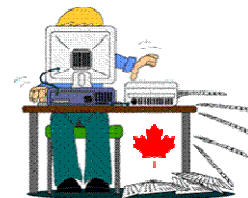


## Media Watch...

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

Office of decedent affairs: Scroll down to [Specialist Publications](#) and 'Involved in the business of death: The social work role in post-mortem care' (p.12), in *Health & Social Work*.

## Canada

### Deaf and dying: How a volunteer team brings palliative care comfort through communication

ONTARIO | *The Ottawa Citizen* – 25 December 2016 – The dying woman had not been deaf, but the experience got [Monica Elaine] Campbell thinking about the communication needs of people like herself: the deaf and hard of hearing. A few years later, Campbell was asked to help a deaf friend who was about to receive bad news about her cancer diagnosis. "I didn't know much about palliative care (PC), but she was struggling with her terminal illness," Campbell said. "I thought, my goodness, what if that was me? I thought, I should talk to my deaf friends about death and dying and what our experiences have been." Those conversations led Campbell and her friend, sign language interpreter Christine Wilson, to start up the Ottawa Deaf Palliative Care Team, a group of volunteers that provide end-of-life care for the deaf and hard of hearing and their families. In 1999, she enrolled in PC courses ... with two deaf colleagues. The group received additional training from Hospice Care Ottawa. It took five years to get up and running, but since 2009, the Deaf Palliative Care Team has helped inform and console the deaf and hard of hearing, breaking through their sense of isolation... <https://goo.gl/W0ZDVM>

### [Specialist Publications](#)

'Utilisation of home-based physician, nurse and personal support worker services within a palliative care programme in Ontario, Canada: Trends over 2005-2015' (p.11), in *Health & Social Care in the Community*.

'A population-based study of care at the end of life among people with HIV in Ontario from 2010 to 2013' (p.11), in *Journal of Acquired Immune Deficiency Syndromes*.

'Understanding the relationship between suffering and capacity at the end of life: A pilot study' (p.11), a Law Commission of Ontario report.

'Health care consent, advance care planning, and goals of care practice tools: The challenge to get it right' (p.12), a Law Commission of Ontario report.

'Speak of the dead: Semantic domination and death taboos in Québec and France' (p.12), in *Québec Studies*.

Cont.

Noted in Media Watch 4 April 2016, #456 (p.13):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 1 April 2016 – ‘**Hearing loss in hospice and palliative care: A national survey of providers.**’ Age-related hearing loss can impair patient-provider communication about symptom management, goals of care, and end-of-life decision making. <http://goo.gl/DCC813>

**N.B.** Additional articles on hearing loss in the context of end-of-life care are noted in this issue of Media Watch.

### Thousands of Canadians languish in limbo as they wait for long-term care

*THE GLOBE & MAIL* | Online – 23 December 2016 – According to the Canadian Institute for Health Information, there were, at last count, 6,671 patients in Canada listed as “alternate level of care,” or ALC,<sup>1</sup> an Orwellian euphemism used to describe patients stuck in this care limbo – too well to be in hospital, not well enough to be at home alone, and no place at the long-term care inn. One study, conducted by Pamela Jarrett, a geriatrician at Horizon Health in Saint John [New Brunswick], found that patients tend to be stuck in this state of “transitional care” for a long time – a median of 182 days, ranging from five days to a mind-boggling 6,852 days (that’s 18.7 years). The ALC problem is not unique to Canada – many countries’ health systems are struggling to adjust to an aging population, soaring dementia rates and getting the proper balance of hospital beds, long-term care beds and home-care services – but the magnitude and the perseverance of the issue is uniquely Canadian. <https://goo.gl/sj8ZNF>

1. ‘Classifications & Terminologies (Alternate level of care),’ Canadian Institute for Health Information, December 2016. <https://goo.gl/ZEAWUI>

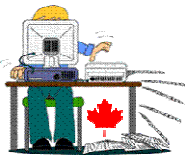
### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CTV News | Online – 28 December 2016 – ‘**At least 744 assisted-deaths in Canada since law passed: CTV News analysis.**’ At least 744 gravely ill adults received a doctor’s help to end their lives since the medical procedure became legal across Canada in 2016, and experts say those numbers are expected to rise. CTV News surveyed provincial and territorial health ministries to gather the most comprehensive picture of the practice to date. The numbers show that, on average, two Canadians per day had medically assisted deaths between 17 June and 16 December. <https://goo.gl/g6LcSU>

