

## **Media Watch...**

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

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

**Effecting change in the illness experience: Scroll down to [Specialist Publications](#) and 'A question of trust: Does mistrust or perceived discrimination account for race disparities in advance directive completion?' (p.13), in *Innovation in Aging*.**

## **Canada**

### **Do-not-resuscitate requests rarely tracked or properly recorded**

ONTARIO | CBC News (Toronto) – 15 September 2017 – Shahnaz Azarbehi is one of an unknown number of Ontario residents who has completed a Do Not Resuscitate Confirmation Form,<sup>1</sup> which can be used outside of the hospital setting. In fact, in most provinces other than Quebec, there is no provincial database of similar documents that allow patients to articulate their CPR preferences. The Ontario form contains a list of interventions that will not be attempted including chest compression, defibrillation and artificial ventilation. It's filled out by a doctor or nurse, and it is the only document that allows paramedics and firefighters in Ontario to forgo CPR when attending to an incapacitated person. CBC News looked into how each jurisdiction deals with DNR outside a hospital setting and found differing approaches across jurisdictions – and sometimes within them. Quebec is the only jurisdiction where residents can add CPR preferences to a database that health-care professionals can access, but those preferences are limited to “common” health scenarios. Quebec's registry, launched June 2016, contained 12,314 names as of June this year. There is also the issue of accessibility during an emergency. Whether paramedics have access to the database is unclear. Quebec's Health Ministry says they can access it, but the Corporation des Paramédics du Québec says that isn't case. <https://goo.gl/JfMPTN>

1. 'Do Not Resuscitate Confirmation Form,' Ontario Ministry of Health & Long-Term Care (Emergency Health Services Branch): <https://goo.gl/wyrD3S>

### **Palliative care benefits both patients and families**

ONTARIO | *The Toronto Star* – 11 September 2017 – Unfortunately, many patients and their loved ones are missing out on the benefits of palliative care (PC). It's common to see PC as a last resort. In reality, research has shown it offers the most benefit when started soon after the diagnosis of a life-threatening illness and alongside medical treatment. Recently, the American Heart Association and the American College of Cardiology Foundation revised their guidelines recommending doctors integrate PC with treatment

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for advanced or life-threatening illnesses, such as congestive heart failure or chronic respiratory conditions.<sup>1</sup> More physicians have started offering this type of care earlier to patients with serious health conditions, but sometimes doctors feel uncomfortable mentioning it. If you or a loved one have a life-threatening illness and have not been advised about PC, don't be afraid to start the conversation with your healthcare team. They will likely be relieved you brought it up. A PC specialist may be brought on to assist. In smaller communities, family physicians who provide PC typically step into this role. No matter who is responsible, the first step is to communicate the patient's wishes for future health care (also known as advanced care planning). This is never an easy discussion, but the advance care plan influences the next steps. <https://goo.gl/Cdi1hX>

1. '2017 American College of Cardiology, American Heart Association & Heart Failure Society of America focused update of the 2013 American College of Cardiology & American Heart Association Guideline for the Management of Heart Failure,' *Journal of the American College of Cardiology*, 2017;70(6):776-803. **Full text:** <https://goo.gl/qmU5NC>

**N.B.** See also 'Palliative care and cardiovascular disease and stroke: A policy statement from the American Heart Association and the American Stroke Association,' *Circulation*, 2016;134(11):e198-e225. **Abstract:** <https://goo.gl/2u9mE2>

Noted in Media Watch 4 September 2017 (#528, p.9):

- *JOURNAL OF THE AMERICAN COLLEGE OF CARDIOLOGY*, 2017;70(10):1276-1289. '**How medicine has changed the end of life for patients with cardiovascular disease.**' Advances in medicine have changed how patients experience the end of life (EoL). Recommendations to improve EoL care for patients with cardiovascular disease include optimizing metrics to assess quality, ameliorating disparities, enhancing education and research in palliative care (PC), overcoming disparities, and innovating PC delivery and reimbursement. **Abstract:** <https://goo.gl/aagwMe>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE CATHOLIC REGISTER* | Online – 15 September 2017 – '**Canadian Mental Health Association policy "inevitably" bound to fail.**' Dr. Tim Lau, founding president of the Canadian Catholic Federation of Catholic Physicians' Societies, said he welcomes the Canadian Mental Health Association stand,<sup>1</sup> which supports existing laws that make it illegal to provide a medically assisted death to psychiatric patients. "However, court challenges will inevitably come, arguing that if suicide is an answer to suffering, why would mental suffering be a just reason to discriminate," Lau said in an email interview. "Since we opened this can of worms, it could be argued that it is a violation of the Charter of Rights & Freedoms. <https://goo.gl/eAMzAE>

1. 'Canadian Mental Health Association Position on Medical Assistance in Dying (MAiD),' 7 September 2017. <https://goo.gl/G1USUj>

## U.S.A.

### Caring at home for a child with cancer can leave family members with risky tasks

*THE WASHINGTON POST* | Online – 16 September 2017 – As more medical care shifts from hospital to home, families take on more complex, risky medical tasks for their loved ones. But hospitals have not done enough to help these families, said Amy Billett, director of quality and safety at the cancer and blood disorders center at the Dana-Farber Cancer Institute/Boston Children's Hospital. "The patient-safety movement has almost fully focused all of its energy and efforts on what happens in the hospital," she said. That's partly because the federal government does not require anyone to monitor infections that patients get at home. Even at the well-resourced, Harvard-affiliated cancer center, parents told Billett in a survey that they did not get enough training and did not have full confidence in their ability to care for their child at home. The center was overwhelming parents by waiting until the last minute to inundate them with instructions – some of them contradictory – on what to do at home, Billett said. <https://goo.gl/aLBss5>

## San Diego Hospice: The end of a journey

CALIFORNIA | KPBS Public Broadcasting (San Diego) – 15 September 2017 – It’s been a long goodbye for San Diego Hospice, an institution that helped people die with dignity and without pain. When Scripps Health announced last month it was getting out of the hospice business, it was the final chapter in a four-year saga to preserve the venerable institution. Scripps had tried to salvage the remains of San Diego Hospice – hiring its employees, taking in its patients and winning a bidding war to buy the Hillcrest facility: a building atop a hillside that had come to represent a legacy of end-of-life care that touched thousands. San Diego Hospice’s decades-long reputation couldn’t endure the beating it took when federal auditors began to ask whether the people it cared for were actually dying. In 2012, news of a two-year Medicare investigation into fraud at the hospice was made public, and it seemed no amount of damage control could stop its freefall. By 2013, the hospice declared bankruptcy and closed. Scripps believed it could pick up the pieces and continue the long tradition of training doctors in end-of-life care, as well as providing it to both young and old. <https://goo.gl/v1o5u5>

**N.B.** Articles noted in the 25 March 2013 issue of Media Watch (#298, p.2) provide additional background information on the San Diego Hospice.

## End-of-life decisions can be difficult. This doctor thinks “nudges” can help

PENNSYLVANIA | STAT – 14 September 2017 – For tax payments, “nudges” have helped municipalities increase revenues and decrease collection-related costs. For energy consumption, “nudges” have helped homeowners save money and utilities preserve capacity. But in health care, the technique has been slower to catch on. First described by the pioneering economists Richard Thaler and Cass Sunstein (who is also a legal scholar), a “nudge” is a way of framing a set of choices to essentially steer people toward a particular option without shutting out other options. Dr. Scott Halpern, a critical care physician at University of Pennsylvania who studies the ethics and effectiveness of nudges in health care, believes the technique can play a greater role in improving the patient experience. This is especially true, he said, for those living with serious illnesses, and who often struggle to make sound decisions at times of great emotional and physical complexity. <https://goo.gl/e1J4HW>

Noted in Media Watch 20 March 2017 (#504, p.7):

- *THE HASTINGS REPORT*, 2017;47(2):32-38. ‘**Justifying clinical nudges.**’ The most straightforward justification for nudge interventions is that they help people bypass their cognitive limitations – for example, the tendency to choose the first option presented even when that option is not the best for them – thereby allowing people to make choices that best align with their rational preferences or deeply held values. **Abstract:** <https://goo.gl/mDEMxg>

### Specialist Publications

‘**Integrative review of the literature on Hispanics and hospice**’ (p.9), in *American Journal of Hospice & Palliative Medicine*.

