

Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compilation of Media Watch 2008-2018 ©

Compiled & Annotated by Barry R. Ashpole

Growing interest in the social aspects of dying, death and bereavement: Scroll down to [Specialist Publications](#) and 'Focus: A moment for dying and death?' (p.11), in *Discover Society*.

Canada

New Commonwealth Fund survey sheds light on seniors' opinions of their health care system

CANADIAN INSTITUTE FOR HEALTH INFORMATION | Online – 8 February 2018 – In an international survey of seniors in 11 countries, Canadian seniors reported the lowest satisfaction with the overall quality of the health care they received. Despite this, Canada's seniors report better perceived health than the international average. The survey,¹ released by the Institute,² shows that only 2 out of 3 Canadian seniors were satisfied with the quality of the health care they received, compared with an average of 76% of seniors in all surveyed countries. When it comes to perceived health, 4 out of 5 Canadian seniors surveyed described their health as "excellent," "very good" or "good." The Canadian survey included questions on home care and end-of-life planning that were not asked in other countries. <https://goo.gl/bvztVd>

Extract from New Commonwealth Fund survey

Questions on medical assistance in dying are new to The Commonwealth Fund this year and weren't asked in other countries as this information is considered a priority for Canadian stakeholders.

12% of Canadian seniors or one of their family members have talked to a health care provider about access to medical assistance in dying.¹

Almost two-thirds of Canadian seniors surveyed are confident that they would be able to obtain medical assistance in dying in their community.¹

1. Canadian seniors and medical assistance in dying.
View video at: <https://goo.gl/XsZUSv>

1. '2017 Commonwealth Fund International Health Policy Survey of Older Adults,' November 2017.
Download/view at: <https://goo.gl/qwBDD2>
2. 'Seniors think Canada's health care systems have room to improve, study finds,' Canadian Institute for Health Information, February 2018. **Download/view at:** <https://goo.gl/6WD9XR>



Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.20.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 9 February 2018 – ‘**We have assisted death. Now we need to get the facts about it.**’ The Supreme Court decision, issued in the particular format reserved for decisions emphasizing the unanimity of opinion, stated that assisted death was legal: “...for the *competent adult* person who 1) *clearly consents* ... and 2) has *grievous and irremediable medical illness, disease or disability* that causes *enduring suffering* that is *intolerable to the individual.*” To a lawyer, that probably seems clear. However, clinicians will tell you that each of the words italicized [by the author of this article] is ambiguous, subjective, context-dependent and likely constantly changing. How do we define *competence*? Ought we to expect different degrees of competence depending on the consequences of the decision? What is *consent*, and how do we determine that someone has capacity to give consent? The fact is there is little data, and no consensus on how to assess capacity in the face of *intolerable suffering*. <https://goo.gl/RBZCmC>
- BRITISH COLUMBIA | *The Aldergrove Star* – 7 February 2018 – ‘**Langley hospice losing volunteers, donors over medically assisted death issue.**’ Some volunteers have informed the Langley Hospice Society they won’t work under a Fraser Health Authority (FHA) directive that says medically assisted deaths must be permitted at the local 10-bed hospice facility. The society has also heard from some donors who have said they will not contribute to the society under the directive that was issued in December, society executive director Nancy Panchuk said. Panchuk explained that the directive said medically assisted deaths will take place in all hospices in the region. “There was no consultation, period, with any of the hospices,” Panchuk said. “Unfortunately, our hands are tied, Panchuk said. <https://goo.gl/wnN2q3>
- BRITISH COLUMBIA | *The Vancouver Sun* – 6 February 2018 – ‘**Delta hospice rebels against Fraser Health’s mandate to provide medical assistance in dying.**’ The operators of the Delta Hospice Society say they’re victims of “bullying” tactics by Fraser Health and medical assistance in dying (MAiD) activists who want the service provided in all non-denominational, hospice palliative care (PC) programs. “Hospice PC is not about hastening death and we object to the bullying currently taking place in British Columbia,” said Janice Strukoff, an administrative leader for the charitable, non-profit society that has a contract with the health region to provide 10 PC beds for the region. It derives just under half its income from the health authority; the other half comes from private donations. Faith-based health facilities have been controversially exempted from obligatory MAiD provision, but there is a more ambiguous situation with non-denominational settings. <https://goo.gl/qBAS8V>

Specialist Publications

‘Assisted dying in U.S. and Canada: Controversy subsides after legalisation’ (p.17), in *British Medical Journal*.



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>

U.S.A.

Talk to your doctor about your bucket list

THE NEW YORK TIMES | Online – 8 February 2018 – Making a bucket list allows us to reflect on our values and goals and identify important milestones and experiences that we want to have in our lifetime. In my experience as an internist, geriatrics and palliative care doctor, most patients have a bucket list. Some give it a lot of thought, while others have a nebulous mental checklist of items. I routinely ask my patients about their bucket lists; I started doing this to forge a personal connection and get a quick glimpse into what matters most to each of them. The responses were fascinating and revealed hidden dimensions of their personalities. In a study¹ ...we asked 3,056 people across the U.S. and found nine out of 10 had a bucket list. Participants who said that faith, religion or spirituality were unimportant to them were the least likely to have a bucket list. <https://goo.gl/9Tez2n>

1. 'Common items on a bucket list,' *Journal of Palliative Medicine*, published online 8 February 2018. **Full text (only available until 8 March 2018):** <https://goo.gl/4WdFH7>

Homelessness and dying with dignity

CALIFORNIA | *Tahoe Daily Tribune* (South Lake Tahoe) – 5 February 2018 – Across the country, programs designed to serve the chronically homeless population will be struggling with death. That is, according to research conducted at the University of Pennsylvania, a large portion of people who have experienced chronic homelessness are part of a large group who first became homeless as young adults in the 1980s when there was a major economic recession. Many remained or cycled in and out of homelessness for years, if not decades. Today, they are in their mid- to late-50s and aging quickly. This raises three important points. First, we need

to get this vulnerable population off the streets. Second, as we work to end homelessness, we must provide housing and services that can accommodate or address accelerated aging experience by this population. Finally, we need to talk about death. <https://goo.gl/3ud1ZN>

Noted in Media Watch 10 July 2017 (#520, p.9):

- *MEDSCAPE* | Online – 3 July 2017 – '**Homeless and dying in America: Facing the end of life alone.**' A major gap in knowledge exists regarding the symptoms experienced by homeless persons at or near the end of life – information that would help clinicians not only manage these symptoms but also assist homeless persons with advance care planning and decision-making around death and dying.¹ **Full text:** <https://goo.gl/zS6BuL>
- 1. 'Homeless individuals approaching the end of life: Symptoms and attitudes,' *Journal of Pain & Symptom Management*, published online 30 December 2016. [Noted in the 2 January 2017 issue of Media Watch (#493, p.18)] **Abstract:** <https://goo.gl/szW4u>

N.B. Additional articles on palliative and end-of-life care for the homeless in the U.S. noted in this issue of Media Watch.