#### [Specialist Publications](#)

‘**Organ donation after medical assistance in dying or cessation of life-sustaining treatment requested by conscious patients: The Canadian context**’ (p.22), in *Journal of Medical Ethics*



#### [Barry R. Ashpole](#)

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

## U.S.A.

### All he wants is to die in his native Cuba

INDIANA | *The Indianapolis Star* – 27 December 2016 – Since that day in 1980 when Lazaro Blanco Garcia set foot in Key West, Florida, he has not returned to his native Cuba. But when doctors told him they could do nothing more to treat the prostate cancer that has plagued him for 11 years, he had just one thought: I want to go home. Garcia, 59, knows he has limited time on this earth, and he wants to spend those days where he began his life, in the coastal city of Matanzas, Cuba, about 65 miles east of Havana. “I feel like I’m American. I have even more years in America than I have living in my own country,” said Garcia, who lives in the Fountain Square area. “I would do anything for America, but I have to go and be next to my family in Cuba for my final wish.” Returning to Cuba will not be easy. Not only does Garcia have to fill out reams of re-entry papers, he realizes it will take money, not only to transport himself and his belongings but also to help support him once he relocates. <https://goo.gl/IBRJHX>

Noted in Media Watch 18 August 2014, #371 (p.11):

- *SUPPORTIVE CARE IN CANCER* | Online – 16 August 2014 – ‘**I want to fly home: A terminal cancer patient’s right to go home.**’ As palliative care physicians, we sometimes find ourselves immersed in the dilemma of a patient with terminal cancer requesting to fly back home, often overseas. This particular situation is filled with an array of complex variables: establishing that the medical condition is stable enough for overseas travel, dealing with a significant cost, securing proper care on the receiving end, symptom management during flight, and dealing with the possibility of in-flight death, among others. <https://goo.gl/WMOtRL>

“Art can help doctors hit the pause button – and refocus our attention on the patient”

### What doctors can learn from looking at art

*THE NEW YORK TIMES* | Online – 22 December 2016 – Medical schools are increasingly using art to teach medicine. One of the first classes was started by Dr. Irwin Braverman, a professor of dermatology at Yale. Dr. Braverman noted that doctors in training often didn’t completely and accurately describe what they saw – instead jumping to conclusions or relying on technology to make a diagnosis. He thought asking students to describe something non-medical, like art, might help them collect and relay visual information. His intuition was correct: Students who took his course were 10% more likely to pick up on important details in their patients. This finding caught the eye of other medical educators, including Dr. Joel Katz at Harvard. Dr. Katz ... director of the internal medicine residency program at Brigham & Women’s Hospital, co-created a nine-week course in 2003 called ‘Training the Eye: Improving the Art of Physical Diagnosis’ for first- and second-year medical students. Students meet weekly with curators at museums throughout Boston to study concepts ranging from symmetry and texture to form and motion. <https://goo.gl/DgOKIR>

### Specialist Publications

‘**Palliative care and patient autonomy: Moving beyond prohibitions against hastening death**’ (p.10), in *Health Service Insights*.

‘**Dementia caregivers and live discharge from hospice: What happens when hospice leaves?**’ (p.14), in *Journal of Gerontological Social Work*.

‘**Supporting family caregivers of older Americans**’ (p.20), in *New England Journal of Medicine*.

## Nursing home for prison inmates...

GEORGIA | *The Atlanta Journal-Constitution* – 19 December 2016 – A former prison doctor has opened a nursing home that will take up to 280 elderly and infirm inmates who otherwise might not have a place to go when they're paroled. "Even for a person who has no health issues, finding appropriate housing when on parole can be very, very complicated," said Sara Totonchi, executive director of the Southern Center for Human Rights. "When you add in health issues or mobility issues or other challenges it can be nearly impossible to find." The Bostick Nursing Center in Milledgeville, on the site of a demolished prison, is the first in Georgia that was conceived specifically for parolees. It will begin accepting parolee-residents early next year. There were already three nursing homes in South Georgia that accepted parolees, but catered to the general public... With no spaces specifically set aside for one-time prisoners, parolees are accepted only if there is room; each has between 10 and 20 parolees in residence... <https://goo.gl/WAw8iT>

