Canada

21.9% of Canadians are immigrants, the highest share in 85 years: Statistics Canada

CBC NEWS | Online – 26 October 2017 – The share of immigrants in Canada has reached its highest level in almost a century, according to 2016 census figures...¹ The Statistics Canada data also shows the Indigenous population is growing at more than four times the rate of the non-Indigenous population, reaching nearly 1.7 million in 2016. [https://goo.gl/JkxBMv](https://goo.gl/JkxBMv)


Noted in Media Watch 9 October 2017 (#533, p.2):

- ONTARIO | Reuters – 4 October 2017 – ‘Immigrants may get more intense care at end of life.’ Recent immigrants may be more likely than other people to receive aggressive treatment in their last six months of life and die in intensive care, a Canadian study suggests.¹ Even after researchers accounted for other factors that can influence end-of-life care such as income, age and cause of death, recent immigrants were 30% more likely to die in intensive care units, the study found. [https://goo.gl/D4izf7](https://goo.gl/D4izf7)

1. ‘Association between immigrant status and end-of-life care in Ontario, Canada.’ Journal of the American Medical Association, published online 2 October 2017. Full text: [https://goo.gl/GRkEsY](https:// goo.gl/GRkEsY)

Nunavut voters want to bring their elders home, is anyone listening?

NUNAVUT | CBC News (Iqaluit) – 25 October 2017 – It’s a common theme for Member of the Legislative Assembly candidates across Nunavut in this year’s territorial election: build facilities to keep elders in Nunavut when they are no longer able to care for themselves – or be cared for – at home. In Rankin Inlet the issue is close to heart. The community of 2,840 people has no long-term elder care facilities. This means elders there or in nearby communities of Whale Cove and Chesterfield Inlet – each with a population of 435 – face the prospect of either having to leave the region, or leave Nunavut entirely, to find room in
an elder care home. According to the most recent statistics, there are more than 1,400 people aged over 65 in Nunavut. Between Rankin Inlet, Whale Cove and Chesterfield Inlet, there are 126 people aged 65 or older. As it stands now, across Nunavut there are just 27 long-term care beds split between Igloolik, Gjoa Haven and Cambridge Bay. There are additional assisted living facilities in Iqaluit, Baker Lake and Arviat. Elders must make their way down south for care if there’s no space available in any of those facilities. This has residents in the constituencies of Rankin Inlet North and Rankin Inlet South asking what the government will do to make it possible for elders to stay closer to home during the last years of their lives.

https://goo.gl/at1CmQ

Noted in Media Watch 12 June 2017 (#516, p.2):

- NUNAVUT | CBC News (Iqaluit) – 5 June 2017 – ‘Nunavut struggles to care for elders closer to home.’ Rankin Inlet Members of the Legislative Assembly are calling on the premier and health minister to find solutions to care for elders closer to home instead of sending them thousands of kilometres away to residential care facilities outside of Nunavut. That means a growing number of elders are sent to residential care facilities in the south. “Elders establish the backbone of Nunavut culture and language and the Inuit fabric across the communities,” said Rankin Inlet South’s Alexander Sammurtok, quoting the government’s strategy on caring for seniors. https://goo.gl/hJGy5j

N.B. Selected articles on palliative and end-of-life care for Canada’s indigenous peoples are noted in the 24 July 2017 issue of Media Watch (#522, p.15). See Statists Canada’s ‘Aboriginal peoples in Canada: Key results from the 2016 Census,’ published online 25 October 2017. https://goo.gl/PjmKrZ

An uncommon option in Canada, hospice care helps woman with ALS live to the fullest

ONTARIO | CBC News (Toronto) – 24 October 2017 – Not all palliative care (PC) patients are able to make the choice Diana [Fitzharris] did, simply because beds are often unavailable. Unlike the U.K., where hospice care started back in 1967 and is now widespread, Canada has just 88 residential hospices, the majority in Ontario and the Montreal region. The rest of the country’s 28 hospices are spread mainly through British Columbia and Alberta. Newfoundland and Saskatchewan have none. Most of Canada’s hospices need to raise 50% of their operating costs privately. And without the estimated 25,000 to 30,000 volunteers who support PC programs, hospices would be nonexistent. This is despite the fact that palliative home care and hospices generally cost the health care system much less per patient than admitting them to acute care hospitals. According to the 2015 Ontario Auditor General’s report,¹ the cost of a residential hospice bed is $460 per day as compared to $1,100 in an acute care hospital. There are also enormous quality-of-life benefits for patients and their families. Dr. Andrew Mai, the medical director of Hospice Care Ottawa, puts it simply: “If you can’t make an environment at home where a person can be cared for, then a hospice is the (best) option for people who are dying.” https://goo.gl/HfciPU


Noted in Media Watch 23 October 2017 (#535, p.1):

Representative sample of recent news media coverage:

- CBC NEWS | Online – 26 October 2017 – ‘Better palliative care essential as Canada considers medically assisted death for youth, pediatricians say.’ The Canadian Paediatric Society is urging improved palliative care (PC) for children and youth as a key part of preparing for the possibility of legalizing medical assistance in dying for certain patients under age 18. When Bill C-14, the law governing medically assisted dying for adults, was passed in June 2016, it included a requirement that the ministers of justice and health initiate an independent review on whether “mature minors” – youth under age 18 but deemed capable of giving consent – should be eligible for medically assisted death. That review is expected to be presented to Parliament by December 2018. Dr. Dawn Davies, who is chairing the working group on mature minors as part of that review, is the lead author of a report released by the Canadian Paediatric Society. The report made the PC recommendation and also summarized the results of surveys asking pediatricians about their views on making assisted death available to terminally ill young patients, and whether they had received any inquiries or requests about it. Much like broader Canadian society, pediatricians are divided on the issue, Davies said. [https://goo.gl/TSW9pc](https://goo.gl/TSW9pc)

  1. ‘Medical Assistance in Dying: A Paediatric Perspective,’ Canadian Paediatric Society, 26 October 2017. Download/view position statement at: [https://goo.gl/TR3L3X](https://goo.gl/TR3L3X)