Specialist Publications

'Removing obstacles to a peaceful death' (p.11), in *The Elder Law Journal*.

'Palliative care leadership centers are key to the diffusion of palliative care innovation' (p.12), in *Health Affairs*.

'Will changes to Medicare payment rates alter hospice's cost-saving ability?' (p.12), in *Journal of Palliative Medicine*.

'A cross-sectional pilot study of compassion fatigue, burnout, and compassion satisfaction in pediatric palliative care providers in the U.S.' (p.10), in *Palliative & Supportive Care*.

International

'Homeless people with terminal illnesses could be offered automatic right to housing' (p.7), in *The Independent* (London, England).

Indiana law dealing with end-of-life medical decisions up for tweaking

INDIANA | Indiana News Service (Indianapolis) – 5 February 2018 – In 2013, lawmakers approved the Physician Orders for Scope of Treatment form, also known as the POST. It's different from a Do Not Resuscitate form in that it deals with the type of medical treatment for people with serious and terminal conditions. Susan Hickman, a professor in the Indiana University School of Nursing, says the current law creates confusion and delays in medical care for many patients. "This just allows them to have those orders recorded on the POST forms so that this plan of care can accompany patients across settings, and essentially supports the goal of the POST, which is to help assure continuity of care throughout the health care system," she explains. Current law requires a doctor's signature for a POST form to be legal. Under a bill ... an advanced practice nurse or physician assistant could also sign POST forms in collaboration with a patient. Patients also could electronically sign the paperwork. The POST form is a legal document that's binding and enforceable during medical emergencies, even if the patient is incapacitated. It will be heard in a Senate committee this month. <https://goo.gl/gzxaW6>

Legislation seeks proper disposal of "end-of-life" medications

KENTUCKY | 88.9 WEKU Radio (Richmond) – 5 February – Kentucky lawmakers are considering legislation to help prevent "end-of-life" pain medications from getting into the wrong hands. The measure is backed by Kentucky's palliative care groups. The legislation pertains to schedule two, three, four, and five controlled substances. That would include drugs like morphine, methadone, certain amphetamines, and over the counter prescriptions with codeine. The measure requires signing an agreement to properly dispose of these medications. If upon a death, the drugs are left in the home, law enforcement or public health officials would be notified. <https://goo.gl/fTZ5rX>

Noted in Media Watch 25 September 2017 (#531, p.5):

- PENNSYLVANIA | Lancaster Online – 17 September 2017 – '**Who's responsible for leftover home hospice care medications in Pennsylvania?**' State regulations forbid hospice personnel from disposing of leftover drugs. And that means that the medications belong to the person responsible for the patient's estate. And, after death, "as we're educating families about what to do next – what to do with the body, calling the funeral home, whether they want to bathe their loved one – we have the opportunity to address the issue of leftover medications." <https://goo.gl/JM5HmP>

Noted in Media Watch 29 May 2017 (#514, p.11):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2017;19(3):256-260. '**Hospice-appropriate universal precautions for opioid safety.**' Universal precautions for opioid safety is one approach to managing the epidemic of prescription pain medication misuse that has been used in pain clinics, primary care practices, and in some hospices. In this project, a set of hospice-appropriate universal precautions was designed, drawing on hospice nursing strengths, and implemented in a mid-size hospice agency. **Abstract:** <https://goo.gl/7Wg1TE>

Related

- FLORIDA | *The Palm Beach Post* – 3 February 2018 – '**Fast-acting morphine running low for hospice patients.**' The injectable morphine that hospice workers in Palm Beach County prefer to use when their patients are hit with intense pain is running out. The supply on hand in the last week of January would typically last only a week, but they are taking measures to stretch the inventory for a couple of months. The scarcity of the injectable may go on for months or even a year. An informal poll by the president of Florida Hospice & Palliative Care Association found similar supply crunches across the state and also in Michigan, New Jersey and rural Missouri. <https://goo.gl/rbQPjW>

Terminally ill people want more access to experimental treatments. Here's why doctors are pushing back

TIME MAGAZINE | Online – 5 February 2018 – Right-to-try laws have passed in some 38 states. While no one wants to argue against giving potentially beneficial drugs to people who need them, not everyone in the medical community is convinced a national right-to-try policy – which has been introduced in the House – will ultimately make life better for patients. The bill for the federal law was passed by Senate in August by unanimous consent. One of the biggest concerns with the federal right-to-try bill is that the Food & Drug administration (FDA) would be cut out of the loop. The bill would allow patients and their doctors to bypass the FDA process and work solely with drug companies for access to unapproved drugs that have undergone at least basic safety testing. <https://goo.gl/3VfEGD>

N.B. Additional articles on “right-to-try” laws noted in 29 January 2018 issue of Media Watch (#548, p.11).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- UTAH | *The Salt Lake Tribune* (Salt Lake City) – 7 February 2018 – **‘House passes bill which would criminalize assisted suicide – despite concerns it could target family members or physicians helping terminally ill patients.’** The Utah House passed a bill that would criminalize helping someone commit suicide – despite some concern from lawmakers that the bill could unintentionally target physicians or family members of terminally ill patients. House Bill 86 would amend Utah’s manslaughter statute to include assisted suicide. This means a person would be guilty of a second-degree felony – which is punishable by up to 15 years in prison – if prosecutors can prove he or she provided “the physical means” for someone to commit suicide. Utah currently doesn’t have any clearly defined assisted suicide laws ... and questions have been raised about whether helping someone commit suicide amounts to murder. <https://goo.gl/QkwbQJ>

Specialist Publications

‘Assisted dying in U.S. and Canada: Controversy subsides after legalisation’ (p.17), in *British Medical Journal*.

International

End-of-life care in England

End-of-life care profiles: Update

U.K. (England) | Public Health England – 6 February 2018 – The profiles are designed to improve the availability and accessibility of information around end-of-life care (EoLC). The data are presented in an interactive tool that allow users to view and analyse them in a user-friendly format. The profiles provide a snapshot overview of EoLC at various geographies. They are intended to help local government and health services to improve care at the end of life. This release includes an update of these indicators by Local Authority: 1) Place of death indicators (hospital, home, care home, hospice and other places by age); and, 2) Underlying cause of death indicators (cancer, respiratory disease and circulatory disease by age). **Download/view at:** <https://goo.gl/5JxTs5>

Specialist Publications

‘End-of-life care for infants, children and young people with life-limiting conditions: Planning and management – the National Institute for Health & Care Excellence guideline 2016’ (p.9), in *Archives of Disease in Childhood: Education & Practice*.

‘Medically timed death as an enactment of good death: An ethnographic study of three European intensive care units’ (p.17), in *Omega – Journal of Death & Dying*.

Integrated palliative care networks from the perspectives of patients: A cross-sectional explorative study in five European countries’ (p.15), in *Palliative Medicine*.

Cont.