‘**Corporate investors increased common ownership in hospitals and the post-acute care and hospice sectors**’ (p.13), in *Health Affairs*.

‘**Patient-clinician communication: American Society of Clinical Oncology Consensus Guideline**’ (p.15), in *Journal of Oncology Practice*.

‘**Characteristics of older adults in primary care who may benefit from primary palliative care in the U.S.**’ (p.17), in *Journal of Pain & Symptom Management*.

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Noted in Media Watch 21 April 2014 (#354, p.8):

- *BMC MEDICAL ETHICS* | Online – 17 April 2014 – “**Nudge**” in the clinical consultation – an acceptable form of medical paternalism? The extremes of autonomy and paternalism are not compatible in a responsive, responsible and moral health care environment, and thus some compromise of these values is unavoidable. Nudge techniques are widely used in policy making and the authors demonstrate how they can be applied in shared medical decision making. **Abstract:** <https://goo.gl/wrlz2c>

## Making sense of California’s End-of-Life Option Act

CALIFORNIA | *Science of Caring* (University of California San Francisco) – 12 September 2017 – When Governor Jerry Brown signed California’s End-of-Life Option Act into law in 2015,<sup>1</sup> Barbara Koenig believed it presented the state with “a bioethics emergency.” A professor in School of Nursing’s Institute for Health & Aging and the director of the university’s bioethics program, Koenig was among those who convened a state-wide conference where stakeholders could begin to hash out their response to the controversial new law, before it went into effect in June 2016. The law allows terminally ill adults to request and receive aid-in-dying medications under specific circumstances. It has a 10-year sun-

set provision, at which point the law can either be revised or extended. Now, Koenig is leading a collaborative project to help California understand emerging best practices as well as the thorny ethical, legal and logistical challenges that have arisen in this first year of implementation. <https://goo.gl/G4ysyV>

### Specialist Publications

‘Giving voice to the voiceless: The Colorado response to unrepresented patients’ (p.14), in *Journal of Clinical Ethics*.

1. ‘End of Life Option Act,’ Center for Health Statistics & Informatics, California Department of Public Health. <https://goo.gl/siEafi>

## Hospice care is short and may start later than needed

CONNECTICUT | *Yale News* (Yale University, New Haven) – 12 September 2017 – Older adults are admitted to hospice for short duration despite experiencing symptoms months prior to the end of life (EoL), according to a Yale-led study.<sup>1</sup> The finding highlights the need for earlier hospice admission or other strategies to address increasing symptoms and disability at the EoL, the researchers said. The researchers found that cancer and advanced dementia were the conditions that most often resulted in hospice admission. Older adults who were frail were least likely to be admitted to hospice. The most common condition leading to death was frailty, followed by organ failure, advanced dementia, and cancer. The study also found that the duration of hospice care was less than 13 days for half of the study participants. This short duration suggests that healthcare providers might need to consider discussing referrals to hospice sooner with people who are approaching the end of their lives. Alternatively, providers may need to develop and test other ways to reduce the high burden of distressing symptoms and disability at the EoL, said the researchers. Referral to hospice at the EoL should be based on an older adult’s burden of pain and other distressing symptoms, suggest the researchers. <https://goo.gl/dum36j>

1. ‘Distressing symptoms, disability, and hospice services at the end of life: Prospective cohort study,’ *Journal of the American Geriatrics Society*, published online 12 September 2017. **Abstract:** <https://goo.gl/kHaRXh>

Noted in Media Watch 22 February 2016 (#450, p.3):

- DARTMOUTH INSTITUTE FOR HEALTH POLICY & CLINICAL PRACTICE (Dartmouth College, Lebanon, New Hampshire) | The Dartmouth Atlas Project – 17 February 2016 – ‘**Our parents, ourselves: Health care for an aging population.**’ Rates of hospice referral across the U.S. often do not reflect patient preferences, which tend to favor comfort measures over medical intervention. Referrals to hospice care that are done too late also adversely affect the quality of care, the reported experiences of patients and families, and their satisfaction with the health care system. <http://goo.gl/dcXa6C>

## Helping create a better death is a new doula concept

PENNSYLVANIA | *The Pittsburgh Post-Gazette* – 11 September 2017 – Doulas are taught to sit, talk with and – especially – listen to terminally ill people in a non-judgmental way. If it goes right, they learn about their lives, build a rapport and help them face whatever fears they may have about the future. They can do so without the baggage of family members or the requirements of hospice staff who may be on a busy schedule to provide personal care and pain relief before moving on to the next client. The end-of-life doula concept is new in southwestern Pennsylvania ... with New York and California among the still relatively rare places in the country where organizations like doulagivers provide detailed training for a fee. Doulas are more commonly associated with births; while employed in only a small minority of those, they are nonetheless accepted as providing non-medical emotional and educational support for new mothers. In either case – for births or deaths – doulas generally lack government certification or regulation and are paid by private resources rather than Medicare, Medicaid or other insurance. <https://goo.gl/sSw4dv>

Noted in Media Watch 10 April 2017 (#507, p.3):

- *USA TODAY* | Online – 7 April 2017 – ‘**Coming full circle, doulas now cradle the dying.**’ Doulas, an ancient Greek term that loosely means a woman helping another woman, have long comforted women during birthing. But the definition has broadened, and doula programs – a combination of male and female volunteers and paid certified staff – are increasingly helping elderly patients fulfill wishes to die at home rather than in hospitals or nursing homes. End-of-life doula specialists are now in at least a half-dozen states, including New York, Colorado and Texas. <https://goo.gl/ULkQbu>

**N.B.** Additional articles on “death doulas” or “death midwives” are noted in Media Watch 18 July 2016 (#471, p.1).

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MASSACHUSETTS | *The Boston Globe* – 14 September 2017 – ‘**Lawmakers to consider doctor-assisted-suicide bill.**’ The controversial issue of medical aid in dying will be the subject of a Public Health Committee hearing later this month as activists pursue additional end-of-life options through both the Legislature and the courts. The Joint Committee on Public Health announced ... that its hearing on 26 September will be devoted to the issue... It appears the committee is expecting the hearing will attract many observers because the committee has scheduled its hearing for two adjacent hearing rooms. <https://goo.gl/adrczY>

## International

### Funeral costs in the U.K.

#### **Families burying loved ones at home as funeral costs soar to over £4,000**

U.K. (England, Northern Ireland, Scotland & Wales) | *The Independent* (London) – 13 September 2017 – Families are opting for cheaper coffins, holding the wake at home and even burying loved ones in the garden to combat the soaring cost of a basic funeral, which has now risen to £4,078. The average cost of burying a loved one rose 4.7% last year and has more than doubled since researchers at SunLife began compiling their annual cost of dying report in 2004.<sup>1</sup> Funeral expenses have risen every year since then, leaving many families struggling to pay. The huge rise is more than three and a half times the rise in house prices over the same period, according to the research. <https://goo.gl/cDJnHM>

1. ‘Cost of Dying: A complete view of funeral costs over time’ (11<sup>th</sup> Edition), SunLife, September 2017. <https://goo.gl/67zDCR>

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Noted in Media Watch 24 April 2017 (#509, p.6):

- U.K. (England, Scotland & Wales) | iNews TV (London) – 16 April 2017 – ‘**Paupers’ funerals rise by 50% in four years.**’ The leap in numbers is attributed to the soaring cost of funerals and people’s savings dwindling as they live longer. Since 2011, cash-strapped authorities have faced an £8.8 million bill for “public health funerals” – an average of more than £60,000 for each town hall. <https://goo.gl/vAx6u2>

### End-of-life care in Ireland

#### **The number of people making “death plans” and living wills is too low**

IRELAND | *The Irish Times* (Dublin) – 12 September 2017 – Although eventual death is the one certainty in life, people are still reluctant to talk about it, let alone prepare for it. Even people who are prudent enough to make wills and set aside money for funeral costs may balk at making contingency plans for the unpalatable thought of being still alive but incapacitated. “We talk a lot about people not wanting to talk about death, but I think there is a second problem – people not wanting to listen to people talk about death,” says Jenny Kitinger, a professor of communications research at Cardiff University, Wales. Research has shown that it’s quite com-

mon for people over 70 being more willing to raise the subject, only to be hushed by their adult children. <https://goo.gl/s5eShK>

#### **Specialist Publications**

**‘The experience of palliative care service provision for people with non-malignant respiratory disease and their family carers: An all-Ireland qualitative study’** (p.13), in *Journal of Advance Nursing*.