**N.B.** End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report can be downloaded at: <http://goo.gl/ZpEJyQ>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- WASHINGTON DC | *The Washington Examiner* – 20 December 2016 – '**DC mayor signs assisted suicide bill.**' District of Columbia Mayor Muriel Bowser signed into law ... a bill that would make assisted suicide legal in the district... If approved by Congress, the district would join six states that allow assisted suicide for the terminally ill. The bill, which the D.C. Council approved last month, would enable someone 18 years or older who is mentally capable and terminally ill to end their life. It sets up reporting requirements for physicians and the district's Department of Health. <https://goo.gl/i7p31q>
- *THE WASHINGTON POST* | Online – 15 December 2016 – '**At last, American psychiatrists speak out on euthanasia.**' The American Psychiatric Association (APA) gave final approval to a policy statement declaring its ethical opposition to psychiatric participation in assisted suicide or euthanasia for a non-terminal patient... Obviously, this is of little immediate practical effect in the U.S., because non-terminal cases are not eligible for assisted death – but given the potential slippery slope in this area, the APA statement lays down an important marker for the future. <https://goo.gl/INqZH8>

## International

### How many minimally conscious patients are there [in the U.K.]?

U.K. (England, Northern Ireland, Scotland, & Wales) | BBC News – 21 December 2016 – Advances in medicine have meant that many more people survive traumatic incidents than in the past. Many people will have "prolonged disorders of consciousness" – either in a coma or vegetative state, where they show no awareness of their environment, or a minimally conscious state ... where they show very limited awareness. However, the National Health Service (NHS) does not publish data on these patients, so ... the BBC requested the information from all individual Clinical Commissioning Groups and NHS bodies across the U.K. The responses showed that more than 100 people with prolonged disorders of consciousness are currently being cared for by the NHS. Many of the 105 patients declared by health authorities have

been in this state for more than six months. The data comes from a BBC Freedom of Information enquiry, but gives a very incomplete picture, as only a quarter of all bodies responded. In the most extreme of these cases ... a patient cared for by the Western Health & Social Care Trust in Northern Ireland had been in a minimally conscious state for 20 years. <https://goo.gl/qopcc1>

### Specialist Publications

'A matter of life and death: Controversy at the interface between clinical and legal decision-making in prolonged disorders of consciousness' (p.15), in *Journal of Medical Ethics*.

## Elder care in Ireland

### Right of older people to decide on care being infringed

IRELAND | *The Irish Times* (Dublin) – 18 December 2016 – The right of older people to make decisions about their care is increasingly being infringed, according to an advocacy group working with residents of nursing homes.<sup>1</sup> Up to 70% of the cases dealt with by Sage, a support and advocacy service for older people, involve family conflicts over care arrangements, it says. The situation is being exacerbated by a delay in implementing new laws to provide older people with guaranteed rights on their independence. The Assisted Decision-Making (Capacity) Act was signed into law by President Higgins a year ago but most of it has yet to be commenced. Sage says it has worked on cases where the views of older people on their care provision have been ignored, where older people have been kept in nursing homes against their will, and where *gardaí* [i.e., state police] have had to be called to protect their property and other rights. The new Act, when it is fully commenced, will see the setting up of decision-support services to assist where people do not have full capacity. <https://goo.gl/mrnQNX>

1. 'Meeting Older People's Preference for Care: Policy, but what about practice?' Irish Association of Social Workers, Age Action, the Alzheimer Society of Ireland, and the School of Social Policy, Social Work & Social Justice, University College Dublin, 2016. <https://goo.gl/BwnVaa>

Noted in Media Watch 6 June 2016, #465 (p.6):

- IRELAND | BreakNews.ie (Blackpool, County Cork) – 3 June 2016 – **'Government "not providing proper support" for people who want to age at home.'** The Government has been accused of only paying lip-service to their promise to help the elderly stay in their own homes, as they age. A new report claims half of all nursing home residents could still be living at home, if they were given the right support.  
<http://goo.gl/KE0ZKb>

Noted in Media Watch 21 March 2016, #454 (p.10):