- THE GLOBE & MAIL | Online – 26 October 2017 – ‘Children, teens, parents asking Canadian pediatricians about assisted dying.’ Doctors across the country are being approached by children, teenagers and parents about accessing medically assisted death, according to a survey that provides the first snapshot of how often minors would request a practice that’s now only legal for adults. A Canadian Paediatric Surveillance Program survey shows the frequency with which pediatricians are having exploratory conversations about, or fielding explicit requests for, medical assistance in dying (MAiD). The findings could inform changes to federal legislation, and underscore the tension between an individual’s right to autonomy and society’s responsibility to protect the most vulnerable. Of the 1,050 pediatricians who participated in the survey, 118 said that over the course of a year, they had MAiD-related discussions with a total of 419 parents; most of the minors in question were children under the age of 13. When it came to explicit MAiD requests, 45 doctors said they dealt with a total of 91 parents. Nearly half of the requests related to infants less than one month old. [https://goo.gl/gimXVo](https://goo.gl/gimXVo)

  1. ‘2016 Survey,’ Canadian Paediatric Surveillance Program, October 2017. Click on ‘CPSP 2016’ and scroll down to ‘Medical assistance in dying: Infants, children, and adolescents’ (pp. 34-35). Download/view report at: [https://goo.gl/FeiSgs](https://goo.gl/FeiSgs)

- QUEBEC | The Montreal Gazette – 26 October 2017 – ‘Assisted-dying cases have jumped 282% since last year: Commission.’ In total, 638 terminally ill Quebecers died following the intervention of a doctor, up from 167 in 2015-2016. The greatest demand for assisted dying occurred in the Montérégie area, followed by Montreal and Quebec City, according to the report by the Commission sur soins fin de vie. The report, tabled in the National Assembly, found that in 31 cases Quebec’s assisted-dying law was flouted, most often because the doctor who was consulted was not independent of the patient, as the law requires. In 2015-2016, the commission noted that in a dozen cases the law was not respected. [https://goo.gl/Yd3Y9K](https://goo.gl/Yd3Y9K)

Hospices: Extract from Kaiser Family Foundation Issue Brief

KAISER FAMILY FOUNDATION | Online – 27 October 2017 – While federal quality standards exist, little is known about hospice care quality at least in part because federal surveys have been infrequent and quality reporting programs are new. Until passage of the federal IMPACT Act required surveys every three years, hospices were only surveyed every eight years. Centers for Medicine & Medicaid (CMS) has not made survey findings publicly available. The new hospice quality measures focus on: obtaining patient treatment preference information and managing pain and symptoms. Hospices have submitted patient admission and discharge data since 2014, and public reporting of quality measures on the CMS Hospice Compare began in August 2017. Six of the seven 2017 hospice measures show relatively little variation with average performance scores at 90% or higher. The pain assessment measure is an exception where only 78% of hospice patients received a comprehensive assessment within a day of experiencing pain. Because 6% patients did not receive a visit in the last three days of life, CMS is developing new quality measures that focus on visits at the time or near the time of death. Concerned about the high number of voluntary discharges from hospice initiated by patients/families, CMS and RTI International are developing measures of potentially avoidable transitions and access to levels of hospice care. Similar to the racial disparities in care quality among nursing homes noted above, two studies found that hospices caring for more minority patients had significantly lower quality measure scores than those with smaller shares of minority patients even though minority hospice patients received similar care within the same hospice. Full text: https://goo.gl/71yfPv

Key issues in long-term services and supports quality

2017 marks the 30th anniversary of the passage of the Nursing Home Reform Act as part of the Omnibus Budget Reconciliation Act of 1987, the federal legislation that substantially strengthened federal standards, inspections and enforcement of nursing home quality. The Act also merged Medicare and Medicaid standards, required comprehensive assessments of residents, set minimal requirements for licensed nursing staff, and required inspections to focus on outcomes of care. While progress has been made, care quality issues in nursing homes and residential care facilities (also called assisted living) continue to be highlighted frequently in the press and by numerous government reports and research studies. Recurring concerns include staffing levels, abuse and neglect, unmet resident needs, quality problems, worker training and competency, and lack of integration with medical care. The last several decades also have seen a shift to home care and other community-based services, with few quality measures for these settings available and little empirical evidence available. This issue brief discusses four key issues related to long-term services and supports including institutional and home and community-based services quality, highlighting major legislative and policy changes over the last 30 years.

“No one is coming”: Investigation reveals hospices abandon patients at death’s door

KAISER HEALTH NEWS | Online – 26 October 2017 – As the [hospice] industry has grown, the hospice care people expect – and sign up for – sometimes disappears when they need it most. Families across the country, from Appalachia to Alaska, have called for help in times of crisis and been met with delays, no-shows and unanswered calls, a Kaiser Health News investigation published in cooperation with TIME shows. The investigation analyzed 20,000 government inspection records, revealing that missed visits and neglect are common for patients dying at home. Families or caregivers have filed over 3,200 complaints with state officials in the past five years. Those complaints led government inspectors to find problems in 759 hospices, with more than half cited for missing visits or other services they had promised to provide at the end of life. The reports, which do not include victim names, describe a 31-year-old California woman whose boyfriend tried for 10 hours to reach hospice as she gurgled and turned blue, and a

Cont.
A panicked caregiver in New York calling repeatedly for middle-of-the-night assistance from confused hospice workers unaware of who was on duty. In Michigan, a dementia patient moaned and thrashed at home in a broken hospital bed, enduring long waits for pain relief in the last 11 days of life, and prompting the patient’s caregiver to call nurses and ask, “What am I gonna do? No one is coming to help me. I was promised help at the end.” Only in rare cases were hospices punished for providing poor care, the investigation showed. https://goo.gl/a4TtDp

**Extract from Kaiser Health News article**

How often hospices fail to respond to families or patients is an understudied question, experts say, in part because it’s hard to monitor. But a recent national survey of families of hospice patients suggests the problem is widespread: 1 in 5 respondents said their hospice agency did not always show up when they needed help, according to the Consumer Assessment of Healthcare Providers & Systems Hospice Survey, designed by the Centers for Medicare & Medicaid Services.