**N.B.** Dr. Kitinger co-authored ‘Increasing understanding and uptake of advance decisions in Wales,’ a 2016 report commissioned by the Minister for Health & Social Services. <https://goo.gl/upiiFU>

### **Media Watch: Editorial Practice**

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

#### **Distribution**

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

#### **Links to Sources**

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

#### **Something Missed or Overlooked?**

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

## The rest of the U.K. should learn from Scotland and stop state “neglect” over preparation of death

U.K. (England, Northern Ireland, Scotland, Wales) | *The Herald* (Glasgow) – 11 September 2017 – A new report ...<sup>1</sup> says that Scotland is leading the way when it comes to “progressive policies” that support citizens’ end-of-life care, which the rest of the U.K. would do well to emulate. In a wide-ranging report, covering all aspects of death, dying and bereavement services, the authors suggest that the U.K. overall is ill-prepared in facing up to the realities of its ageing population and the care and support its people will require. But it highlights advances that have been made north of the border when it comes to re-establishing a vision of the welfare state that properly supports its citizens “to the grave.” It argues that Scotland has used powers and resources devolved to it through devolution to “grasp the nettle about the scale of the issue.” The authors suggest that more must be done to join-up policies and to share best practice. But the report says that despite the scale of the issue, for too long sensitive issues surrounding death and dying have been “pushed into the long grass, not featuring prominently in policy or parliamentary debates, absent from the airwaves, and barely registering in the public debate.” That has meant insufficient access to palliative care, lack of support for families whose children are dying, inadequate and badly reformed bereavement benefits and what it described as “growing funeral poverty.” It suggests public policies on death have evolved “piecemeal over decades and in silos,” leading to “significant variance in the quality and quantity of policy and guidance available throughout the country.” <https://goo.gl/AeALQd>

### Institute for Policy Research report

#### **“Postcode lottery” for dying children’s care, report finds**

U.K. (England, Northern Ireland, Scotland, Wales) | BBC News – 12 September 2017 – The Institute says that 49,000 children have life-limiting or life-threatening conditions in the U.K. According to children’s charity Together for Short Lives – which contributed to the report – seriously ill children are “being forgotten or ignored” by nearly one in ten clinical commissioning groups (CCGs) in England as important services are not being made available. Only 73% of CCGs provide palliative children’s nursing out of hours and at weekends, meaning children have to go into hospital rather than be treated in the community, the report found. <https://goo.gl/Gdm3tC>

### **NICE** National Institute for Health and Care Excellence

#### **End-of-life care for infants, children and young people, September 2017**

This quality standard, endorsed by National Health Service England, covers end-of-life care for infants, children and young people (from birth to 18 years) who have a life-limiting condition. Life-limiting conditions are those that are expected to result in an early death for the person. It also covers support for family members and carers. It describes high quality care in priority areas for improvement. <https://goo.gl/a3gLi4>

1. ‘Death, Dying & Devolution,’ Institute for Policy Research, University of Bath, September 2017. <https://goo.gl/FHj7oU>

Noted in Media Watch 7 August 2017 (#524, pp.5-6):

- U.K. (Scotland) | *The Scotsman* (Edinburgh) – 2 August 2017 – ‘**Scotland in top 10 countries for palliative care.**’ Scotland is in the top ten countries in Europe for levels of palliative care (PC), although a new study has said there remains “room for improvement.”<sup>1</sup> There are 23 specialist PC inpatient units in Scotland, containing a total of 349 beds. In addition, there are 27 specialist PC hospital support teams and 38 specialist PC home care teams. Relative to other European Union countries, Scotland ranked seventh for provision of specialist PC inpatient units and hospital support teams, and fifth for home care teams. Statistics for Scotland had only been included with U.K. data before, but the Scottish Atlas of Palliative Care ... means more detailed information is available.<sup>2</sup> <https://goo.gl/6xxSuT>

1. ‘The level of provision of specialist palliative care services in Scotland...,’ *BMJ Supportive & Palliative Care*, published online 2 August 2017. **Full text:** <https://goo.gl/JD4Yr3>
2. ‘Scottish Atlas of Palliative Care,’ End-of-Life Studies Group, University of Glasgow, September 2016. [Noted in Media Watch 26 September 2016 (#481, p.4)] <https://goo.gl/Sf3DCy>

## Why the Irish get death right

IRELAND | *The Guardian* (London, England) – 9 September 2017 – In the Anglo-Saxon world, death is a whisper. Instinctively we feel we should dim the lights, lower our voices and draw the screens. We want to give the dead dying and grieving room. We say we do so because we don't want to intrude. And that is true, but not for these reasons. We don't want to intrude because we don't want to look at the mirror of our own death. We have lost our way with death. On the Irish island ... death still speaks with a louder voice. Along with the weather reports of incoming Atlantic storms, the local Mayo country and western radio station runs a thrice daily deaths announcement enumerating the deaths and the funeral arrangements of the 10 or so daily freshly departed. There is even a phone line ... just so you can check up on those corpses you might have missed. There should be nothing strange about this. In the absence of war and catastrophe, humans across the planet die at an annual rate of 1%; 200,000 dead people a day, 73 million dead people a year. An even spread. It's happening all round you even as you read this article; the block opposite, the neighbouring street and your local hospital. If the local radio in London or New York did the same as that Mayo station, the announcer would have to read out the names of 230 dead strangers, three times a day, just to keep up. More shocking still then would be the discovery of another country where dying ... the living, the bereaved and the dead still openly share the world and remain bound together in the Irish wake. <https://goo.gl/JC8sEN>

Noted in Media Watch 21 December 2015 (#441, p.8):

- U.K. (Northern Ireland) | BBC News (Belfast) – 14 December 2015 – **'How can we wake our father in a nursing home?'** The traditional Irish wake is a gentle leave taking. It is a time for the soft flicker of candles, a crucifix, and crisp white linen cloths. The loved one's body is laid out in a quiet room; clocks are stopped at the moment of death, blinds are drawn down, friends and neighbours gather. It is a long night's vigil – a watch over the dead one. <https://goo.gl/sLw9cV>

Noted in Media Watch 15 February 2010 (#136, p.6):

- IRELAND | *The Irish Times* (Dublin) – 9 February 2010 – **'Recognising the beauty of an Irish lament.'** Whatever has been lost in Irish culture, the tradition of funeral going has not died. Attending funerals remains an integral part of cultural life. Funeral going is psychologically complex. It is comforting to those who mourn, recognition of the life of those who have died, and a celebration of their existence. <https://goo.gl/v96Cqj>