- *IRISH JOURNAL OF MEDICAL SCIENCE* | Online – 16 March 2016 – **'The Assisted Decision-Making (Capacity) Act 2015: What it is and why it matters.'** The Act outlines three levels of decision-making assistance: "decision-making assistant," "co-decision-maker" (joint decision-maker) and "decision-making representative" (substitute decision-maker). There are procedures relating to "enduring power of attorney" and "advance healthcare directives"; in the case of the latter, a "refusal of treatment" can be legally binding, while a "request for a specific treatment" must "be taken into consideration." <https://goo.gl/VcC5Qy>

## Specialist Publications

'Barriers to the development of pediatric palliative care in Italy' (p.6), in *Annali dell'Istituto Superiore di Sanità*.

'New legal regulations for palliative care with implications for politics and practice [in Germany]' (p.7), in *Bundesgesundheitsblatt – Gesundheitsforschung – Gesundheitsschutz*.

'Advances in hospice and palliative care in Japan: A review paper' (p.16), in *Korean Journal of Hospice & Palliative Care*.

'Palliative sedation: The position statement of the Italian National Committee for Bioethics' (p.19), in *Minerva Anestesiologica*.

'Position paper of the Italian Association of Medical Oncology on early palliative care in oncology practice (simultaneous care)' (p.17), in *Tumori Journal*.

## Specialist Publications

### **Palliative care processes embedded in the ICU workflow may reserve palliative care teams for refractory cases**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 21 December 2016 – Palliative care (PC) teams have been shown to be instrumental in the early identification of multiple aspects of advanced care planning (ACP). Despite an increased number of services to meet the rising consultation demand, it is conceivable that the numbers of PC consultations generated from an ICU alone could become overwhelming for an existing PC team. A structured, PC, quality-improvement program was implemented and evaluated in the ICU at Kaiser Permanente Medical Center in Hawaii. This included selecting trigger criteria, a care model, forming guidelines, and developing evaluation criteria. Main outcome measures included the early identification of the multiple features of ACP, numbers of proactive ICU and PC family meetings, and changes in code status and treatment upon completion of either meeting. Early identification of goals-of-care, advance directives, and code status by the ICU staff led to a proactive ICU family meeting with resultant increases in changes in code status and treatment. The numbers of PC consultations also rose, but not significantly. <https://goo.gl/9tkTM8>

#### **Related**

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 21 December 2016 – ‘**Palliative workforce development and a regional training program.**’ Given the shortage of palliative medicine specialist providers, hospitals may be better served by having members of palliative medicine teams have time allocated to the education of health care providers who would benefit from a foundation in primary palliative care (PC) skills, such as communication skills and skills in pain and symptom management. The high demand for services without commensurate changes in staffing levels leads to concerns of clinician burnout and adverse impact on the sustainability of PC team and programs. <https://goo.gl/99QEh0>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 21 December 2016 – ‘**Illustrating and analyzing the processes of interprofessional collaboration: A lesson learned from palliative care in deconstructing the concept.**’ Transformative change in healthcare education and clinical practice involves interprofessional collaboration of colleagues within, across, and beyond universities/colleges and healthcare systems and agencies. Advocating for teamwork has to go beyond talking about being a team player or not to having the language and behaviors we need to observe and measure. This article not only provides key processes in interprofessional collaboration, but also identifies key attitudes and behaviors critical to teamwork. <https://goo.gl/iFoFzw>

### **Barriers to the development of pediatric palliative care in Italy**

*ANNALI DELL'ISTITUTO SUPERIORE DI SANITÀ*, 2016;52(4):558-564. It has become evident many of the barriers are strictly related to the political, social, cultural, traditional, legislative, geographical and organizational characteristics of the country. Other countries may be faced with similar or different difficulties depending on their specific social, political and health care organization. For this reason a comparison between the Italian situation and that of other countries has not been considered in this study. Numerous crucial issues and barriers have been identified. Some, like the political and cultural issues, are difficult to modulate and modify, while others are easier to influence and overcome, such as the shortage of appropriate training programs for healthcare professionals. All these issues and barriers necessitate a change of approach: the problem of pediatric palliative care (PPC) needs to be acknowledged socially, professionally and at planning level, and be recognized as an indispensable service for incurable pediatric patients. The authors' analysis ... provides the necessary basis for formulating proposals and establishing strategies for implementing, supporting, correcting PPC services in Italy. <https://goo.gl/iQfzW2>

**N.B.** Italian language article.

Cont.