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**Hospice scrambled during wildfires to evacuate patients determined to die at home**

CALIFORNIA | KQED News (San Francisco) – 25 October 2017 – They didn’t want to leave because they wanted to die in their home,” said Karna Dawson, a social worker with Hospice by the Bay. “They didn’t want to leave because they didn’t realize the severity of the problem.” At critical moments, when the worst wildfires in state history were ravaging Wine Country, Dawson and other members of the hospice team had to intervene in several such standoffs with terminally ill clients. “Some people were feeling like if they were going to die they wanted to die in their house, and [were] not really thinking that through very clearly,” she said. “We’re not talking about dying of your cancer. We’re talking about dying in a fire. And those are two very different deaths.” When the fires broke out 8 October, nurses and staff with Hospice by the Bay were providing home care, pain management, and spiritual counseling to 108 patients in Napa and Sonoma counties. Half of those patients had to be evacuated. Under federal rules, hospice agencies that receive payment from the Medicare program are required to have a disaster plan in place for their patients, including how to get bed-bound patients out of their homes. https://goo.gl/g3DQCG

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**Specialist Publications**

‘An advanced directive may be hazardous to your health: End-of-life documents in a disaster’ (p.15), in Medscape.

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**A look inside the nation’s first residential hospice for dying homeless folks**

UTAH | Deseret News (Salt Lake City) – 25 October 2017 – Candace Cowles was always anxious, but in late January 2016, she was suffering pain and beginning to panic. Her hospice nurse ordered a pain pump so she’d get more relief from the disease that was eating at her stomach. Cancer had stolen everything that felt familiar to the 62-year-old – her health, her job, her apartment. It would keep stealing until it got her life. But though she had become homeless, Cowles would not die alone on the street as many in such straits have done. She would be in a real bed with someone dear sitting vigil beside her. That someone was a woman named Matilda Lindgren, who’d also been homeless for a time and turned things around before volunteering and later joining the staff at The INN Between, the nation’s first residential hospice for dying homeless folks, where Cowles spent her final days. About 50 homeless people die each year in Salt Lake City. As if homelessness were not challenging enough, those with terminal illnesses sometimes must manage serious sickness while living under viaducts, in a camp or in a crowded dorm-like shelter. The INN Between residential hospice opened in 2015 to provide shelter, comfort and dignity to those who lack almost everything else. https://goo.gl/CbvB42

Cont.
The symptoms of protracted dying

THE NEW YORK TIMES | Online – 24 October 2017 – In every other part of medicine, doctors make recommendations for medications, lifestyle changes and surgeries. We don’t offer cancer patients six different chemotherapy regimens and ask them to weigh the pros and cons. Yet when it comes to end-of-life decisions, doctors are terrified of violating patient autonomy. We are scared of our own medical opinions. Instead of saying, “I recommend...” we often offer a platter of life-prolonging measures, most of which are unlikely to improve a patient’s quality of life, but which offer the possibility of hope. The patient’s heart will still beat. Her personality will be gone, but her chest will still rise and collapse. Families see an opportunity for loss to be delayed, perhaps even dodged. Then we are surprised when they take us up on the offer to prolong dying. https://goo.gl/LAowRf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- OREGON | The Oregonian (Portland) – 27 October 2017 – ‘20 years of Oregon’s Death with Dignity Act.’ Oregon’s Death with Dignity Act went into effect on 27 October 1997, marking the first such law in the nation. It was endorsed twice by voters, in 1994 and 1997, and upheld in federal court. The state has tracked the law through annual reports. The state reports show a steady growth in the law’s use. The latest statistics ... show that from 1998 through last June 1,857 people got a lethal prescription, and 1,179 people died after taking it. To put that in perspective, a total of 614,972 adults died in Oregon during the same period. About 40% of patients who get a prescription don’t take it for a variety of reasons, state reports indicate. Some aren’t able to swallow the drugs. Others may change their minds. Others die naturally. https://goo.gl/7EBAsm

- THE WASHINGTON POST | Online – 24 October 2017 – ‘Legalizing assisted suicide has stalled at every level.’ Three years ago, Brittany Maynard’s viral video launched the issue of medically assisted suicide into the national spotlight. But while advocates have notched a few wins since then, they’ve also run up against some strong, bipartisan resistance. Two states — California and Colorado — have made it legal for doctors to prescribe life-ending medication to terminally ill patients since Maynard, diagnosed with an aggressive form of brain cancer, publicized her decision to end her life. Physician-assisted suicide is legal in six states, including Vermont, Oregon, Washington and Montana, as well as the District [i.e., Washington DC]. Yet none of the 27 states where such measures were introduced this year passed them into law, according to tracking done by Compassion and Choices, a group that backs assisted suicide. The bills were either quashed in committee or passed one legislative chamber, but not the other. That was the case even in states run by Democrats, including Connecticut, Rhode Island and Hawaii. https://goo.gl/veUeo7
International

National Health Service staff given a “safe space” to share the emotional, social or ethical challenges they face are less stressed and show greater empathy towards patients

U.K. (England) | The Daily Mail – 28 October 2017 – National Health Service (NHS) staff given a “safe space” to share experiences and concerns reduces stress by half and increases their empathy to patients, a new study claims. Doctors and nurses who regularly share the emotional, social or ethical challenges they face suffer less psychological distress and better teamwork too. A team of British researchers examined the impact of Schwartz Centre Rounds or “Rounds” on both clinical and non-clinical staff. Staff who regularly attended the meetings to discuss their feelings halved their psychological distress from 25% to 12%, they discovered. Rounds are monthly forums that offer a safe space for staff to talk to their colleagues and discuss the challenges they face in their work and its impact on them. They were increasingly introduced following the Francis report into the poor care at the Mid-Staffordshire hospitals, one of the greatest NHS scandals.1 The report was undertaken by researchers at the University of Surrey, Kings College London, the University of Sheffield and The King’s Fund. The first in-depth U.K. study suggested that Rounds could be a way of fostering good teamwork and improving morale amongst staff. https://goo.gl/QnShLM

Specialist Publications

‘Teamwork and conflicts in paediatric end-of-life care’ (p.8), in Acta Paediatrica.