## Why people nearing the end of life need the same protection we offer children

U.K. | *The Conversation* – 7 September 2017 – In many societies, the **THE CONVERSATION** approach to end-of-life care requires us to continue as active and responsible citizens for as long as our mental capacities allow – to make choices about what kind of care we want, and where. In anticipation of losing capacity, people are urged to act responsibly and make preferences known in advance while they are still able. This approach to policy has not of course prevented a series of elder care scandals in hospitals and care homes in Britain. That is because these scandals were not about lack of choice, but about neglect and abandonment: patients not turned over in bed, food being left out of reach, residents not helped to the bathroom. Those with complex interacting conditions (typical of those without cancer who die in frail old age that most readers of this article will themselves face) too often get shunted around a complex health and social care system with, it seems, no one consistently in charge of their case. As well as badly structured and poorly funded health and social care systems, an underlying cause of these scandals may be traced to a blind spot in Western democracies. The single-minded valuing of individual autonomy fails those whose deteriorating body or mind compromises this very autonomy. <https://goo.gl/g3LQ7W>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW ZEALAND | TVNZ 1 News (Auckland) – 16 September 2017 – ‘**Two-thirds of Kiwis in favour of euthanasia for patients with terminal illness, Vote Compass results show.**’ Two thirds of New Zealanders are in favour of euthanasia, when it comes to patients with terminal illnesses. That’s according to data from 1 NEWS’ online election tool Vote Compass. The results show 68% of voters agreed, or strongly agreed with the statement: “Patients with terminal illnesses should be allowed to end their own lives with medicinal assistance.” Nineteen per cent of participants were opposed to euthanasia, with 12% neutral, and 1% undecided. The results follow a Colmar Brunton poll in July, which found 74% of eligible voters supporting euthanasia. <https://goo.gl/cNajNK>
- AUSTRALIA | *The Guardian Australia* (Surry Hills, New South Wales) – 13 September 2017 – ‘**Assisted dying laws to be debated in New South Wales and Victoria.**’ Australia’s two biggest states are about to debate contentious assisted dying laws, with Victoria’s bill expected to go to parliament next week and New South Wales’ (NSW) proposed law to be introduced on 21 September. Victoria’s health minister, Jill Hennessy, will introduce the bill, with full debate expected in October. In NSW, five MPs from across the political spectrum have developed a bill. The close timing with Victoria is coincidental and it is understood NSW may delay debating it in parliament until Victoria has considered its law. There have been dozens of attempts in state parliaments to legalise assisted dying or voluntary euthanasia, but none have succeeded since the Northern Territory’s historic legislation was overturned by the federal parliament in 1997. <https://goo.gl/jF8sbH>
- BELGIUM | *The Catholic Herald* (London, England) – 12 September 2017 – ‘**Belgian Brothers of Charity defy Vatican over euthanasia.**’ The group said in a statement that it “continues to stand by its vision statement on euthanasia for mental suffering in a non-terminal situation” and that they “emphatically believe” the practice is compatible with Catholic teaching. The group also claimed the decision had “come about starting from the Christian frame of thought” and that they “always take into account the shifts and evolutions within society.” Last month, Pope Francis approved a Vatican demand that Brothers of Charity must stop offering euthanasia by the end of August. <https://goo.gl/wV8Rmz>

## Specialist Publications

### Integrative review of the literature on Hispanics and hospice

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 15 September 2017 – The provision of optimal end-of-life care to Hispanics receiving hospice care requires familiarity with hospice-specific variables. For example, a preference for non-disclosure of terminal prognosis in some Hispanics is incongruous with traditional hospice practice. In addition, the Spanish word for hospice, “hospicio,” has negative connotations about abandonment of loved ones. Added to cultural considerations are socio-economic considerations. Many marginalized Hispanic individuals may experience distinct challenges when enrolling in hospice due to socio-economic hardships relating to poverty, citizenship, and lack of insurance. This systematic integrative review examines the research literature on Hispanics and hospice to report on the state of the science for this topic. Reviewed articles were identified systematically using computer research databases and inclusion and exclusion criteria. Of the 21 reviewed articles, many are survey and low-inference qualitative designs with limited validity and trustworthiness. Most survey instruments were not validated for Spanish language or Hispanic culture. None of the qualitative studies included theoretical sampling or follow-up interviews. Few study designs considered heterogeneity within the Hispanic population. Interpreting results cautiously, there is evidence that some Hispanics find some satisfaction with hospice care in spite of cultural incongruities and socioeconomic challenges. **Abstract:** <https://goo.gl/UaMshV>

**N.B.** Additional articles on end-of-life care in the Hispanic community in the U.S. are noted in the 8 May 2017 issue of Media Watch (#511, p.13).

## End-of-life care in Victoria, Australia

### **Locating advance care planning facilitators in general practice increases consumer participation**

*AUSTRALIAN FAMILY PHYSICIAN* (Urology), 2017;46(9):691-695. This study supports co-locating facilitators in general practice as an effective method for increasing advance care planning (ACP) participation. The authors agree with recommendations to incorporate ACP into routine healthcare practices, preferably when the person is medically stable and has time to reflect on their values and preferences.<sup>1</sup> Initiating and integrating ACP as part of routine assessments in general practice (e.g. health assessments for people aged 75 years and older introduced by the federal government) appears to be a sensible strategy for encouraging ACP conversations in general practice and subsequent referrals to ACP programs. The as estimate that less than 25% of consumers aged over 65 years in the Barwon region have participated in ACP despite more than 10 years of ACP endorsement and facilitation. Continued promotion and re-sourcing of ACP are required to “ensure people’s preferences are discussed, documented, actioned and reviewed by implementing advance care planning.”<sup>2</sup> **Full text:** <https://goo.gl/XkScm9>

1. ‘Advance care planning: Have the conversation. A strategy for Victorian health services 2014-2018,’ Department of Health & Human Services, Victoria, 2014. <https://goo.gl/8aGDA2>
2. ‘Victoria’s end of life and palliative care framework. A guide for high-quality end-of-life care for all Victoria,’ Department of Health & Human Services, Victoria, 2016. <https://goo.gl/DwwAi8>

#### **Related**

- BMJ Supportive & Palliative Care | Online – 16 September 2017 – ‘**Prospective comparative effectiveness cohort study comparing two models of advance care planning provision for Australian community aged care clients.**’ Case managers [i.e., study participants] were expected to initiate advance care planning (ACP) with all clients... Outcomes were quantity of new ACP conversations and quantity and quality of new advance care directives (ACDs). ACP was initiated with 65% of clients. However, fewer clients completed ACP, there was low numbers of ACDs, and document quality was generally poor. **Full text:** <https://goo.gl/d2Cbw3>

Noted in Media Watch 13 June 2016 (#466, p.7):

- AUSTRALIA (Victoria) | Palliative Care Victoria – 9 June 2016 – ‘**Parliament of Victoria inquiry into end-of-life choices.**’ The 440-page report of the Legal & Social Issues Committee of the Victorian Legislative Council conveys the complexity of the issues under consideration. Forty-nine recommendations are presented, which covers three main sections: 1) Towards a community based approach to PC; 2) Improving advance care planning; and, 3) Legalising assisted dying. The report recognises the value of palliative care (PC) and makes 28 specific recommendations to strengthen PC and end-of-life care across Victoria. **Full report:** <http://goo.gl/XDOvF5>

### **Continuation of non-essential medications in actively dying hospitalised patients**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 September 2017 – Non-essential medications continue to be administered to actively dying patients. Discontinuation of these medications may be facilitated by interventions that enhance recognition and consideration of patients’ actively dying status. In this study, five non-essential medications, clopidogrel, donepezil, glyburide, metformin and propoxyphene, were ordered in less than 5% of cases. More common were orders for simvastatin, calcium tablets, multivitamins, ferrous sulfate, diphenhydramine and subcutaneous heparin. Significant decreases were found for donepezil, propoxyphene, metformin and multivitamins. Orders for one or more non-essential medications were less likely to occur in association with palliative care consultation, do-not-resuscitate orders and orders for death rattle medication. Patients who died in an intensive care unit were more likely to receive a non-essential medication, as were older patients. **Abstract:** <https://goo.gl/jVWDzF>

**N.B.** Additional articles on discontinuation of potentially inappropriate medications at the end of life are noted in the 20 February 2017 issue of Media Watch (#500, p.14).