Noted in Media Watch 12 May 2014, #357 (p.12):

- *THE LANCET*, 2014;383(9928):1547-1548. '**A charter for the rights of the dying child.**' The death of a child is a devastating and tragic event for all those involved... But, it is the children who pay the highest price, suffering, and coping directly with the burden of incurable illness and death, the trauma of separation, the loss of their future and often, in solitude, the consequences of their illness, fears, and emotions. In September 2012, a group of professionals working with children affected by incurable illness in Italy launched a project to formulate a charter of rights for children approaching the end of their lives [i.e., The 'Trieste Charter – The Charter of the Rights of the Dying Child']. <https://goo.gl/RNtS8D>

### **Development and validation of a new patient experience tool in patients with serious illness**

*BMC PALLIATIVE CARE* | Online – 31 December 2016 – Patients with serious chronic illnesses face increasingly complex care and are at risk of poor experience due to a fragmented health system. Most current patient experience tools are not designed to address the unique care aspects of this population and the few that exist are delivered too late in the disease trajectory and are not administered longitudinally which makes them less useful across settings. The authors developed a new tool designed to address these gaps. The 25 item scale was tested and refined using randomly cross-validated exploratory and confirmatory factor analyses. Participants were not yet hospice eligible, but sick enough to receive benefits of a supportive care approach in the last 2 to 3 years of life. When administered earlier in the chronic illness trajectory, the new patient experience scale focused on care teams across settings, communication, and care goals, displayed strong reliability and performed well psychometrically. <https://goo.gl/arITYk>

#### End-of-life care in Germany

### **New legal regulations for palliative care with implications for politics and practice**

*BUNDESGESUNDHEITSBLATT – GESUNDHEITSFORSCHUNG – GESUNDHEITSSCHUTZ* | Online – 19 December 2016 – In 2015, two different laws were adopted. Both are of importance for palliative care (PC). One criminalizes commercial, "business-like" assisted suicide, the other aims to improve hospice and PC in Germany. The new Improve Hospice & Palliative Care Act focuses ... on: 1) Better funding of hospice services, by raising the minimum grant for patients in inpatient hospices paid per day by the health insurance funds by about 28.5%, and for outpatient hospice services by about 18%; 2) Further development of general outpatient nursing and medical PC, and the networking of different service providers; 3) Introduction of an arbitration procedure for service provider agreements to be concluded between the health insurance funds and the teams providing specialized home PC; 4) The right to individual advice and support by the health insurance funds; 5) Care homes may offer their residents advance care planning programs to be funded by the statutory health insurers; 6) PC units in hospitals can be remunerated outside the diagnosis-related-groups system by *per diem* rates; 7) Separate funding and criteria for multi-professional PC services within a hospital. <https://goo.gl/rSM5Yn>

**N.B.** German language article.

#### **Related**

- *MORTALITY* | Online – 21 December 2016 – '**When the dying do not feel tabooed: Perspectives of the terminally ill in Western Germany.**' This paper primarily examines the perspectives of dying persons in Germany, in terms of if and when the dying feels lonely during their final weeks. The paper explores how and where the dying persons included in the study want to pass away. The dying individuals involved did not feel tabooed or ignored by non-dying persons. <https://goo.gl/MU1eGS>



### 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.22.

## Ensuring quality in online palliative care resources

*CANCERS* | Online – 13 December 2016 – Evidence and information is an integral part of the processes enabling clinical and service delivery within health. It is used by health professionals in clinical practice and in developing their professional knowledge, by policy makers in decision making, and is sought by health consumers to help them manage their health needs and assess their options. Increasingly, this evidence and information is being disseminated and sought through online channels. The internet is fundamentally changing how health information is being distributed and accessed. Clinicians, patients, community members, and decision makers have an unprecedented capacity to find online information about palliative care (PC) and end-of-life care. However, it is clear that not all individuals have the skills to be able to find and assess the quality of the resources they need. <https://goo.gl/c1RC98>

