientific literature can be a powerful weapon. Of course, you can also seek out examples of scientists writing for the public. But be wary: not all scientists are willing to do this; we are, on the whole, very picky about details and don't like generalisations. So try to engage with scientific literature where you can: it will be hard work in the beginning if you have no scientific background, but it's a skill that can be developed. **Full text:** https://goo.gl/HEQANw

AMERICAN MEDICAL WRITERS ASSOCIATION

### A journalist's guide to writing health stories

*AMERICAN MEDICAL WRITERS ASSOCIATION JOURNAL*, 1999;14(1):32-42. Reporting health stories requires judgment about how to interpret evidence and about the implications of evidence for the public. But most journalists have little formal training in assessing the validity of evidence that bears on health issues, so inaccurate or deceptive reporting seems common. Many obstacles confront the health journalist, including limitations of time and space, editorial priorities, and the need to create stories that are compelling enough to warrant space in a publication. This journalist's guidelines will not help with those issues. However, even given other constraints, understanding principles of scientific inquiry into human health problems will help journalists to produce more informed articles. **Download/view at:** https://goo.gl/JGS5n9

### 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.

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

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

**Canada**

CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: https://goo.gl/BLgxy2

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

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

[Scroll down to ‘Additional Resources’]

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): https://goo.gl/lOSNC7

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**Europe**

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

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

**South America**

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

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