## Implementing person-centred approaches

*BRITISH MEDICAL JOURNAL* | Online – 11 September 2017 – Political and policy declarations now widely acknowledge that the individual should be at the heart of the health system. A person centred approach has been advocated on political, ethical, and instrumental grounds and is believed to benefit service users, health professionals and the health system more broadly. The underlying premise is that people requiring healthcare should be treated with respect and dignity, and that care should take into account their needs, wants, and preferences. However, although there is widespread agreement that person centredness is important, the concept itself remains subject to debate, with different perspectives attaching different meanings and with different implications. Studies exploring understanding of self management – a core component of a person centred approach – have shown that many outcomes important to people receiving care are rarely mentioned by health professionals. **Introduction:** <https://goo.gl/nVDRV5>

### Related

- *HEALTH POLICY* | Online – 8 September 2017 – ‘**An exploration of person-centred concepts in human services: A thematic analysis of the literature.**’ There is no common definition of what it means to be person-centred, despite being a core feature of contemporary health and human service policy, and this suggests that its inclusion facilitates further misunderstanding and misinterpretation. A common understanding and policy conceptualisation of person-centredness is likely to support quality outcomes in service delivery especially where organisations work across human service groups. **Abstract:** <https://goo.gl/W8r6fw>

## Palliative care in neuromuscular diseases

*CURRENT OPINION IN NEUROLOGY* | Online – 13 September 2017 – Most neuromuscular disorders (NMDs) are not amenable to curative treatment and would thus qualify for palliative care (PC). Amyotrophic lateral sclerosis is a relentlessly progressive disease, which leads to death about 2 years after onset due to respiratory muscle weakness. Increasingly, neurologists caring for these patients learn to apply the principles of PC. However, this does not yet apply to other well known and frequently occurring NMDs. There is sparse literature on PC in NMDs such as Duchenne muscular dystrophy, spinal muscular atrophy, muscular dystrophies, some congenital myopathies, Pompe's disease and myotonic dystrophy type 1. These NMDs are often associated with imminent respiratory insufficiency and/or heart failure leading to a reduced life expectancy. Reasons for underutilization may include misconceptions about PC amongst patients, family carers and healthcare professionals or lack of awareness of the usefulness of this approach in these severely affected patients and the possibilities of integration of palliative principles into care for children and adults with NMDs. **Abstract:** <https://goo.gl/Qs5Hxy>

Noted in Media Watch 7 August 2017 (#524, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 3 August 2017 – ‘**Integrating palliative care into neurology services: What do the professionals say?**’ The authors present survey results describing the current levels of collaboration between neurology and palliative care (PC) services and exploring the views of professionals towards a new short-term integrated PC service. Collaborations between the two specialties were reported as being “good/excellent” by 36% of neurology and by 58% of PC professionals. However, nearly half (45%) of neurology compared with only 12% of PC professionals rated current levels as being “poor/none.” **Abstract:** <https://goo.gl/UxpJfY>

**N.B.** Additional articles on palliative care for patients living with a neurological disease are noted in the 24 July 2017 issue of Media Watch (#522, p.14).



### 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.21.

## How to survive the medical misinformation mess

*EUROPEAN JOURNAL OF CLINICAL INVESTIGATION* | Online – 7 September 2017 – Most physicians and other healthcare professionals are unaware of the pervasiveness of poor quality clinical evidence that contributes considerably to overuse, underuse, avoidable adverse events, missed opportunities for right care and wasted healthcare resources. The medical misinformation mess comprises four key problems. First, much published medical research is not reliable or is of uncertain reliability, offers no benefit to patients, or is not useful to decision makers. Second, most healthcare professionals are not aware of this problem. Third, they also lack the skills necessary to evaluate the reliability and usefulness of medical evidence. Finally, patients and families frequently lack relevant, accurate medical evidence and skilled guidance at the time of medical decision-making. Increasing the reliability of available, published evidence may not be an imminently reachable goal. Therefore, efforts should focus on making healthcare professionals, more sensitive to the limitations of the evidence, training them to do critical appraisal, and enhancing their communication skills so that they can effectively summarize and discuss medical evidence with patients to improve decision-making. Similar efforts may need to target also patients, journalists, policy makers, the lay public and other healthcare stakeholders. **Abstract:** <https://goo.gl/gbjegV>

### Gaps in patients' understanding of palliative chemotherapy. Can we better communicate that treatment is not curative?

*EXPERT REVIEW OF QUALITY OF LIFE IN CANCER CARE* | Online – 11 September 2017 – Misunderstanding in cancer patients receiving chemotherapy is common; 50% of cancer chemotherapy is given with palliative intent. Many patients receiving chemotherapy for incurable cancer may not understand that chemotherapy is unlikely to be curative. Cancer patients expect to share treatment decisions with their oncologist. Provision of a question prompt list and endorsement by physicians enhances patient participation in consultations and promotes patient questions about prognosis. Audio-recordings of oncologist consultations with newly detected incurable cancer patients document that most patients were informed about the aim of cancer treatment and that their disease was incurable. Oncologists checked patient understanding in only 10% of consultations. **Abstract:** <https://goo.gl/9bsjhl>

#### Related

- *BMC MEDICAL RESEARCH METHODOLOGY* | Online – 13 September 2017 – **'Measuring the burden of treatment for chronic disease: Implications of a scoping review of the literature.'** Treatment burden (TB) represents the active work patients need to do including learning about treatments and their consequences, completing administrative tasks, such as paper work, adhering to complex treatment regimens, managing medications, changing lifestyle behaviours, visiting multiple health professionals, and undertaking medical and other laboratory tests, etc. TB is concerned with the negative experiences resulting from the process of undertaking treatment. **Full text:** <https://goo.gl/qyaYRJ>
- *EUROPEAN JOURNAL OF CANCER CARE* | Online – 11 September 2017 – **'Living with life-prolonging chemotherapy – control and meaning-making in the tension between life and death.'** The right use of palliative chemotherapy is a complex issue and there are many aspects to take into consideration. The main findings showed that the narrators [i.e., study participants] considered their lives worth living in spite of the treatment. They seemed to take control and build a new life on "what was left after the storm," and described how they found meaning living in the tension between life and death. **Abstract:** <https://goo.gl/fYRUrR>

Noted in Media Watch 5 June 2017 (#515, p.15):

- *THE ONCOLOGIST* | Online – 26 May 2017 – **'Curative, life-extending, and palliative chemotherapy: New outcomes need new name.'** Given the growing disconnect between names and expected outcomes with chemotherapy, the authors' recommend a re-naming such that the terms curative, life-extending, and palliative chemotherapy correspond to the current outcomes expected to result from the administration of chemotherapy. **Abstract:** <https://goo.gl/EnQ4j>

## Hospice care in the U.S.

### **Corporate investors increased common ownership in hospitals and the post-acute care and hospice sectors**

*HEALTH AFFAIRS*, 2017;36(9):1547-1555. The sharing of investors across firms is a new antitrust focus because of its potential negative effects on competition. Historically, the ability to track common investors across the continuum of health care providers has been limited. Thus, little is known about common investor ownership structures that might exist across health care delivery systems and how these linkages have evolved over time. The authors used data from the Provider Enrollment, Chain & Ownership System of the Centers for Medicare & Medicaid Services to identify common investor ownership linkages across the acute care, post-acute care, and hospice sectors within the same geographic markets. To the authors' knowledge, this study provides the first description of common investor ownership trends in these sectors. They found that the percentage of acute care hospitals having common investor ties to the post-acute or hospice sectors increased from 24.6% in 2005 to 48.9% in 2015. These changes have important implications for antitrust, payment, and regulatory policies. **Abstract:** <https://goo.gl/UoC59P>

### **A question of trust: Does mistrust or perceived discrimination account for race disparities in advance directive completion?**

*INNOVATION IN AGING* | Online – 7 September 2017 – Advance directive (AD) completion is associated with end-of-life quality indicators such as dying at home and receiving hospice care. Black older adults are less likely to complete ADs than their white counterparts. The underlying reasons for these race disparities are not well understood. In two related studies, data from the Health & Retirement Study were used to examine whether mistrust in health care providers and/or perceived discrimination accounted for lower rates of AD completion by black older adults in the U.S. In Study 1, controlling for medical mistrust did not reduce the gap between black and white participants' odds of possessing ADs. In Study 2, higher percentages of black participants reported experiencing medical and non-medical discriminatory treatment. However, none of the measures of discrimination accounted for black participants' lower odds of possessing ADs. These results call into question the common assertion that mistrust in medical providers or the health care system contributes to lower rates of advance care planning by black older adults. Future research should examine the potential relationships between advance AD completion and other dimensions of discrimination. **Abstract:** <https://goo.gl/4yQR2k>

Noted in Media Watch 17 April 2017 (#508, p.10):