Related

- U.K. (England) | *The Guardian* (London) – 6 February 2018 – ‘**Call for National Health Service to do more to help terminally ill people die at home.**’ The call by the National Institute for Health & Care Excellence comes after figures showed that fewer patients were dying in hospital and more were passing away at home or in a care home or hospice. Almost one in four of the 500,000 people a year who die in England do so at home. According to new data published by Public Health England (PHE) that is the highest figure for 12 years. The percentage of people dying in hospital fell by 11% over the same period, from 57.9% in 2004 to 46.9% in 2016, according to PHE’s latest end-of-life care profiles. <https://goo.gl/jiEAMM>

End-of-life care in Scotland

Terminally ill being failed over care needs

U.K. (Scotland) | *Third Force News* (Edinburgh) – 6 February 2018 – One in four Scots who have known a relative or close friend with a terminal illness said they did not get the care they needed. This figure is so high, believes Marie Curie, because services are not always shaped around the needs of the individual. The charity has carried out a survey which reveals that nearly one in three Scots (29%) are not confident that they would receive the high-quality care they need if they were diagnosed with a terminal illness. Its research shows that nearly two thirds of people blame lack of health service funding and an increase in the number of people living with terminal conditions for the failings. People also said they doubted Scotland’s health and care system because of an increase in the number of people having more than one terminal condition and less availability of high quality care at home. However, the survey results also show that Scots have more confidence in Scottish health and social care than they do in English health-care – over half (54%) believe that they would get better quality care in Scotland than they would in England. <https://goo.gl/QHH9NV>

Noted in Media Watch 29 January 2018 (#548, p.7):

- *BMC PALLIATIVE CARE* | Online – 26 January 2018 – ‘**Palliative and end-of-life care research in Scotland 2006-2015: A systematic scoping review.**’ The Scottish Government set out its 5-year vision to improve palliative care in its Strategic Framework for Action 2016-2021.¹ Areas highlighted for future research include palliative interventions for people with non-malignant illness and multi-morbidity; physical and psychological symptom assessment and management; interventions to support carers; and bereavement support. **Full text:** <https://goo.gl/CwMGZu>

1. ‘Strategic Framework for Action on Palliative & End-of-Life Care: 2016-2021,’ Scottish Government, December 2015. [Noted in the 21 December 2015 issue of Media Watch (#441, p.8)] **Download/view at:** <http://goo.gl/CKePjU>

N.B. Additional articles on palliative and end-of-life care in Scotland noted in the 20 November 2017 issue of Media Watch (#539, p.6).

Palliative Care Network

Updated 02.01.2018

Prison Hospice: Backgrounder

End-of-life care in the prison system has been high-lighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report can be downloaded/viewed at: <https://goo.gl/YLckx6>

World Cancer Day: Pakistan lacks treatment facilities

PAKISTAN | *The News International* (Rawalpindi) – 5 February 2018 – Cancer that has emerged as a major health threat in Pakistan claims not less than 50,000 deaths a year, but still Pakistan lacks badly the facilities for treatment and management of cancers and it is ironical that even the palliative care (PC) is not available to cancer patients across the country. According to health experts, PC that is considered as urgent humanitarian need for people with cancer in Pakistan may help people live more comfortably. It is important to mention that the federal government has been working out establishment of a cancer hospital in Islamabad, however, the scheme being added in the federal budgets for last five years has an unapproved status so far. According to Head of Community Medicine at CMH Lahore Medical College Pro-

fessor Muhammad Ashraf Chaudhry, PC is particularly required in places like Pakistan with a high proportion of patients with advanced stages where there is little chance of cure. <https://goo.gl/Y4PDuq>



The focus of a supplement to the February issue of the *Journal of Pain & Symptom Management* (Vol. 55(2):S1-180) is palliative care development in resource limited countries. **Supplement contents page:** <https://goo.gl/RPxYaN>

Noted in Media Watch 28 November 2016 (#489, p.10):

- *INDIAN JOURNAL OF MEDICAL ETHICS* | Online – 18 November 2016 – ‘**Palliative care in Pakistan.**’ Insufficient public healthcare facilities, poorly regulated private health sector, low budgetary allocation for health, improper priority setting while allocating limited resources, have resulted essentially in an absence of palliative care (PC) from the healthcare scene. This article traces the social and cultural perspectives in Pakistan with regards to accessing PC in the context of healthcare facilities available. **Full text:** <https://goo.gl/kJCECM>

Homeless people with terminal illnesses could be offered automatic right to housing

U.K. (England) | *The Independent* (London) – 5 February 2018 – Homeless people with terminal illnesses who are “dying on doorsteps” will be offered an automatic right to housing under new plans going before Parliament. Sir Ed Davey wants to tackle gaps in the law to make it easier for homeless people with cancer or long-term illnesses to get end-of-life care and stable housing. Under current laws, many people who are sleeping rough, living in hostels or staying on friends’ sofas are not automatically eligible for long-term housing if they are dubbed “intentionally homeless” – where the local authority deems they have other options. The Liberal Democrat MP wants to change the law to remove the “intentionally homeless” distinction for dying people

and use GP palliative care registers to flag up people who are expected to die in the next 12 months. It comes after the number of people sleeping rough in England hit record highs, as official data revealed 4,751 people were sleeping on the streets each night last autumn, a figure that has more than doubled since 2010.¹ <https://goo.gl/kmJsZw>

[U.S.A.](#)

‘**Homelessness and dying with dignity**’ (p.3), in *Tahoe Daily Tribune* (South Lake Tahoe, California).

1. ‘Number of homeless people sleeping on streets in England hits highest level on record,’ *The Independent*, 25 January 2018. <https://goo.gl/JEVpZz>

N.B. Additional articles on palliative and end-of-life care for the homeless in the U.K. noted in 4 December 2017 issue of Media Watch (#541, p.7).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Times* (London) – 8 February 2018 – ‘**Doctors urge legalisation of assisted dying.**’ Assisted dying has more support than ever in Britain and should be legalised, according to leading medical experts. Writing in *The British Medical Journal (BMJ)* they urged the British Medical Association to drop its opposition to assisted dying, where doctors provide or administer drugs to help patients end their lives.¹ Surveys have shown support from up to 80% of the public for a change in the law. A poll last October found 55% of doctors wanted it to be made legal, subject to safeguards. Fiona Godlee, the journal’s editor-in-chief, said: “The *BMJ* supports the legalisation of assisted dying. The great majority of the British public are in favour and there is now good evidence it works well in other parts of the world.” <https://goo.gl/kCcith>

1. ‘Assisted dying: It’s time to poll U.K. doctors,’ *British Medical Journal*, published online 8 February 2018.