Palliative care sector raises concerns over Brexit

U.K. (Scotland) | Scottish Partnership for Palliative Care – 26 October 2017 – The Partnership has written to David Davis, Secretary of State for Exiting the European Union, raising concerns over the impact that withdrawal from the European Union (EU) may have on the care of the dying in Scotland. The open letter, signed on behalf of the Partnership’s governing council, calls on Mr. Davis to recognise the part that EU health and social care staff play in end-of-life care (EoLC) in Scotland, and to pay due attention to sustaining staff numbers. There is little capacity to absorb any detrimental impacts of Brexit, the letter states. The letter points to research that reveals Brexit could have a disruptive impact on care of the dying in Scotland: 1) Uncertainty over Brexit has already reduced the numbers of EU nurses registering to practice in the U.K. (Nursing & Midwifery Council); 2) 4% of nurses and midwives in National Health Service Scotland are non-British EU nationals, as are 1,400 doctors; and, 3) 6% of the care home workforce are non-British EU nationals. It also expresses concern over the future of EU research funding and cross-border collaboration into the improvement of EoLC. Clinical medicine and biosciences research received well over £200 million in EU research funding in 2014-2015. https://goo.gl/pV9hrz

“Having an atheist chaplain is about patient choice”

U.K. (England) | The Guardian (London) – 25 October 2017 – The stress of coming into hospital can take its toll on patients and relatives alike and Jane Flint’s role as a member of the chaplaincy at University Hospitals of Leicester National Health Service (NHS) trust is to offer emotional and spiritual support to patients, visitors and staff. The difference between her and the other 12 chaplains is that she is an atheist. Duties are the same as for the other chaplains bar offering prayers, rituals or a religious perspective. Like them, Flint will see non-religious and religious people alike who request her services. The role, says Flint, is about “just being there”, whether to hear people’s life stories, to provide a sounding board, or to bear witness to somebody’s pain. https://goo.gl/RQiIEK
Palliative and end-of-life care in Russia

State Duma MPs to draft bill on palliative care for gravely ill persons

RUSSIA | Russian Legal Information Agency (Moscow) – 24 October 2017 – The State Duma lawmakers are working on a bill that writes down a right of patients to receive palliative care (PC) on the whole territory of Russia, the statement on the official VKontakte account of the lower house of parliament reads. The bill introduces a special status for patients requiring PC and regulates procedures related to organization and provision of this type of care for both children and adults. MP Petr Tolstoy expressed hope that work on the document will be completed before the New Year. He added that there is a need for clear rules regulating sensitive fields such as oncology and PC, not only for officials but for doctors too.

https://goo.gl/jw2FPZ

N.B. VKontakte is a Russian-based online social media and social networking service.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Western Australia) | The Conversation – 24 October 2017 – ‘We need to address questions of gender in assisted dying.’ One of the principal motivations behind current efforts to legalise assisted suicide in Victoria and New South Wales (NSW) – and most jurisdictions – is patient autonomy. However, research suggests “gendered risks” may thwart women’s autonomy in end-of-life decisions, making them uniquely vulnerable to assisted suicide laws. While eligibility under the Victorian and NSW bills requires that a patient must be suffering from a terminal illness from which they will likely die in 12 months, the concern for women is that the final decision to end their lives may nevertheless be influenced by risk factors that challenge the rhetoric of “choice.” https://goo.gl/2ayAJN

- SOUTH KOREA | Yonhap News Agency (Seoul) – 22 October 2017 – ‘South Korea to start trial operation of end-of-life care.’ Thirteen hospitals in South Korea will launch trial operations of end-of-life care (EoLC), just over three months before a law on dying with dignity comes into effect. The law, which will take effect from February next year, was passed by the National Assembly in January last year and allows terminally ill patients to seek the right to die when there is no chance of recovery. During the three-month trial operations the hospitals will consult with terminally ill patients or their family members EoLC, according to the Ministry of Health & Welfare. The hospitals will also test how they treat the terminally ill patients who seek the right to die. https://goo.gl/dH29GQ

Specialist Publications

Teamwork and conflicts in paediatric end-of-life care

ACTA PAEDIATRICA | Online – 18 October 2017 – The paper by Archambault-Grenier et al ... is a great example of a team systematically examining the origins and nature of conflict in their own workplace. The professionals were physicians, nurses, psychologists, physiotherapists and inhalotherapists. The aim of the study was to investigate their experiences with end-of-life (EoL) conflicts and to explore other details of these conflicts, such as frequency, perceived importance, contributing factors and strategies for conflict resolution and coping. The authors report several important results. First, they state that a very high proportion of healthcare professionals (71%) had experienced at least one conflict in the preceding five years and these were more frequent between professionals (58%) than between professionals and...
parents (33%). This finding is remarkable and differs from most of the earlier paediatric studies, which reported conflicts between healthcare teams and families as the most common type of conflict. One interesting, and potentially worrisome, finding was the observation that most of the nurses did not express their opinions. The authors’ suggestion was that this phenomenon could be a barrier to truly interdisciplinary decision-making and that theory seems realistic. It may also be that these nurses suffered in silence, because they were involved in conflicts but their voices were not heard or taken into account. Those of us who work in paediatric EoL care should recognise and address those risks. **Full text:** [https://goo.gl/X4c8Dz](https://goo.gl/X4c8Dz)

1. ‘Survey highlights the need for specific interventions to reduce frequent conflicts between healthcare professionals providing paediatric end-of-life care,’ *Acta Paediatrica*, published online 5 September 2017. **Abstract:** [https://goo.gl/xJ2GbV](https://goo.gl/xJ2GbV)

**Australian doctors’ knowledge of and compliance with the law relating to end-of-life decisions: Implications for LGBTI patients**