- *JOURNAL OF RACIAL & ETHNIC HEALTH DISPARITIES* | Online – 13 April 2017 – **'Reversing racial inequities at the end of life: A call for health systems to create culturally competent advance care planning programs within African American communities.'** Racial and cultural barriers inherent in health systems have made the delivery of culturally relevant end-of-life (EoL) care that aligns with patient preferences a particular challenge across African American patient populations. The (EoL) experience has been cited as a public health crisis by the Institute of Medicine,<sup>1</sup> and this crisis is one felt even more acutely by patients of this minority race. **Abstract:** <https://goo.gl/FvKT3m>

1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in Media Watch 22 September 2014 (#376, p.4)] **Full report:** <http://goo.gl/mm4o6W>

### **The experience of palliative care service provision for people with non-malignant respiratory disease and their family carers: An all-Ireland qualitative study**

*JOURNAL OF ADVANCE NURSING* | Online – 14 September 2017 – Globally, palliative care (PC) is recommended as an appropriate healthcare option for people with advanced non-malignant lung disease. Yet, there is limited evidence regarding the integration of PC for this client group. Carers' interviews yielded three overarching themes: 1) Lack of preparedness for death, due to ambiguity regarding disease

Cont.

trajectory; 2) Lack of consistency in PC delivery, in relation to the receipt of generalist and specialist PC; and, 3) Role ambiguity, related to their caregiving role. Focus groups identified two overarching themes: 1) Barriers to appropriate PC; and, 2) The future direction of PC for patient with non-malignant respiratory disease. The uncertain disease trajectory was not only experienced by carers but also healthcare professionals. Although referral to specialist PC services was perceived as increasing, the availability and coordination of generalist and specialist PC services were fragmented and varied dependent on geographical location. **Abstract:** <https://goo.gl/MTuz4v>

### **Giving voice to the voiceless: The Colorado response to unrepresented patients**

*JOURNAL OF CLINICAL ETHICS*, 2017;28(30):204-211. Medical decision making on behalf of unrepresented patients is one of the most challenging ethical issues faced in clinical practice. The legal environment surrounding these patients is equally complex. This article describes the efforts of a small coalition of interested healthcare professionals to address the issue in Colorado. A brief history of the effort is presented, along with discussion of the legal, ethical, practical, and political dimensions that arose in Colorado's effort to address decision making for unrepresented patients through an extension of the existing Colorado Medical Treatment Decision Act. A discussion of lessons learned in the process is included. **Abstract:** <https://goo.gl/XuuJ47>

#### **Selected articles on decision-making for “unbefriended” or “unrepresented” patients**

- *JOURNAL OF BIOETHICAL INQUIRY* | Online – 6 March 2017 – ‘**The role of a hospital ethics consultation service in decision-making for unrepresented patients.**’ Despite increased calls for hospital ethics committees to serve as default decision-makers about life-sustaining treatment for unrepresented patients who lack decision-making capacity or a surrogate decision-maker and whose wishes regarding medical care are not known, little is known about how committees currently function in these cases. [Noted in Media Watch 13 March 2017 (#503, p.11)] **Abstract:** <https://goo.gl/iRHu1y>
- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 22 November 2016 – ‘**American Geriatrics Society position statement: Making medical treatment decisions for unbefriended older adults.**’ The authors define unbefriended older adults as patients... Given the vulnerable nature of this population, clinicians, health care teams, ethics committees and other stakeholders working with unbefriended older adults must be diligent when formulating treatment decisions on their behalf. [Noted in Medias Watch 28 November 2016 (#489, p.11)] **Abstract:** <https://goo.gl/68dZQy>
- *NEW ENGLAND JOURNAL OF MEDICINE*, 2013;369(21):1976-1978. ‘**Making medical decisions for patients without surrogates.**’ People who are decisionally incapacitated, but haven't provided advance directives and have no health care surrogates, are some of the most powerless and marginalized members of society. Most are elderly, homeless, mentally disabled, or socially alienated. Medical decision making for these vulnerable patients often lacks even minimally sufficient safeguards and protections. [Noted in Media Watch 25 November 2013 (#333, p.9)] **Abstract:** <https://goo.gl/43cGHY>

### **Burnout in palliative care settings compared with other settings: A systematic review**

*JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2017;19(5):442-451. Of the 539 studies retrieved, 7 cross-sectional studies were included in this review. Of these, six were conducted with nurses, and six used the Maslach Burnout Inventory. Working in palliative care (PC) ... was associated with lower levels of emotional exhaustion and depersonalization, as well as higher levels of personal accomplishment, compared with working in other settings. Evidence indicates that burnout levels seem to be lower among professionals working in PC compared with professionals working in other settings. Further research is needed to explore the strategies used by nurses working in PC that help them deal with burnout and to apply these same strategies to professionals working in other settings. **Abstract:** <https://goo.gl/w5dZLC>

**N.B.** Additional articles on burnout in the context of hospice and palliative care are noted in the 21 August 2017 issue of Media Watch (#526, pp.3-4).

## Patient-clinician communication: American Society of Clinical Oncology Consensus Guideline

*JOURNAL OF ONCOLOGY PRACTICE* | Online – 11 September 2017 – The systematic review included 47 publications. With the exception of clinician training in communication skills, evidence for many of the clinical questions was limited. Draft recommendations underwent two rounds of consensus voting before being finalized. In addition to providing guidance regarding core communication skills and tasks that apply across the continuum of cancer care, recommendations address specific topics, such as discussion of goals of care and prognosis, treatment selection, end-of-life care, facilitating family involvement in care, and clinician training in communication skills. Recommendations are accompanied by suggested strategies for implementation. **Abstract:** <https://goo.gl/rcZ2Rn>

### Related

- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 7 September 2017 – ‘Talking about death.’ Cancer is a human drama, an existential crisis for patients, their loved ones, and the health care team who cares for them and for one another. For all our progress, we still die, and most of us have an awkward relationship with that reality. We have trouble talking about it. It is scary and uncomfortable. So we talk instead about taking the brakes off the immune system and turning off the signals that allow the cancer to grow. **Abstract:** <https://goo.gl/yMzx3n>

## The nexus between the documentation of end-of-life wishes and awareness of dying: A model for research, education and care

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 15 September 2017 – The convergence of medical treatment that can extend life with written medical orders that make it possible to refuse such treatment brings the differential dynamics of contemporary end-of-life (EoL) decision-making into sharp focus. Communication between families and clinicians can be confusing, uncertain and pressured when death is imminent. These situations create distress that ultimately influences the EoL experience for people who are dying and those who care for them. This paper presents the analysis of the decisional dynamics that emerge from the intersection of the patient-family-provider awareness that death is near with the presence or absence of documentation of expressed wishes for end-of-life care. A heuristic analysis was conducted with data from three studies about urgent decision-making at the EoL. Four decisional contexts emerged from the intersection of awareness of dying and documentation of wishes: 1) Aware-documented; 2) Aware-undocumented; 3) Unaware-documented; 4) Unaware-undocumented. This generalizable model, which is agnostic of setting, can help clinicians more astutely recognize the clinical situation when death is imminent, assess patients and caregivers, and intervene to help focus conversation and direct decision-making. The model can also inform research, education and care for people in some of the most vulnerable moments of life. **Abstract:** <https://goo.gl/eX89Me>



### [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>



Media Watch: Behind the Scenes

<http://goo.gl/XDjHxz>

## Is there ever a role for the unilateral do not attempt resuscitation order in pediatric care?

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 12 September 2017 – Care for children as they near the end of life (EoL) is difficult and very complex. More difficult still are the decisions regarding what interventions are and are not indicated during these trying times. Occasionally, families of children who are nearing the EoL disagree with the assessment of the medical team regarding these interventions. In rare cases, the medical team can be moved to enact a do not attempt resuscitation (DNAR) order against the wishes of the patient's parents. The authors present one such illustrative case and discusses the ethical issues relevant to such challenging clinical scenarios. They posit that such a unilateral DNAR order is only appropriate in very limited circumstances in pediatric care. Instead, focus should be placed on open discussion between parents and members of the clinical team, shared decision-making, and maintenance of the clinician-parent relationship while simultaneously supporting members of the clinical team who express discomfort with parental

decisions. The authors propose an alternative framework for approaching such a conflict based on clinician-parent collaboration and open communication. **Abstract:** <https://goo.gl/Hkv4kJ>