Full text: <https://goo.gl/8joqLk>

Specialist Publications

Providing palliative care across the continuum to reduce readmissions from community settings

ANNALS OF LONGTERM CARE, 2018;26(1):27-32. A transition team was created to track each patient’s discharge disposition over the course of 12 months ... and any hospital readmission within 30 days of discharge. Frequent readmissions were identified for all patients, but special attention was paid to those discharged to a skilled nursing facility. Partnering with a health system’s community palliative care (PC) team allowed the authors to extend PC into partner facilities via a palliative nurse trained in communication skills to facilitate the transition of patients to hospice or community-based PC services as appropriate. Over the course of this year-long project, readmission rates for all PC patients decreased from 22% to 16%. In particular, readmission rates of patients being discharged to partner facilities decreased from 26% to 10%. This pilot project demonstrates an opportunity for collaboration between inpatient PC teams and community partners in order to improve care transitions and reduce hospital readmissions in this subset of patients. Full text: <https://goo.gl/mv7Hgd>

Journal Watch

‘An update on the “empirical turn” in bioethics: Analysis of empirical research in nine bioethics journals’ (p.17), in *BMC MEDICAL ETHICS*.

Related

- *PALLIATIVE MEDICINE* | Online – 5 February 2018 – ‘**Circumstances of hospital admissions in palliative care: A cross-sectional survey of patients admitted to hospital with palliative care needs.**’ Reducing hospital admissions has become a focus for high-income countries as they work to manage the financial implications of an ageing population. However, the circumstances by which patients with palliative care needs are admitted to hospital remain poorly understood. Those with a non-cancer diagnosis and those aged over 75 years were less likely to have hospice involved prior to the admission. Abstract: <https://goo.gl/Fok9jT>

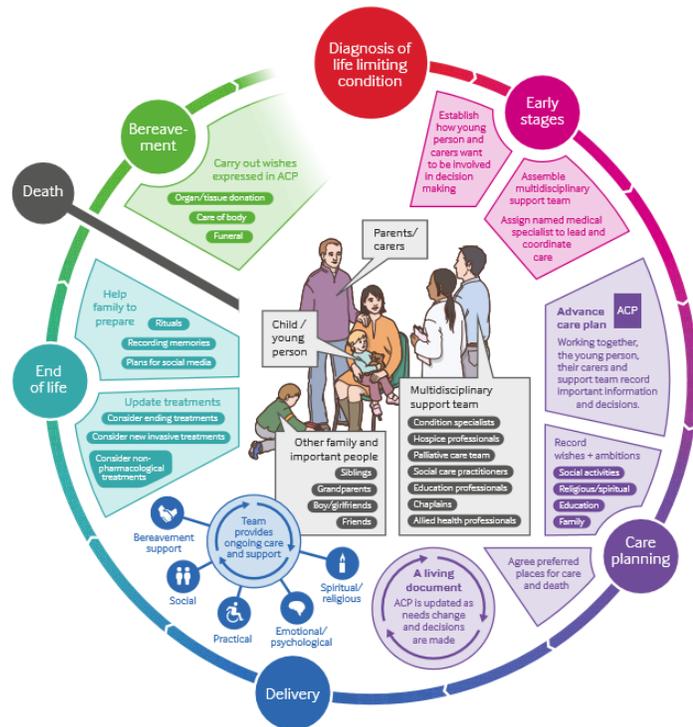
Palliative Care Network

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

End-of-life care for infants, children and young people with life-limiting conditions: Planning and management – the National Institute for Health & Care Excellence guideline 2016

ARCHIVES OF DISEASE IN CHILDHOOD: EDUCATION & PRACTICE | Online – 6 February 2018 – The guideline highlights the importance of a holistic approach to the care of infants, children and young people with life-limiting illnesses.¹ It recognises that care delivery to the infant, child and wider family needs to be consistent, responsive and seamless throughout childhood, despite unpredictable and variable disease trajectories. This needs to involve coordinated interdisciplinary team-working by health, education and social care providers from the public sector and non-statutory organisations, in geographically distinct care settings. Today, there are 49,000 infants, children and young people (0-18 years) living with life-limiting conditions in the U.K. The recommendations aim to support a wide variety of professionals, and infants, children and young people with life-limiting conditions and their families, with issues regarding end-of-life and palliative care. Guidance on basic symptom management, communication, advance care planning and service delivery is included. This is the first U.K. published guideline on this subject, but there have been several published frameworks, care pathways, drug formularies and symptom management guidelines in this. **Abstract:** <https://goo.gl/BCzVS>



1. 'End-of-life care for infants, children and young people with life-limiting conditions: Planning and management,' National Institute for Health & Care Excellence, December 2016. [Noted in the 12 December 2016 issue of Media Watch (#491, p.12). **Download/view at:** <https://goo.gl/8GLw37>

Related

- *CHILDREN* | Online – 7 February 2018 – '**Pediatric palliative care in infants and neonates.**' This article addresses the history, current considerations, and anticipated future needs for palliative and hospice care in the neonatal intensive care unit, and is based on recent literature review. Neonatologists have long managed the entirety of many newborns' short lives, given the relatively high mortality rates associated with prematurity and birth defects, but their ability or willingness to comprehensively address of the continuum of interdisciplinary palliative, end of life, and bereavement care has varied widely. While neonatology service capacity has grown worldwide during this time, so has attention to pediatric palliative care (PC) and, specifically, neonatal-perinatal PC. **Full text:** <https://goo.gl/GPkMRU>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 7 February 2018 – '**Predictors of late palliative care referral in children with cancer.**' Optimal timing for palliative care (PC) consultation is not standardized, and variables that influence timing of PC integration for children with cancer remain unknown. Hematologic malignancy, cancer-directed therapy at the end of life, and delayed advance directives documentation are associated with late PC involvement in children who died with cancer. Identification of these variables affords opportunities to study targeted interventions to enhance access to earlier PC resources and services for children with high-risk cancer and their families. **Abstracts:** <https://goo.gl/F8kcq8>

Cont.

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 6 February 2018 – ‘**Pediatric oncology provider perceptions of a pediatric palliative care service: The influence of emotional esteem and emotional labor.**’ The pediatric oncology providers in this study held a highly favorable opinion about their institution’s pediatric palliative care service (PPCS) and agreed that early consultation is ideal. However, they also described that formally consulting PPCS is extremely difficult because of what the PPCS symbolizes to families and the emotional labor that the provider must manage in introducing them. Interventions to encourage the early initiation of palliative care in this population may benefit from a focus on the emotional experiences of providers. **Abstract:** <https://goo.gl/qVmxhL>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 7 February 2018 – ‘**Physician perspectives on palliative care for children with advanced heart disease: A comparison between pediatric cardiology and palliative care physicians.**’ Both groups indicated pediatric palliative care (PPC) consultation occurs “too late.” PPC physicians reported greater competence in advance care planning, communication and symptom management. They more often described obstacles to PPC consultation as “many” or “numerous and overestimated how much pediatric cardiologists worry about PPC introducing inconsistency in approach, perceive lack of added value from PPC, believe PPC involvement will undermine parental hope, and perceive PPC is poorly accepted by parents. **Abstract:** <https://goo.gl/jifccs>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 5 February 2018 – ‘**A cross-sectional pilot study of compassion fatigue, burnout, and compassion satisfaction in pediatric palliative care providers in the U.S.**’ Compassion fatigue (CF) is secondary traumatic distress experienced by providers from contact with patients’ suffering. Burnout (BO) is job-related distress resulting from uncontrollable workplace factors that manifest in career dissatisfaction. Compassion satisfaction (CS) is emotional fulfillment derived from caring for others. The literature on BO in healthcare providers is extensive, whereas CF and CS have not been comprehensively studied. The prevalence of CF, BO, and CS was 18%, 12%, and 25%, respectively. **Abstract:** <https://goo.gl/Mhb4u6>
- *PEDIATRIC & BLOOD CANCER* | Online – 8 February 2018 – ‘**Perceptions of barriers and facilitators to early integration of pediatric palliative care: A national survey of pediatric oncology providers.**’ Most respondents agreed the palliative care team (PCT) does not negatively impact the role of the oncologist; however, there were concerns that optimal patient care may be limited by pediatric oncologists’ need to control all aspects of patient care. Furthermore, oncologists, more than any provider group, identified that the emotional relationship they form with the patients and families they care for influences what treatment options are offered and how these options are conveyed. Respondents reached consensus that early integration of a PCT would provide more potential benefits than risks and most would not limit access to palliative care based on prognosis. **Abstract:** <https://goo.gl/goZZUL>