*CULTURE, HEALTH & SEXUALITY | Online – 25 October 2017 –* In most developed countries, competent patients have the legal right to refuse any medical treatment; advance care planning mechanisms extend this right to non-competent patients. However, some groups, including lesbian, gay, bisexual, transgender and intersex (LGBTI) people, risk their wishes not being respected if they lose capacity, more than others. Little is known about medical practitioners’ knowledge of, or attitudes to, the law in this area, especially in relation to LGBTI people, or how the law influences their decision-making. An Australian postal survey explored knowledge and attitudes of medical specialists to legal issues relating to withdrawing/ witholding life-sustaining treatment from adults without capacity. Less than one-third of respondents correctly identified the same-sex partner as the legally authorised decision-maker. LGBTI people face multiple obstacles to having their end-of-life wishes respected. Where healthcare providers are also ignorant of the partner’s legal right to make such decisions, the problem is compounded. Improved legal education for clinicians and promotion of educational resources for members of the LGBTI community is needed. **Abstract:** [https://goo.gl/iNFuu5](https://goo.gl/iNFuu5)

Noted in Media Watch 29 May 2017 (#514, p.9):

- **JOURNAL OF GAY & LESBIAN SOCIAL SERVICES | Online – 19 May 2017 – ‘Exploring the utilization of end-of-life documentation among an online sample of sexual- and gender-minority individuals in the U.S.’** Lesbian, gay, bisexual, transgender, and queer (LGBTQ) persons often receive end-of-life care incongruent with wishes. Little is known about the knowledge, attitudes, and willingness regarding utilization of these documents among LGBTQ persons. Approximately one-third of survey respondents believed documents would be enforced more for heterosexual persons than themselves. This result indicates sexuality or gender minority-related stigma may be a barrier to document utilization. **Abstract:** [https://goo.gl/lXlz8n](https://goo.gl/lXlz8n)

**N.B.** Selected articles on end-of-life and palliative care for LGBTQ communities are noted in the 22 May 2017 issue of Media Watch (#513, pp.18-19).

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**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](http://goo.gl/5CHoAG)
Living well, dying well: The importance of housing

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2017;24(5):199-202. The place where we live, patterns of housing tenure, and the extent to which a home is “fit for purpose” are all highly relevant as we get older or become ill and have to consider our emerging or long-term care needs. One current idea is the generation of “compassionate communities” that foster mutuality and shared concerns and the capacity to promote common understandings and practical action in the face of end-of-life issues. Dumfries and Galloway has an ageing population, and we have been considering how the idea of “housing with care” opens up new possibilities for living – and for dying when the time comes. The authors see the establishment of a “care campus” as providing for a full spectrum of needs – from completely independent living to long-term care facilities – and including care at the very end of life. Key to the idea of the care campus is the fostering of an innovative approach to later life, which meets the housing, and health and social care needs of people in Dumfries and Galloway, while contributing to academic activity related to healthy ageing, end-of-life care, and cross-generational synergy, understanding and sharing.

What’s next for palliative care

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2017;24(5):210-21. Palliative care (PC) can occur in a variety of settings and has expanded over the years from end-of-life symptom control to holistic care that may begin from the time of diagnosis. As the population continues to age, demand for PC services is increasing and a major challenge for services lies in extending the excellent level of care to more patients, while surviving funding cuts to the National Health Service. One approach to this challenge is empowering those involved in all aspects of a patient’s care to provide the holistic care currently provided by specialist palliative care services. This requires embedding the principles of PC throughout medicine and surgery, mobilising communities to provide non-specialist care and support, and utilising technology to increase patients’ access to specialist knowledge.

Related

- JOURNAL OF THE ROYAL COLLEGE OF PHYSICIANS OF EDINBURGH | Inprint – Accessed 23 October 2017 – “End-of-life care: Where do we go from here?” Death and dying are inevitable. High quality and accessible palliative and end of life care can help people who are facing progressive life-threatening and life-limiting illness, and those dear to them, by focusing on their quality of life and addressing the problems associated with their situation. This paper draws attention to the scale of the challenge, some of the key areas we could address and the shifts in culture, mindset and leadership approach that are needed. Abstract: https://goo.gl/g4Za6b

Psychological ideas in palliative care: Denial

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2017;24(5):218-223. The fifth article in the series ‘Psychology in palliative practice’ looks at the concept of “denial,” a term whose meaning has evolved since its original application in the psychological sense by Freud. Once meaning a total rejection of reality, denial now encompasses a range of situations frequently encountered in patients receiving palliative care. But these patients are not usually denying the reality of their condition – rather, they are using various mechanisms, including disavowal and dual thinking, as coping strategies. The author explains how these strategies work and advises on how palliative care professionals can work with these patients effectively.
Body language and metaphors revealed through applications of movement psychotherapy in a hospice

EUROPEAN JOURNAL OF PSYCHOTHERAPY & COUNSELLING | Online – 16 October 2017 – The authors describe a clinical case illustrative of many of the situations in which facing death was particularly tormenting. The emotional pressure can produce a barrier of communication with the risk of rupturing the therapeutic relationship. The movement therapist’s function is to clarify the elements of body language and this has important implications for clinical practice because the end-of-life decisions are difficult, like palliative sedation therapy (PST). Even if procedural guidelines for PST help physicians and care teams through the decision-making process and make them more comfortable when responding to physical suffering, physicians more frequently report an emotional pressure when their patients experience psychological symptoms, with the risk that PST could become a potential “counterphobic defence to treat.”

Abstract: https://goo.gl/BQZxcZ

N.B. Italian language article.