### Looking after each other when a child dies

*ARCHIVES OF DISEASE IN CHILDHOOD* | Online – 13 September 2017 –The death of a child is obviously and necessarily a very hard thing for parents and siblings. It can also be difficult for the professionals looking after a child, and if the death takes place in hospital it will affect medical, nursing and other staff, both senior and junior. Child deaths in hospital happen in many ways: for example, the failed resuscitation of a desperately ill or moribund child in the emergency department; death in intensive care after some hours or days of highly invasive treatment; expected and unexpected deaths on paediatric wards; deaths of babies after longer or shorter episodes of neonatal intensive care and many others. **Introduction:** <https://goo.gl/7E8daJ>

Noted in Media Watch 26 June 2017 (#518, p.11):

- *PEDIATRIC EMERGENCY CARE* | Online – 12 June 2017 – ‘**An ethical justification for termination of resuscitation protocols for pediatric patients.**’ The aim of this article was to compare specific characteristics and outcomes among adult and pediatric out-of-hospital cardiac arrest patients to show that the existing literature warrants the design and implementation of pediatric studies that would specifically evaluate termination of resuscitation protocols. The authors also address the emotional and practical concerns associated with ceasing resuscitation efforts on scene when treating pediatric patients. **Abstract:** <https://goo.gl/EVA7sU>

**N.B.** See also ‘No small matter: Pediatric resuscitation,’ *Current Opinion in Critical Care*, 2017;23(3):193-198. The authors present advancements in pediatric cardiac arrest research, highlighting articles most relevant to clinical practice published since the latest international guidelines for cardiopulmonary resuscitation. **Abstract:** <https://goo.gl/AgdSjB>

### Related

- *BIOETHICS* | Online – 13 September 2017 – ‘**Family interests and medical decisions for children.**’ Medical decisions for children are usually justified by the claim that they are in a child's best interests. More recently, following criticisms of the best interests standard, some advocate that the family's interests should influence medical decisions for children, although what is meant by family interests is often not made clear. **Full text:** <https://goo.gl/6thho1>
- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 15 September 2017 – ‘**Pediatric-specific end-of-life care quality measures: An unmet need of a vulnerable population.**’ None of the current quality measures [in the U.S.] focus on the unique needs of dying pediatric patients and their caregivers. To evolve the existing infrastructure to better measure and report quality pediatric end-of-life (EoL) care, the authors propose two changes. First, They outline how existing adult quality measures may be modified to better address pediatric EoL care. Second, they suggest the formation of a pediatric quality measure EoL task force. These are the next steps to evolving EoL quality measures to better fit the needs of seriously ill children. **Abstract:** <https://goo.gl/GJIFE7>

## Utilization of hospice services in a population of patients with Huntington's Disease

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 12 September 2017 – Although the early and middle stages of Huntington's Disease (HD) and its complications have been well described, less is known about the course of late-stage illness. In particular, little is known about the population of patients who enroll in hospice. In this retrospective cohort study of electronic medical record data from 12 not-for-profit hospices in the U.S. from 2008 to 2012, patients with HD are admitted to hospice at a younger age compared to other patients (57 versus 76 years old), but have a significant symptom burden and limited functional status. Although hospice care emphasizes the importance of helping patients to remain in their homes, only a minority of these patients were able to die at home. **Abstract:** <https://goo.gl/WwQVB2>

**N.B.** Additional articles on end-of-life care for patients and family living with Huntington's disease are noted in the 19 June 2017 issue of Media Watch (#517, p.6)]

## Characteristics of older adults in primary care who may benefit from primary palliative care in the U.S.

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 12 September 2017 – Older adults with advanced illness and associated symptoms may benefit from primary palliative care (PC), but limited data exist to identify older adults in U.S. primary care to benefit from this care. Among visits by older adults to primary care [i.e., patient population studied], 7.9% of visits were related to advanced illness. A higher proportion of advanced illness visits was among males vs. females (8.9% vs. 7.2%) and adults aged 75 and older, non-Hispanic Whites (8.3%) and Blacks (8.2%) vs. Hispanic (6.7%) and non-Hispanic other (2.5%), dually eligible for Medicare and Medicaid, and from patient Zip Codes with lower median household incomes (below \$32,793). A higher percentage of visits with advanced illness conditions to primary care was COPD, CHF, dementia, and cancer, and symptoms reported with these visits were mostly pain, depression, anxiety, fatigue, and insomnia. In the U.S., approximately 8% of primary care visits among older adults was related to advanced illness conditions. Advanced illness visits were most common among those most likely to be socio-economically vulnerable and highlight the need to focus efforts for high quality PC for these populations. **Abstract:** <https://goo.gl/WpWa1V>

Noted in Media Watch 26 June 2017 (#518, p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 20 June 2017 – ‘**Awareness and misperceptions of hospice and palliative care: A population-based survey study.**’ Despite the documented benefits of palliative and hospice care on improving patients' quality of life, these services remain underutilized. Multiple factors limit the utilization of these services, including patients' and caregivers' lack of knowledge and misperceptions. **Abstract:** <https://goo.gl/FBn4ut>

## Recent progress in chaplaincy-related research

*JOURNAL OF PASTORAL CARE & COUNSELING*, 2017;71(3):163-175. In light of the continued growth of chaplaincy-related research, this paper presents an overview of important findings. The review summarizes research in six broad areas: 1) What chaplains do; 2) The importance of religion and spiritual care to patients and families; 3) The impact of chaplains' spiritual care on the patient experience; 4) The impact of chaplain care on other patient outcomes; 5) Spiritual needs and chaplain care in palliative and end-of-life care; and, 6) Chaplain care for staff colleagues. It concludes with a description of several innovative and important new studies of chaplain care and notes areas for future investigation. **Abstract:** <https://goo.gl/1RSrbH>

**N.B.** Selected articles on the role of chaplains in end-of-life care are noted in the 17 July 2017 issue of Media Watch (#521, pp.3-4).

## **Caring science conscious dying: An emerging metaparadigm**

*NURSING SCIENCE QUARTERLY*, 2017;30(1):58-64. Caring science is an extant theory of human relationship, guiding the profession of nursing with the understanding and application of a moral-ethical praxis that promotes, protects, and provides human dignity throughout the life continuum. Over the past 30 or more years, caring science has transformed nursing by calling for a heightened ethical perspective of human dignity in how nurses practice, educate, research, and evolve the profession. Conscious dying is a framework rooted in a human caring ontology, which strives to deepen the nurse healer's awareness in tending to a patient's dying and death, returning death to its sacred place in the cycle of life. **Abstract:** <https://goo.gl/dwYccf>

## **Effects of early integrated palliative care on caregivers of patients with lung and gastrointestinal cancer: A randomized clinical trial**

*THE ONCOLOGIST* | Online – 11 September 2017 – The family and friends (caregivers) of patients with advanced cancer often experience tremendous distress. Although early integrated palliative care (PC) has been shown to improve patient-reported quality of life and mood, its effects on caregivers' outcomes is currently unknown. Early involvement of PC for patients with newly diagnosed lung and gastrointestinal cancers leads to improvement in caregivers' psychological symptoms. The findings of this trial demonstrate that the benefits of the early, integrated PC model in oncology care extend beyond patient outcomes and positively impact the experience of caregivers. These findings contribute novel data to the growing evidence base supporting the benefits of integrating PC earlier in the course of disease for patients with advanced cancer and their caregivers. **Abstract:** <https://goo.gl/6zmwGN>

## **End-of-life care in Finland**

### **The indirect costs of palliative care in end-stage cancer: A real-life longitudinal register- and questionnaire-based study**

*PALLIATIVE MEDICINE* | Online – 12 September 2017 – Healthcare costs have been reported to be highest during the last year of life, but studies on the actual costs of palliative care (PC) are scarce. In this study of cancer patients' resource use and costs, the mean duration of the PC period was 179 days. The healthcare cost accounted for 55%, informal care for 27%, and productivity costs for 18% of the total costs. The last two weeks of life contributed to 37% of the healthcare cost. The 45% share of indirect costs is substantial in end-of-life care. The healthcare costs increase towards death, which is especially true of patients living alone. This highlights the significant role of caregivers. More attention should be paid to home care and caregiver support to reduce inpatient care needs and control the costs of end-of-life care. **Abstract:** <https://goo.gl/Da3ZAW>