End-of-life care in Australia

Carer experience of end-of-life service provision: A social network analysis

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 10 February 2018 – The results of the authors’ analysis revealed the relatively marginal positioning of formal service providers as perceived by informal networks. Despite these perceptions, opportunities arose in end-of-life (EoL) caring to build networks of support among family, friends, community and service providers. However, when palliative care (PC) practice focuses on actions for the physical comfort of the dying person and possibly their principal carers, and informal networks are preoccupied with relationships, there is a separation of agency and communion that is detrimental to the growth of social capital. The effective implementation of health-promoting palliative care (PC) policy would encourage a mutually enhancing relationship between agency and communion for anyone involved in EoL care. Although health-promoting PC is prescribed throughout state and national PC policies in Australia, the findings of this study confirm previous work with service providers showing health-promoting PC is not widely practised. However, the authors also found that formal service providers would like to engage with the health-promoting PC approach. On this basis, they recommend interventions be designed and evaluated for building stronger networks between formal and informal networks to relieve stress on the principal carer and improve the experiences of the dying person. **Full text:** <https://goo.gl/Q6XChL>

N.B. Additional articles on carer’s support networks noted in the 9 October 2017 issue of *Media Watch* (#533, p.12).

Focus: A moment for dying and death?

DISCOVER SOCIETY | Online – 6 February 2018 – Over 20 years ago, one of the contributors to this special edition, sociologist Tony Walter, asserted that the “revival of death” was underway. It seems he was right. A recent newspaper article describes “how death got cool.” It features burgeoning examples of contemporary death practices, from funerals as artistic expressions of a life well lived, to conversations taking place around the world in death cafes, the interest of young people in all things mortal, and the rise of a death acceptance collective to promote “the good death.” Lists of best-selling books can now include explorations of death, dying and bereavement, illness narratives, pathographies, and reflections by clinicians on how they encounter mortal illness, pain and suffering in the course of their work. Death literature, commentary and representation are pervasive in contemporary culture. Dying and death appear to be “having a moment.” Modernity’s construction of death as taboo, privatised, suppressed even, seems less convincing these days. We see less support for the argument that death is silenced, hidden, confined to institutions, the work of professionals or even “specialists’ in end-of-life care.” There is growing evidence that people want to talk about these things. Former silences

End-of-life care in the U.S.

Removing obstacles to a peaceful death

THE ELDER LAW JOURNAL | Online – Accessed 6 February 2018 – We all will die, but the American health care system often impedes a peaceful death. Instead of a quiet death at home surrounded by loved ones, many of us suffer through overutilization of sometimes-toxic therapeutic interventions long past the time when those interventions do more good than harm. This article proposes revisions to health professional training and payment policy to eliminate as much as possible physical and existential suffering while progressing through the terminal phase of illness. The solution lies in seamless progression from treatment with integrated palliative care (PC) to hospice before death, but provider attitudes and payor practices must change for that to occur. Thus, this article proposes increased training in communicating truthfully about prognosis and prospective benefit of therapies; further adoption of interprofes-

are giving way to new narratives, representations, constructions that “open up” discourses about human mortality and promulgate wider interest in the social aspects of dying, death and bereavement. **Full text:** <https://goo.gl/Y2xm3G>

DISCOVER SOCIETY

The contributors to the 6 February 2018 issue of *Discover Society* include members of the interdisciplinary End-of-Life Studies Group at the University of Glasgow. Topics/subjects include:

‘A look inside family life when someone is dying.’

‘It seems people don’t fear death, as much as they fear the process of dying.’

‘Advance care planning and societal ownership of death and dying.’

‘“Assisted dying” – what it is, where it’s practised, and what the future might hold.’

‘Dying in a hospital setting: it’s complicated.’

Access the full text of each of the articles at: <https://goo.gl/2J8DRV>

sional practice, which would familiarize more professionals with the team-based approach of PC; and, revision of payment mechanisms to incentivize high-quality care whether it is of low or high density. **Full text:** <https://goo.gl/oyz9r1>

Extract from *The Elder Law Journal*

Although access to palliative care (PC) in the U.S. is improving, many hospitals still lack PC programs. The latest research shows that 67% of hospitals with fifty or more beds have a PC program. In addition, PC programs are more prevalent in some regions of the country, such as the Northeast, than in others, leading to overall inadequate access to PC in certain places. Finally, there is a documented shortage of PC specialists overall, which creates an additional hurdle to access for many patients.

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Noted in Media Watch 5 October 2015 (#430, p.14):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 29 September 2015 – ‘**The growth of palliative care (PC) in U.S. hospitals: A status report.**’ This study demonstrates continued steady growth in the number of hospital PC programs in the U.S., with almost universal access to services in large U.S. hospitals and academic medical centers.¹ Nevertheless access to PC remains uneven and depends on accidents of geography and hospital ownership. **Full text:** <https://goo.gl/3bMMWu>

1. ‘America’s Care of Serious Illness: 2015 State-By-State Report Card on Access to Palliative Care in Our Nation’s Hospitals,’ Center to Advance Palliative Care & National Palliative Care Research Center, September 2015. **Download/view at:** <https://reportcard.capc.org/>

Noted in Media Watch 5 February 2018 (#549, p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 2 February 2018 – ‘**The growing demand for hospice and palliative medicine physicians: Will the supply keep up?**’ The current U.S. supply of hospice and palliative medicine (HPM) specialists is 13.35 per 100,000 adults 65 and over. Using alternate assumptions for future supply and demand, the authors project need in 2040 will range from 10,640 to almost 24,000 HPM specialist physicians. **Abstract:** <https://goo.gl/jPGwPB>