U.S. Choosing Wisely campaign

Choosing Wisely: How to fulfill the promise in the next 5 years

HEALTH AFFAIRS | Online – 24 October 2017 – Low-value care – the use of unnecessary and potentially harmful health care services – accounted for roughly $200 billion in wasteful spending in the U.S. in 2011. In 2012 the American Board of Internal Medicine Foundation and Consumer Reports [a nonprofit organization] launched the Choosing Wisely campaign, inspired by the idea that professional societies and health care providers should take the lead in defining and motivating efforts to reduce the use of low-value care. But decreases in that use have been slow in coming. The authors discuss the campaign’s significant accomplishments in the past five years and summarize the work that is needed to fulfill the promise of Choosing Wisely. They focus on innovations in three main: 1) Identifying high-priority clinical targets; 2) Developing theory-based interventions; and. 4) Evaluating interventions in ways that are clinically meaningful. Full text: https://goo.gl/yKPLlp

Related

- HEALTH AFFAIRS | Online – 24 October 2017 – ‘Choosing Wisely campaign: Valuable for providers who knew about it, but awareness remained constant, 2014-2017.’ Despite continued publicity and physician outreach efforts, [surveys indicate that] there were no significant changes between 2014 and 2017 in awareness of the campaign among physicians or physician-reported difficulty in talking to patients about avoiding a low-value service. Barriers to the adoption of recommendations included malpractice concerns, patient demand and satisfaction, and physicians’ desire for more information to reduce uncertainty. Full text: https://goo.gl/P79RTs


Noted in Media Watch 31 July 2017 (#523, p.9):

- GERONTOLOGY & GERIATRIC MEDICINE | Online – 24 July 2017 – ‘Physician preferences for aggressive treatment at the end of life and area-level health care spending: The Johns Hopkins Precursors Study.’ Choosing Wisely is an effort of the American Board of Internal Medicine Foundation with over 70 professional organizations as partners to encourage conversations between providers and patients to carefully consider the value of tests and procedures that may be of limited benefit to the patient. However, it remains to be seen whether such efforts are sufficient to change physician and patient behaviors and reduce health care spending. Abstract: https://goo.gl/87jdvz
The role of a palliative care intervention in moderating the relationship between depression and survival among individuals with advanced cancer

HEALTH PSYCHOLOGY | Online – 19 October 2017 – Randomized controlled trials (RCTs) of early palliative care (PC) interventions in advanced cancer have positively impacted patient survival, yet the mechanisms remain unknown. This secondary analysis of two RCTs assessed whether an early PC intervention moderates the relationship between depressive symptoms and survival. Higher baseline Center for Epidemiologic Studies-Depression (CES-D) scores were significantly associated with greater mortality risk... However, participants with higher CES-D scores who received the intervention had a lower mortality risk ... even when controlling for demographics, cancer site, and illness-related variables. This study is the first to demonstrate that patients with advanced cancer who also have depressive symptoms benefit the most from early PC. Future research should be devoted to exploring the mechanisms responsible for these relationships. Abstract: https://goo.gl/dFBWBs

Palliative and end-of-life care in the U.S.

Changing focus: End-of-life care in a New York State managed long-term care program

JOURNAL OF APPLIED GERONTOLOGY | Online – 19 October 2017 – In the U.S., managed long-term care (LTC) programs offer a non-institutional approach to meeting the needs of increasing numbers of frail elders. Providing services that support both quality of life and quality of dying poses unique challenges. The authors explored these challenges from the perspectives of care providers. Themes were identified using qualitative content analysis techniques applied to transcripts of 33 semi-structured interviews. Professionals comprising an interdisciplinary care team and home health aide direct care providers described cues by which they identified movement into the end-of-life phase, their understandings of how care changed, and their concerns and recommendations for improvement. When the changing care needs could be met, a “good death” ensued, but that was not always possible. Managed LTC programs are called upon to develop the capacity to integrate the phase of dying into the full story of each life for which they care. Abstract: https://goo.gl/oanFmm

Handling challenges inherent in the hospice chaplain role

JOURNAL OF HEALTH CARE CHAPLAINCY | Online – 25 October 2017 – With an increasing number of terminal patients in the U.S. dying in the context of hospice, the role that hospice chaplains play in providing spiritual care for patients and their families is important to examine. The hospice chaplain role requires careful navigation of the development of relationships that may end abruptly, the expectations of hospice organizations, and the needs of both patients and families. The current study uses the concept of competing role dialectics to further our understanding of the challenges chaplains face as they enact this crucial role. Data from 45 current and former hospice chaplains reveal four major role tensions hospice chaplains must develop strategies to handle: 1) Fostering relationships versus fostering autonomy; 2) Acting as team members versus acting as individuals; 3) Serving the family unit as a whole versus serving particular family members; and. 4) Following the agendas of patients and families versus following one’s own agenda. Abstract: https://goo.gl/8QYZ2v

Noted in Media Watch 18 September 2017 (#530, p.17):

- JOURNAL OF PASTORAL CARE & COUNSELING, 2017;71(3):163-175. ‘Recent progress in chaplaincy-related research.’ 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).
Healthcare provider limitation of life-sustaining treatment without patient or surrogate consent

*JOURNAL OF LAW, MEDICINE & ETHICS* | Online – 18 October 2017 – In June 2015, the major North American and European critical care societies released new joint guidelines that delineate a process-based approach to resolving intractable conflicts over the appropriateness of providing or continuing life-sustaining treatment (LST). This article frames the new guidelines within the history, ethical arguments, legal landscape, and empirical evidence regarding limitation of LST without surrogate consent in cases of intractable conflict. **Abstract:** [https://goo.gl/GzLkaH](https://goo.gl/GzLkaH)


**N.B.** This Official Policy Statement of the American Thoracic Society (ATS) was approved by the ATS, January 2015, the American Association for Critical Care Nurses (AACN), December 2014, the American College of Chest Physicians (ACCP), October 2014, the European Society for Intensive Care Medicine (ESICM), September 2014, and the Society of Critical Care Medicine (SCCM), December 2014.