### Related

- *JOURNAL OF HEALTH COMMUNICATION* | Online – 21 December 2016 – ‘**The influence of eHealth literacy on perceived trust in online health communication channels and sources.**’ eHealth literacy [in this study] positively predicted perceived trust in online health communication channels and sources, but disparities existed by socio-demographic factors. Segmenting audiences according to eHealth literacy level provides a detailed understanding of how perceived trust in discrete online health communication channels and information sources varies among diverse audiences. <https://goo.gl/6ru4yR>

**N.B.** Researchers have observed that Wikipedia, by default, is “the world’s chief source of information.” The quality of that information, however, is “highly variable.” [See Media Watch 22 June 2015, #415 (p.15)]  
**BRA**

## Not “out of sight, out of mind”: Interventions to relieve suffering for bereaved families after an ICU death

*CRITICAL CARE MEDICINE*, 2017;45(1):134-136. Bereaved family members of ICU decedents suffer from a high burden of emotional and psychologic distress when a loved one dies. The burden can be especially high for family members who participated in end-of-life decisions. Complicated grief is five-fold higher in bereaved families of patients who die in the ICU compared with the general population, and anxiety, depression, and post-traumatic stress disorder (PTSD) symptoms affect 30-50% of bereaved family members months and even years following the loss of their loved one. A 2010 Task Force from the Society of Critical Care [Medicine] proposed the term “post-intensive care syndrome-family” to describe these persistent symptoms.<sup>1</sup> To date, interventions to improve outcomes for bereaved ISU families have primarily been tested prior to or during ICU admission. Interventions such as preparation of advance directives, informational brochures, improving communications with the ICU team, and providing additional support with palliative care specialists and structured family meetings during the ICU admission are associated with reduced anxiety, depression, and PTSD symptoms up to six months after a loved one dies. Unfortunately, the overall impact of these interventions has been relatively modest. <https://goo.gl/t0DVSe>

1. ‘Post-intensive Care Syndrome,’ Society of Critical Care Medicine, 2010. <https://goo.gl/vzLweQ>

Noted in Media Watch 27 June 2016, #468 (p.9):

- *AMERICAN JOURNAL OF CRITICAL CARE*, 2016;25(2):110-117. ‘**Bereavement services offered in adult intensive care units in the U.S.**’ Most survey respondents reported that their ICUs did not offer bereavement follow-up services, and many barriers were noted. When bereavement follow-up care was offered, it was mainly informal (e.g., condolence cards, brochures). ICUs in hospitals with palliative care (PC) were almost eight times more likely to provide bereavement support than were ICUs in hospitals without PC. <http://goo.gl/48KIL7>



## **Palliative care and chronic obstructive pulmonary disease: Where the lines meet**

*CURRENT OPINION IN PULMONARY MEDICINE* | Online – 21 December 2016 – Chronic obstructive pulmonary disease (COPD) is a leading cause of morbidity and mortality worldwide and is expected to increase as the population ages. Patients have a high symptom burden, low healthcare quality of life, and unmet needs at the end of life. This review highlights specific palliative care (PC) needs of patients with advanced COPD and opportunities to integrate PC into standard practice. There are many barriers to providing integrated PC in COPD, including difficulty with prognostication, communication barriers surrounding advance care planning, and lack of access to specialty PC. Because of the unique disease trajectory, emphases on early and primary PC are being studied in this patient population. The line between life prolonging and PC undoubtedly overlaps and maximizing quality of life throughout the continuum of care should be prioritized for patients with this progressive illness. <https://goo.gl/r1rv5d>

### **Selected articles on palliative care and chronic obstructive pulmonary disease**

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 8 July 2016 – ‘**Resource use and health care costs of chronic obstructive pulmonary disease patients at the end of life: A systematic review.**’ Patients with chronic obstructive pulmonary disease in their final months of life potentially place a high burden upon health care systems. Concrete knowledge about resources used and costs incurred by those patients at the end of life is crucial for policymakers. [Noted in Media Watch 18 July 2016, #471 (p.12)] <http://goo.gl/kONp25>
- *BMC PALLIATIVE CARE* | Online – 13 February 2016 – ‘**Towards integration of palliative care in patients with chronic heart failure and COPD: A systematic literature review of European guidelines and pathways.**’ The results of this study illustrate that there is a growing awareness for the importance of palliative care in patients with advanced chronic heart failure and chronic obstructive pulmonary disease. At the same time, however, they signal the need for the development of standardized and conceptually unambiguous strategies so existing barriers are alleviated. [Noted in Media Watch, 15 February 2016, #449 (p.9)] <http://goo.gl/YSVbDV>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 17 May 2015 – ‘**Evaluation of the patterns of care provided to patients with COPD compared to patients with lung cancer who died in hospital.**’ The authors compared the end-of-life care provided patients with chronic obstructive pulmonary disease versus patients with lung cancer who died in hospital over a 12-month period... Patients with COPD received less palliative care services and underwent more diagnostic tests and received more life-prolonging measures. [Noted in Media Watch, 25 May 2015, #411 (p.14)] <http://goo.gl/YpTdql>