Related

- *HEALTH AFFAIRS*, 2018;37(2):231-239. ‘**Palliative care leadership centers are key to the diffusion of palliative care innovation.**’ Between 2000 and 2015 the proportion of U.S. hospitals with more than fifty beds that had palliative care (PC) programs tripled, from 25% to 75%. The rapid adoption of this high-value program, which is voluntary and runs counter to the dominant culture in U.S. hospitals, was catalyzed by tens of millions of dollars in philanthropic support for innovation, dissemination, and professionalization in the PC field. The authors describe the dissemination strategies of the Center to Advance Palliative Care in the context of the principles of social entrepreneurship, and they provide an in-depth look at its hallmark training initiative, Palliative Care Leadership Centers. Over 1,240 hospital PC teams have trained at the Leadership Centers to date, with 80% of them instituting PC services within two years. **Abstract:** <https://goo.gl/xhbCXD>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 7 February 2018 – ‘**Will changes to Medicare payment rates alter hospice’s cost-saving ability?**’ Medicare costs were reduced from hospice election until death using both 2009-2010 and new 2016 payment structures and rates. Mean cost savings were \$1,527 with actual payment rates, and would have been \$2,105 with the new payment rates. Cost savings were confirmed by reducing the number of days used for cost comparison by three days for those with hospice stays of at least four days. Cost savings were greater for males versus females and greatest in cancer followed by debility and failure to thrive and congestive heart failure; dementia patients had higher costs. When adding 3 days to the comparison period, hospice increased costs to Medicare. Medicare savings could continue with the 2016 payment rate change. Cost savings were found for all primary diagnoses analyzed except dementia. **Abstract:** <https://goo.gl/opN8XD>

Addressing spirituality during critical illness: A review of current literature

JOURNAL OF CRITICAL CARE, 2018;45(3):76-81. The purpose of this review is to provide an overview of research on spirituality and religiosity in the intensive care setting that has been published since the 2004-2005 ‘American College of Critical Care Medicine (ACCM) Clinical Practice Guidelines for the Support of Family in the Patient-Centered Intensive Care Unit’ with an emphasis on its application beyond palliative and end-of-life care. The guidelines emphasized the importance of spiritual and religious support in the form of four specific recommendations: 1) Assessment and incorporation of spiritual needs in ICU care plan; 2) Spiritual care training for doctors and nurses; 3) Physician review of interdisciplinary spiritual need assessments; and, 4) Honoring the requests of patients to pray with them. The authors reviewed 26 studies published from 2006 to 2016 and identified whether studies strengthened the grade of these recommendations. They further categorized findings of these studies to understand the roles of spirituality and religiosity in surrogate perceptions and decision-making and patient and family experience. **Abstract (w. list of references):** <https://goo.gl/Uow8bd>

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Noted in Media Watch 29 January 2018 (#548, pp.15-16):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 23 January 2018 – ‘**Spiritual care training in health-care: Does it really have an impact?**’ This study describes the impact of a spiritual care training program on practice and cultural change in a Canadian hospice. The authors’ data suggest the program had a profound personal impact on attendees and contributed to a slight shift in practice patterns in their organization. Using a program not specifically tailored to local and organizational cultural contexts resulted in some unanticipated challenges such as the range of tensions between personal and cultural boundaries. **Abstract (w. list of references):** <https://goo.gl/4DBeKQ>

Noted in Media Watch 1 January 2018 (#544, p.17):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 16 December 2017 – ‘**Developing a healing environment for broken souls of patients with life-threatening illnesses and their caregivers.**’ Patients with life-threatening illnesses can struggle with physical, emotional, and existential and spiritual concerns and the suffering of caregivers. A key goal of supportive and palliative care (PC) teams is to alleviate patient and caregiver suffering. Each member of the PC team becomes a single collective spirituality or soul with common goals, values, and belonging, with a main goal of providing the best care for patients and caregivers in the alleviation of suffering. **Abstract:** <https://goo.gl/53jf2z>

Noted in Media Watch 24 July 2017 (#522, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online 18 July 2017 – ‘**State of the science of spirituality and palliative care research: Research landscape and future directions.**’ Spirituality frequently plays a central and complex role in patients’ and families’ experiences of incurable illness, including influencing quality of life and medical decision-making. Advances in this field that expand the understanding of the relationships between spirituality and health outcomes and lead to the rigorous development of interventions to address patient and family spiritual needs hold tremendous potential for improving a comprehensive approach to care in serious illness. **Abstract:** <https://goo.gl/uNe8G3>

N.B. ‘Screen, assessment and interventions’ (Part 2 of this article). **Abstract:** <https://goo.gl/EiWqdd>

Family meetings in in-patient specialist palliative care: A mechanism to convey empathy

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 5 February 2018 – Families [i.e., study participants] reported more empathy from staff following a family meeting... Some families with relatives who do not speak with each other reported that meeting facilitators were unable to manage the pre-existing dynamics. It would be beneficial to have more specific preparation and planning by the clinical team for meetings with people who have a history of familial conflict, and those where the staff’s agenda is around discharge planning. Published guidelines could be adapted to better support staff to run meetings where there are complex family dynamics. Adoption of family meetings in outpatient settings has the potential to improve perceptions of empathy with a larger patient group. **Abstract:** <https://goo.gl/w8eXh5>

Noted in Media Watch 1 January 2018 (#544, p.24):

- *REVISTA BRASILEIRA DE ENFERMAGEM*, 2018;71(1):206-213. ‘**Family conference in palliative care: Concept analysis.**’ A family conference (FC), a therapeutic instrument used by the palliative care team, emerges as a moment of planned dialogue between patient, family and team. Although it is of particular importance, the FC is still less widespread among health professionals. In addition to the scarcity of studies, it can be seen that there is no single definition in the literature about FCs. **Full text:** <https://goo.gl/MjQwpi>

N.B. Full text of the *Revista Brasileira de Enfermagem* article is available in both Portuguese and English. Additional articles on family conferences/meetings in the context of palliative and end-of-life care noted in this issue of Media Watch..

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Related

- *BMC PALLIATIVE CARE* | Online – 5 February 2018 – ‘**Transitions as experienced by persons in palliative care circumstances and their families: A qualitative meta-synthesis.**’ This study shows how persons with palliative care needs and their families experience transitions in a palliative context. Maintaining normality, experiencing changing roles, and anticipating the future are central phenomena for these groups. Based on the model discussed, health care professionals can identify available resources and support the family in their self-management strategies. **Full text:** <https://goo.gl/YGH3C8>

Defining the scope of prognosis: Primary care clinicians’ perspectives on predicting the future health of older adults

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 5 February 2018 – The perspectives of primary care clinicians in this study confirm that prognostic considerations can go beyond precise estimates of mortality risk and life expectancy to include a number of outcomes and approaches to predicting those outcomes. They spoke about future health in terms of a variety of health outcomes in addition to life expectancy, including independence in activities and decision making, quality of life, avoiding hospitalization, and symptom burden. They described approaches in predicting these health outcomes, including making observations about the overall trajectory of patients to predict health outcomes and recognizing increased risk for adverse health outcomes. The participants in this study expressed reservations about using estimates of mortality risk and life expectancy to think about and communicate patients’ future health. They discussed ways in which future research might help them in thinking about and discussing patients’ future health to guide care decisions, including identifying when and whether interventions might impact future health. **Abstract:** <https://goo.gl/Aax1tX>