**Related**

- **JOURNAL OF LAW, MEDICINE & ETHICS** | Online – 18 October 2017 – ‘The medical surrogate as fiduciary agent.’ The author proposes a new approach to surrogate decision-making, the fiduciary agency approach. On this approach, the surrogate has authority to not only act on the patient’s behalf as the patient’s agent, but also to decide on the patient’s behalf as the patient’s fiduciary. One upshot is that surrogates must sometimes go against the expressed dictates of the patients’ advance directives not necessarily because doing so would be in the patient’s best interest, but rather because doing so would best represent the patients’ will. **Abstract:** [https://goo.gl/wXkJbC](https://goo.gl/wXkJbC)

- **NARRATIVE INQUIRY IN BIOETHICS**, 2017;7(2):171-178. “We didn’t consent to this.” Patients and their families have identified the need for ongoing and effective communication as one of the important aspects of medical care, especially when the cessation of disease-modifying therapies is being considered at the end of life. Despite recognizing that this communication is extremely important, clinicians are uneasy and find themselves inadequately trained to “break bad news” and manage emotional responses from the patient/family. **Abstract:** [https://goo.gl/QBiEXb](https://goo.gl/QBiEXb)

The “French exception”: The right to continuous deep sedation at the end of life

*JOURNAL OF MEDICAL ETHICS* | Online – 23 October 2017 – In 2016, a law came into force in France granting terminally ill patients the right to continuous deep sedation (CDS) until death. This right was proposed as an alternative to euthanasia and presented as the “French response” to problems at the end of life (EoL). The law draws a distinction between CDS and euthanasia and other forms of symptom control at the EoL. France is the first country in the world to legislate on CDS. **Abstract:** [https://goo.gl/7YBY9S](https://goo.gl/7YBY9S)

End-of-life palliative care practices and referrals in Uganda

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 23 October 2017 – While early involvement and integration of palliative care (PC) with oncology can positively impact quality of life and survival of patients with advanced cancer, there is a dearth of information regarding this integration in sub-Saharan Africa. The authors examined the rate of referrals of cancer patients to palliative specialists via a chart review, while also surveying and interviewing doctors at the Uganda Cancer Institute (UCI) about their approaches to PC. Sixty-six (11.1%) of 595 patients were referred to PC specialists. Doctors explained a low referral rate and short life expectancy after referral by limited palliative resources and a reticence to have end-of-life management conversations with patients due to cultural taboos. Despite recognized benefits of palliative collaboration, doctors at the UCI seldom refer patients to PC specialists due to limited staffing, cultural barriers, and difficult inter-service communication. **Abstract:** [https://goo.gl/7jvKCh](https://goo.gl/7jvKCh)

**N.B.** Selected articles on palliative and end-of-life care in Sub-Sahara Africa, specifically Uganda, are noted in the 16 October 2017 issue of Media Watch (#534, p.13).
Communicating with a human voice: Developing a relational model of empathy

JOURNAL OF THE ROYAL COLLEGE OF PHYSICIANS OF EDINBURGH, 2017;47(3):266-270. The medical profession has adopted a cognitive model of empathy, or detached concern, in its professionalism and practice. As a consequence there is now an empathy gap which has been demonstrated by lapses in patient care in the U.K. There may also be an empathy gap developing in medical students during their training. This paper argues for the adoption of a relational view of empathy which embraces emotional and moral dimensions of the concept, acknowledges the importance of the clinical context and prioritises the relationship between the doctor and patient. A relational model extends to encompass the patient’s family and all members of the healthcare team. By exploring the process of empathising in clinical practice I develop a relational model that is more appropriate for modern patterns of patient care and medical education than detached concern. Adoption of a relational model of empathy in training and practice can help bridge the empathy gap. Abstract: https://goo.gl/zmJqZi

N.B. Click on pdf icon to access full text.

Noted in Media Watch 3 July 2017 (#519, p.12):

- JOURNAL OF THE ROYAL SOCIETY OF MEDICINE | Online – 27 June 2017 – ‘Overthrowing barriers to empathy in healthcare...’ Practitioners often complain that their capacity to practise empathically is undermined by “tyrannical guidelines,” insufficient time, and an ever-increasing burden of paperwork. Clinicians often see this system as lacking empathy – uninterested in practitioners’ perspectives, health or welfare. As a result, patients suffer, claiming clinicians do not communicate adequately, often leaving their needs and concerns insufficiently addressed. Abstract: https://goo.gl/2Yu4sB

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

Impact of nursing home palliative care teams on end-of-life outcomes: A randomized controlled trial

MEDICAL CARE | Online – 24 October 2017 – Deficits in end-of-life care in nursing homes (NHs) are reported, but the impact of palliative care teams (PCTeams) on resident outcomes remains largely untested. In all, 25 New York State NHs completed the trial (5,830 decedent residents) and 609 NHs were in the non-randomized group (119,486 decedents). Overall, the authors found no statistically significant effect of the intervention. However, independent analysis of the interview data found that only 6 of the 14 treatment facilities had continuously working PCTeams throughout the study period. Decedents in homes with working teams had significant reductions in the odds of in-hospital death compared to the other treatment, control, and non-randomized control. Decedents in these NHs had reduced rates of depressive symptoms, but not pain or hospitalizations. The intervention was not equally effective for all outcomes and facilities. As homes vary in their ability to adopt new care practices, and in their capacity to sustain them, reforms to create the environment in which effective palliative care can become broadly implemented are needed. Abstract: https://goo.gl/PSBmYn

Noted in Media Watch 5 June 2017 (#515, p.13):

- JOURNAL OF POST ACUTE & LONG-TERM CARE MEDICINE, 2017;18(6):465-469. ‘International survey of end-of-life care in nursing homes.’ This article reports the findings of a survey on end-of-life (EoL) care in nursing homes of 18 long-term care (LTC) experts across 15 countries. Overall experts strongly agreed that hospice and palliative care should be available in LTC facilities and that both are defined by holistic, interdisciplinary approaches using measures of comfort across domains. However, it appears the experts felt that in most countries the reality fell short of what they believed would be ideal care. As a result, experts call for increased training, communication, and access to specialized EoL services within the nursing home. Abstract: https://goo.gl/U3c3Xy

Cont.
An advanced directive may be hazardous to your health: End-of-life documents in a disaster