## **Roma never die alone**

*QUALITATIVE HEALTH RESEARCH* | Online – 14 September 2017 – A common characteristic of Roma as a cultural group is that they do not allow their elderly to die alone. Nevertheless, rooted in a mainstream cultural perspective of health provision services, public institutions usually do not allow Roma people to be with their loved ones in their last moments. The authors conducted a communicative case study on the death of the most relevant female Roma leader in Catalonia. She was accompanied by more than two hundred family members and friends in her room and corridor at an important hospital in Barcelona. They performed their research in the 2 years following her death to obtain the reflections of the Roma members involved. These reflections revealed the egalitarian dialogue forged between these Roma members and the hospital personnel, which enabled the former to embrace their culture and support their loved ones before death. Because this dialogue was possible and fruitful, the acknowledgment of cultural diversity and the improvement of the quality of services offered to Roma might also be possible in other health institutions. **Abstract:** <https://goo.gl/hc3bas>

Noted in Media Watch 24 August 2015 (#424, p.15):

- *JOURNAL OF BIOETHICAL INQUIRY* | Online – 18 August 2015 – ‘**Roma women’s perspectives on end-of-life decisions.**’ Spain’s Roma community has its own cultural and moral values, which influence end-of-life decision-making, for example: 1) The important role of the family in end-of-life care (EoLC), especially of women; 2) The influence of community opinion over personal or family decisions; 3) The different preferences women had for themselves compared to that for others regarding desired EoLC; and, 4) Unawareness or rejection of advance directives. Roma women wish for their healthcare preferences to be taken into account, but “not in writing.” **Abstract:** <https://goo.gl/P9VyUJ>

Noted in Media Watch, 5 November 2012 (#278, p.10):

- *JOURNAL OF IMMIGRANT & MINORITY HEALTH* | Online – 25 October 2012 – ‘**Dying and death in some Roma communities: Ethical challenges.**’ Five important themes about the Roma people facing dying and death identified: 1) Perception of illness in the community as reason for shame and the isolation that results from this; 2) Importance of the family as the major support for the ill/dying individual; 3) Belief that the patient should not be told his/her diagnosis for fear it will harm him/her; 4) Reluctance of the Roma to decide on stopping life prolonging treatment; and, 5) View of death as “impure.” **Abstract:** <https://goo.gl/tq2iGE>

## Ethics and palliative care in the perinatal world

*SEMINARS IN FETAL & NEONATAL* | Online – 13 September 2017 – The perinatal world is unique in its dutiful consideration of two patients along the lines of decision-making and clinical management – the fetus and the pregnant woman. The potentiality of the fetus-newborn is intertwined with the absolute considerations for the woman as autonomous patient. From prenatal diagnostics, which may be quite extensive, to potential interventions prenatally, postnatal resuscitation, and neonatal management, the fetus and newborn may be anticipated to survive with or without special needs and technology, to have a questionable or guarded prognosis, or to live only minutes to hours. This review addresses the ethical ramifications for prenatal diagnostics, parental values and goals clarification, birth plans, the fluidity of decision-making over time, and the potential role of prenatal and postnatal palliative care support. **Abstract:** <https://goo.gl/1A55qf>

Noted in Media Watch 10 August 2015 (#422, p.8):

- *AMERICAN JOURNAL OF MATERNAL CHILD NURSING*, 2015;40(1):44-50. ‘**Clinician perspectives of barriers in perinatal palliative care.**’ Among the study participants, both nurses and physicians expressed similar feelings of distress and helplessness when caring for families expecting a fetal or neonatal demise. Participants in the study also reported a lack of societal support and understanding about perinatal palliative care. **Abstract:** <https://goo.gl/Tb44j8>

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *JOURNAL OF LEGAL MEDICINE*, 2017;37(1-2):155-166. ‘**An ethical analysis of euthanasia and physician-assisted suicide: Rejecting euthanasia and accepting physician assisted suicide with palliative care.**’ This article begins with a discussion of euthanasia and physician-assisted suicide (PAS) using the moral principles of autonomy, non-maleficence, beneficence, and justice. This is followed with a discussion of the rights of patients and the duties of physicians in order to further this analysis on euthanasia and PAS. Current laws regarding euthanasia and PAS are analyzed. **Introduction:** <https://goo.gl/VaazJs>
- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 15 September 2017 – ‘**Responding to patient requests for hastened death: Physician aid in dying and the clinical oncologist.**’ Physician aid in dying (PAD) or assisted suicide is becoming legal in more U.S. jurisdictions. Meanwhile, the needs of

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terminally ill patients with cancer are receiving greater attention, including the integration of palliative care into oncology practice. This article highlights a case vignette of a patient with advanced cancer who requests PAD from her oncologist, as a backdrop to help the practicing oncologist examine his or her moral stance regarding participation in aid in dying. The article concludes by offering a framework within which the practicing oncologist can receive and process a patient's request for PAD. **Abstract:** <https://goo.gl/Ugz7GP>

- *JOURNAL OF PSYCHIATRIC PRACTICE* | Online – 8 September 2017 – ‘**Contending with pre-planned death: Questions for clinicians.**’ Studies indicate that, for their own end-of-life circumstances, physicians would prefer a briefer, higher quality life to prolonged low-quality life, dignity in infirmity and death, and avoidance of terminal suffering. Lay people generally endorse similar preferences. Although contemporary society generally shuns contemplating preplanned death, cultural attitudes regarding preplanned death are rapidly evolving, and variations of "Death with Dignity" legislation have gained traction in increasing numbers of US states as well as internationally. As yet, no broad consensus exists as to how clinicians should manage circumstances involving preplanned death. **Abstract:** <https://goo.gl/hjWDbS>
- *MEDICAL LAW REVIEW* | Online – 11 September 2017 – ‘**A human rights perspective of assisted suicide: Accounting for disparate jurisprudence.**’ This article critically examines the decision of the New Zealand High Court in *Seales v Attorney-General* (2015), which rejected the claim that that country's blanket ban on assisted suicide violated various rights enshrined in the New Zealand Bill of Rights. That outcome runs contrary to the Canadian Supreme Court's decision in *Carter v Canada* (Attorney General) (2015). This disparity in result arose despite overt similarities between the rights documents in each of the jurisdictions and, more significantly, notwithstanding the fact that the trial judge in *Seales* placed heavy reliance upon the decision in *Carter*. With two new challenges to the blanket ban on assisted suicide in England & Wales progressing through the lower courts, and given proposed amendments to the ban in both New Zealand and its antipodean neighbours – the Australian states of Victoria and New South Wales – it is a propitious time to consider the reasons for the disparate outcomes in *Seales* and *Carter*. **Abstract:** <https://goo.gl/SnxXPc>

**N.B.** *Seales v Attorney-General* is discussed in the August 2015 issue of *Policy Quarterly*, the journal of the Institute for Governance & Policy, University of Wellington, New Zealand (beginning on p.27). [Noted in Media Watch 24 August 2015 (#424, p.20)]. Journal archives: <https://goo.gl/enYTQT>



14 October 2017

*Universal health coverage and palliative care – Don't leave those suffering behind*

<https://goo.gl/diYn7i>

**Palliative Care Network Community**

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

## Media Watch: Online

### International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/nZMuK7>

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://goo.gl/frPgZ5>

PALLIATIVE CARE NETWORK COMMUNITY: <http://goo.gl/8JyLmE>

PALLIMED: <http://goo.gl/7mrqMQ>

[Scroll down to 'Aggregators' and 'Media Watch by Barry Ashpole']

### Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/XO4mD>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <https://goo.gl/JL3j3C>

### Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLqxy2>  
[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/IOSNC7>

ONTARIO | Mississauga Halton Palliative Care Network: <https://goo.gl/ds5wYC>  
[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

### Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W>  
[Scroll down to International Palliative Care Resource Center – IPCRC.NET]

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

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

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**Barry R. Ashpole**  
Guelph, Ontario CANADA

'phone: 519.837.8936  
e-mail: [barryashpole@bell.net](mailto:barryashpole@bell.net)