Islamic considerations on the application of patient’s autonomy in end-of-life decision

JOURNAL OF RELIGION & HEALTH | Online – 7 February 2018 – In end-of-life situation, the need for patient’s preference comes into the picture with the intention of guiding physicians in the direction of patient care. Preference in medical directive is made by a person with full mental capacity outlining what actions should be taken for his health should he loses his competency. This is based on the reality of universal paradigm in medical practice that emphasises patient’s autonomy. A specific directive is produced according to a patient’s wish that might include some ethically and religiously controversial directives such as mercy killing, physician-assisted suicide, forgoing life-supporting treatments and do-not-resuscitate. In the future, patient autonomy is expected to become prevalent. The extent of patient autonomy has not been widely discussed among Muslim scholars. In Islam, there are certain considerations that must be adhered to. **Abstract (w. list of references):** <https://goo.gl/ToQ8vT>

N.B. Selected articles on the Islamic perspective on end-of-life and end-of-life care noted in the 5 January 2018 issue of Media Watch (#549, p.8).

Sitting with silence in end-of-life cancer care

ONCOLOGY NURSE ADVISOR | Online – 8 February 2018 – Modern medicine with its emphasis on cure frequently discovers itself struggling with an array of challenges in end-of-life care (EoLC). Studies on the influence of compassionate silence in EoLC have indicated that clinicians’ focus solely on “doing” may actually be inappropriate at times and inhibit their ability to effectively address and meet the needs of the person who is terminally ill. A prominent theme was that the “do, fix, and hopefully cure” mandate in modern medicine may not be appropriate at the end of life and, in fact, may need to be balanced with the quality of being present with those who are suffering. Being “present” to patients who are nearing death therefore entails that clinicians possess a certain comfort level in terms of “sitting with the silence” and offering the “gift of presence.” The research of Back and colleagues¹ outlined three types of silences that

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can manifest between patients and clinicians in the clinical encounter: awkward, invitational, and compassionate. In regard to awkward silences, they write, “silence most often feels like it is dragging on too long when a well-meaning clinician thinks he should be ‘using silence.’ While we recognize that new skills have a learning curve before they can be performed smoothly, we also think that the problem with a directive to stop doing something is unlikely to produce the quality of silence that is actually therapeutic.” **Full text:** <https://goo.gl/U7Nrs4>

1. ‘Compassionate silence in the patient–clinician encounter: A contemplative approach,’ *Journal of Palliative Medicine*, 2009;12(12):1113-1117 (first published online 21 August 2009). [Noted in the 24 August 2009 issue of *Media Watch* (#111, p.5)] **Abstract:** <https://goo.gl/DNuVxy>

Noted in *Media Watch* 14 August 2017 (#525, p.5):

- *PALLIATIVE MEDICINE* | Online – 8 August 2017 – ‘**Silence as an element of care: A meta-ethnographic review of professional caregivers’ experience in clinical and pastoral settings.**’ Silence is acknowledged as integral to interpersonal communication and compassionate care, but is also noted as a complex and ambiguous phenomenon. International, interdisciplinary research and opinion endorses the value of silence in clinical care. As a multi-functional element of interpersonal relationships, silence operates in partnership with speech to support therapeutic communication. As a caregiving practice, silence is perceived as particularly relevant in spiritual and existential dimensions of care when words may fail. **Abstract:** <https://goo.gl/aXHib8>

Integrated palliative care networks from the perspectives of patients: A cross-sectional explorative study in five European countries

PALLIATIVE MEDICINE | Online – 5 February 2018 – Although examining perspectives of patients on integrated palliative care (PC) organisation is essential, available literature is largely based on administrative data or healthcare professionals’ perspectives. The authors recruited 157 patients from 23 integrated PC initiatives in Belgium, Germany, the U.K., Hungary and The Netherlands. About 33% reported contact with a PC specialist and 48% with a PC nurse. Relationships with PC specialists were rated significantly higher than other physicians. Compared to patients with cancer, patients with chronic obstructive pulmonary disease and chronic heart failure had significantly lower odds of reporting contact with PC specialists and patients with chronic obstructive pulmonary disease had significantly lower odds of reporting contact with PC nurses. Perceptions of main responsible healthcare professionals or caregivers in patient’s care networks varied across countries. Perceived integration was significantly associated with overall satisfaction. Expert PC involvement needs to be explicated especially for non-cancer patients. One healthcare professional should support patients in understanding and navigating their PC network. Patients seem satisfied with care provision as long as continuity of care is provided. **Full text:** <https://goo.gl/5Rj7yP>

Noted in *Media Watch* 6 April 2015 (#404, p.7):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 31 March 2015 – ‘**Palliative care patients’ perceptions of the work involved in understanding and managing the network of care provision surrounding them.**’ The main theme of “patient work – their strategies and project management” is presented. Sub-themes included: being organised and keeping records; planning ahead and coordinating care; information gathering; understanding the hierarchy and knowing who the key people are; strategies to remember names and roles; understanding and “working the system.” Challenges faced by patients and families included limited information; uncertainty when care is transferred between different teams or locations; deciding who to contact and how; and negotiating through gatekeepers. **Abstract:** <https://goo.gl/rVesfJ>

Family carers' experiences of coping with the deaths of adults in home settings: A narrative analysis of carers' relevant background worries

PALLIATIVE MEDICINE | Online – 5 February 2018 – Internationally, evidence on the support needs of family carers who look after a terminally ill adult in home settings is incomplete. Carers were interviewed in their home setting, having been purposively recruited via general practitioner practices in two study sites in England. Evidence is provided on the importance of what the authors conceptualise as carers' "relevant background worries"; these varied in nature, significance and impact. Four case studies are presented where these worries constituted psychosocial factors that impacted on caregivers' actions and emotional well-being. Two themes are discussed: 1) Whether relevant background worries are important enough to be identified and responded to; and 2) How such worries could be picked up and managed by professionals. It is argued that the quality of clinical practice could be improved if specialist palliative care teams in community contexts both identified and responded to significant support needs associated with family carers' relevant background worries. **Abstract:** <https://goo.gl/D5FZLH>

Open communication strategies between a triad of "experts" facilitates death in usual place of residence: A realist evaluation

PALLIATIVE MEDICINE | Online – 5 February 2018 – In order to meet policy drivers on death in usual place of residence, it is key to understand how shared decision-making can be facilitated in practice. An integrated care pathway was implemented in primary care in the North East of England to facilitate death in usual place of residence. Death audit data of 4,182 patients were readily available from 14 general practitioner practices. Three focus groups were conducted with primary and secondary care staff, voluntary sector organisations and care home representatives. Interviews with bereaved relatives were carried out in participants' homes. An empirically supported theory of how, for whom and in which circumstances death in usual place of residence happens is provided, which has important implications for both policy and practice. **Abstract:** <https://goo.gl/ZjXQgn>