MEDSCAPE | Online – 27 October 2017 – In a disaster ... if a patient is not currently in end-of-life (EoL) care, a living will or Physician Orders for Life-Sustaining Treatment (POLST) document could actually place that individual in harm’s way. First responders are trained to move quickly to provide care, and thus, they will move in a direction toward those patients wanting to receive care. If that patient has a document such as a living will or POLST, their perception could be that that individual may not want to receive care and treatment. It has been shown through TRIAD (Realistic Interpretation of Advanced Directives) VIII and previous TRIAD studies that it is common, when confronted with a critically ill patient, for providers to act too aggressively or not aggressively enough to save a life. A patient-to-clinician video can be beneficial for the patient and the provider because it is factual, it is directional, and it is not an interpretation or a guess. There is a push right now to have all patients create living wills and POLST documents and place them in their natural disaster toolbox. Rather than placing all patients in harm’s way, the author believes that we should only recommend these to patients who have terminal illnesses or are at high risk for an EoL scenario. Those patients should keep a living will or POLST documents in their toolboxes. Full text: https://goo.gl/QAtcCr

Improving hospital discharge for patients at the end of life

NURSING TIMES | Online – 23 October 2017 – In 2016, the quality of rapid discharges at North Middlesex University Hospital Trust was measured against the five “priorities for care of the dying person.” This followed a first audit conducted in 2009 and improvements in equipment delivery, time of discharge approval, communication between hospital and community teams and staff education. However, the second audit found that 15 out of the 40 patients, whose case notes were reviewed, died at the hospital waiting to be discharged. The audit shows the discharge of patients with complex palliative care needs still needs to be improved. Earlier referral to the palliative care team and joint team working are needed to achieve high-quality end-of-life care for patients and families. Clinicians can find it difficult to refer patients early due to the curative nature of hospital care, but delaying referral can prevent timely advance care planning (ACP) discussions. Due to staff turnover, there is always a need for education on the continuing healthcare framework, rapid discharges and ACP. To improve the service, the appointment of a nurse who would be in charge of ACP, staff education, patient discharge and liaison with community care has been suggested. There is also the wider issue of the lack of beds in the community; until this is also addressed, patients will continue to deteriorate and eventually die in hospital. Full text: https://goo.gl/fIXWKn

1. ‘One Chance to Get it Right: Improving People’s Experience of Care in the Last Few Days and Hours of Life,’ Leadership Alliance for the Care of Dying People, June 2014. [Noted in Media Watch 30 June 2014 (#364, p.7)] Download/view the report at: https://goo.gl/bCg4UY

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology
http://goo.gl/OTpc8I
“Mourning with the morning bell”: An examination of secondary educators’ attitudes and experiences in managing the discourse of death in the classroom

OMEGA – JOURNAL OF DEATH & DYING | Online – 24 October 2017 – A plethora of research exists about death and dying, particularly with regard to the prescriptive strategy on how teachers should address death in their classrooms. However, there is a gap in the literature about teachers’ perceived preparedness to discuss a student’s death in their classrooms. The following qualitative study used focus groups to explore teachers’ experiences with and beliefs about death, dying, coping, student death, and preparedness to address student death in the classroom. Data were transcribed and thematically analyzed. Themes and subthemes for all research questions are presented and explained; some themes explored include teachers’ views of death, death versus dying, initial and long-term coping, difficulties in addressing student death, the teachers’ role after a student’s death, feelings of being prepared versus unprepared to address student death in the classroom. Abstract: https://goo.gl/XvHdmT

Assisted (or facilitated) death

Representative sample of recent journal articles:

- ANNALS OF INTERNAL MEDICINE | Online – 17 October 2017 – ‘Physician-assisted suicide: Finding a path forward in a changing legal environment.’ Imagine yourself with a disease that has recently become terminal. What kinds of treatments and options would be most important to you? Almost everyone would want to be sure their physicians had considered, if not tried, all potentially effective disease-directed therapy and best possible palliative treatments to maximize their quantity and quality of life. Many patients would want to consider a timely transition to hospice care if no acceptable disease-directed therapies existed, hoping to live as fully as possible for their remaining time, and then to die peacefully. On these points the authors are completely in sync with the American College of Physicians’ position paper. Abstract: https://goo.gl/UKzHb7

1. ‘Ethics and the legalization of physician-assisted suicide: An American College of Physicians position paper,’ Annals of Internal Medicine, published online 19 September 2017. [Noted in Media Watch 25 September 2017 (#531, p.17)] Full text: https://goo.gl/GLQPyi

- BMJ OPEN | Online – 25 October 2017 – ‘Euthanasia and physician-assisted suicide not meeting due care criteria in The Netherlands: a qualitative review of review committee judgements.’ Whether an euthanasia and physician-assisted suicide (EAS) oversight system based on mutual trust would translate into a system with “strict limits” in other jurisdictions is an important point for discussion. In jurisdictions considering EAS laws, debates over how best to regulate the practice should focus on the goals of an oversight system. If the primary objective is to directly oversee that only truly eligible patients are receiving EAS, then a prospective independent assessment system (as has been proposed in the U.K.) may be more fitting than a system that entrusts the physicians to apply difficult-to-interpret criteria and to self-judge whether their cases are reportable, without any serious consequences for violations. In The Netherlands, the data appear to raise questions about whether a trust-based retrospective review system provides adequate oversight for particularly vulnerable patients (such as psychiatric patients and incapacitated patients), especially when the EAS physician is sponsored by an advocacy organisation. Full text: https://goo.gl/dofE4s

- QUT LAW REVIEW, 2017;17(1):127-146. ‘Medical assistance in dying: Lessons for Australia from Canada.’ Canada has recently witnessed dramatic changes in end of life law and policy. Most notably, we have moved from a prohibitive to a permissive regime with respect to medical assistance in dying (MAiD). As a number of Australian states are actively engaged in debates about whether to decriminalise MAiD, it is worth reviewing the Canadian experience and drawing out any lessons that might usefully inform the current processes in Australia. Full text: https://goo.gl/Zh1EJc
Media Watch: Editorial Practice

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

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6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Media Watch: Online

International

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INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://goo.gl/frPgZ5
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[Scroll down to ‘Aggregators’ and ‘Media Watch by Barry Ashpole’]

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ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): https://goo.gl/IOSNC7
ONTARIO | Mississauga Halton Palliative Care Network: https://goo.gl/ds5wYC
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U.K. | Omega, the National Association for End-of-Life Care:  http://goo.gl/UfSZtu

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