Related

- *PSYCHO-ONCOLOGY* – 5 February 2018 – '**Physicians' emotion regulation during communication with advanced cancer patients.**' The authors investigated physicians' emotion regulation during communication with advanced cancer patients, in relation to physicians' (stress, training, and alexithymia) and patients' (sadness, anxiety, and alexithymia) characteristics. Physicians [i.e., study participants] used several defence mechanisms when communicating with their patients. Overall defensive functioning was negatively related to physicians' alexithymia. The number of defence mechanisms used was positively related to physicians' stress and alexithymia as well as to patients' sadness and anxiety. Neither physicians' experience and training nor patients' alexithymia were related to the way physicians regulated their emotions. The study generated several hypotheses on how physicians' emotion regulation relates to contextual variables during health care communication in cancer care. **Abstract:** <https://goo.gl/SWdv1F>

Dying in care homes, when advance care planning requires wraparound care

PALLIATIVE MEDICINE, 2018;32(2):312-313. Entry to a care home often occurs when other services are no longer appropriate. The older person is unlikely to benefit from curative treatments, and their needs have exceeded what can be provided within their home. It also signals someone is in the last year(s) of life. There are growing programmes of research work that articulate well the palliative care (PC) needs of residents and tested and developed education and training interventions that are context-specific and dementia-sensitive. Less well articulated is how the different configurations of services that work with and around care homes improve, sustain or hinder end-of-life care (EoLC) provision to care home residents. What kind of infrastructure and "wraparound" support is needed to ensure continuity, consistency and management of the inevitable uncertainties that arise when providing PC to this population? Care homes

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as standalone organisations often nurture relationships over time with visiting PC generalists and specialists including doctors, nurses, therapists and social workers. The quality of these associations however are highly variable and range from episodic, reactive resident specific encounters to those that have the capacity to discuss and jointly plan EoLC services. Evidence suggests interventions that facilitate integrated working, that breakdown narratives of “them and us” can reduce duplication of effort, improve use of urgent and emergency services and foster reciprocal working. **Full text:** <https://goo.gl/mYeH3x>

Noted in Media Watch 29 January 2018 (#548, p.12):

- *BMC GERIATRICS* | Online – 25 January 2018 – ‘**Description of an advance care planning intervention in nursing homes: Outcomes of the process evaluation.**’ This study provides detailed descriptions of the implementation process, the definition of successful implementation and information on the involvement of staff, which facilitates replicability and meaningful comparisons with future studies as well as the adaptability of the knowledge to the clinical field. **Full text:** <https://goo.gl/cFrq8F>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BRITISH MEDICAL JOURNAL* | Online – 7 February 2018 – ‘**Assisted dying in U.S. and Canada: Controversy subsides after legalisation.**’ What happens when the law changes to allow some terminally ill people to choose how and when they die? The author reports on doctors’ and public attitudes in the North American jurisdictions that allow medical aid in dying. More than a quarter of Americans and Canadians now have the option of choosing a medically assisted death. California and Canada legalised the procedure in 2016, following five other U.S. states and Washington, DC, in offering terminally ill patients access to drugs to induce death if they meet strict legal criteria. Although plans to adopt assisted dying have caused much controversy, most places have found that once the political decision has been made this tends to subside. The pattern has been repeated many times, beginning 20 years ago in the state of Oregon. **Full text:** <https://goo.gl/LfhKPf>

N.B. Several recent postings on the journal website focus on “assisted dying”: <https://goo.gl/iisvpZ>

- *OMEGA – JOURNAL ON DEATH & DYING* | Online – 5 February 2018 – ‘**Medically timed death as an enactment of good death: An ethnographic study of three European intensive care units.**’ Intensive care is a domain of contemporary biomedicine centered on invasive and intense efforts to save lives in acute, critical conditions. It echoes our culture’s values of longevity. Nevertheless, mortality rates are elevated. Many deaths follow from non-treatment decisions. Medicalized dying in technological medical settings are often presented as unnatural, impersonal, and undesirable ways of dying. How does this affect the way in which death is experienced by intensive care professionals? What might the enactment of dying in intensive care reveal about our cultural values of good and bad dying? **Abstract:** <https://goo.gl/81bdNe>

Journal Watch

An update on the “empirical turn” in bioethics: Analysis of empirical research in nine bioethics journals

BMC MEDICAL ETHICS | Online – 7 February 2018 – In the quarter century of data now available from the nine bioethics journals studied in two separate reviews, the amount of empirical publications continues to increase, albeit at a reduced pace, indicating a trend toward empirical research in bioethics. The findings that the authors have so far illustrate that the field is not and will possibly never be a solely normative field again. They also conclude that this trend noted so far from the nine journals captured is driven by two journals (*Journal of Medical Ethics* and *Nursing Ethics*). Hence, seven of the nine bioethics journals evaluated in two reviews continue to be normatively oriented and publish much greater propor-

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tions of non-empirical manuscripts than empirical research in bioethics. Thus, to truly capture the scope and nature of “empirical turn in bioethics,” studies examining a wider range of journals, including new and emerging bioethics journals as well as empirical bioethics work in non-bioethics journals will be necessary. These studies would provide valuable information to further map the field of empirical work in bioethics and may result in future studies that delve into the debate about the methodological questions related to the rigor of empirical methods used, and when and how the integration of the normative and the empirical can be done. **Full text:** <https://goo.gl/MiqwTQ>

**Topics examined in empirical manuscripts published in the nine bioethics journals reviewed
(Topics specific or related to end-of-life care highlighted. *BRA*)**

Main topic	Frequency
Informed consent (including information provision and participation)	106
Palliative care, Euthanasia, Assisted Suicide	99
Theoretical perspectives on ethical behaviors	75
Medical communication and decision making	72
Ethics education and training	67
Professional ethics	67
Research ethics	60
Care ethics	52
Caring for vulnerable groups	49
End of life decision making	47
Genetic research and testing	34
Relationships (doctor-patient/Professional-professional)	33
Healthcare organization and resource allocation	32
Confidentiality and privacy	30
Dignity and Autonomy	30
Public health ethics	23
Organizational climate	23
Organ donation and transplantation	20
Religion and culture	20
Death/Suicide/Autopsy	14
Reproductive ethics	14
Involuntary care	12
Ethics of various broad disciplines	9
Quality of life	4
Other topics	15
TOTAL	1007

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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 'Aggregators' and 'Media Watch by Barry Ashpole'; see also 'Media Watch: Behind the Scenes' at <https://goo.gl/6vdk9v>]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/ZRngsv>

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

Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLqxy2>

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

[Scroll down to 'Additional Resources']

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[November/December 2017 issue (Scroll down to 'Vulnerable populations: From the homeless to the unbefriended)']

HUNGARY | Magyar Hospice Alapítvány: <http://goo.gl/5d1I9K>

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

Barry R. Ashpole
Guelph, Ontario CANADA

'phone: 519.837.8936
e-mail: barryashpole@bell.net