## **Improving cancer care for children in the developing world: Challenges and strategies**

*CURRENT PEDIATRIC REVIEWS* | Online – 30 December 2016 – Cancer is a global health problem particularly in developing countries where the burden of cancer is ever increasing and claiming the lives of about 100,000 children under the age of 15 years every year. Majority of these occur in the low- and middle-income countries where 90% of world children live. Contributing factors to this trend is the reduction of communicable diseases and emergence of new infections, improvement of nutrition and socio-economic conditions, industrialization and urbanization. However, due to its complexity, childhood cancer is given the least priority by the governments’ funding. The weak health systems, poor and late access to diagnosis and care, fewer numbers of trained health care professionals and lack of cancer drugs are amongst the many challenges faced. A major challenge for the future is extending the work to reach the many children who die without access to cancer treatment and palliation. In resource-limited settings without specialized services, much can still be done to support and offer curative and palliative treatment. <https://goo.gl/fDJuFB>

## Palliative care in heart failure: Facts and numbers

*ESC HEART FAILURE* | Online – 28 December 2016 – Despite enormous advances in care that have improved outcome, heart failure remains associated with a poor prognosis. Worldwide, there is poor short-term and long-term survival. The 1 year survival following a heart failure admission is in the range of 20-40% with between-country variation. For those living with heart failure, the symptom burden is high. Studies report that 55 to 95% of patients experience shortness of breath and 63 to 93% experience tiredness. These symptoms are associated with a high level of distress (43-89%). Fewer patients experience symptoms such as constipation (25-30%) or dry mouth (35-74%). However, when they do, such symptoms are associated with high levels of distress (constipation: 15-39%; dry mouth: 14-33%). Psychological symptoms also predominate with possibly as many as 50% experiencing depression. Palliative care (PC) services in heart failure are not widely available. Even in countries with well-developed services, only around 4% of patients are referred for specialist PC. Many patients and their families would benefit from receiving specialist PC support. <https://goo.gl/erqxTu>

### Related

- *HEART & LUNG*, 2017;46(1):1-2. **‘Generating high quality evidence in palliative and end-of-life care.’** Palliative care (PC) .. is receiving increasing attention as an essential component of care in critical and complex illness. Research to develop, test and validate best practice in PC during critical and complex illness is, however, sparse. In this special issue of *Heart & Lung*, we have assembled a set of exemplary research in measurement, intervention development, and health services across the continuum of care in critical and complex illness. <https://goo.gl/0xpRtl>

**N.B.** This issue of *Heart & Lung* includes several articles on end-of-life care. Journal contents page: <https://goo.gl/7dl9hk>

## Palliative care and patient autonomy: Moving beyond prohibitions against hastening death

*HEALTH SERVICE INSIGHTS*, 2016;9:37-42. The [U.S.] National Hospice & Palliative Care Organization (NHPCO) upholds policies prohibiting practices that deliberately hasten death. The authors find these policies overly restrictive and unreasonable. They argue that under specified circumstances it is both reasonable and morally sound to allow for treatments that may deliberately hasten death; these treatments should be part of the NHPCO guidelines. Broadening such policies would be more consistent with the gold standard of bioethical principles, i.e., respecting the autonomy of competent adults. We have yet to reach consensus on the reasonableness of hastening death. Recent expansion of physician assisted suicide (PAS) legislation indicates that PAS will likely be legal in most if not all states in the foreseeable future. Some dying patients are already taking matters into their own hands by requesting PAS and, where not available, engaging in voluntarily stop eating and drinking. The desire on the part of dying patients to be more in control of their deaths is unlikely to diminish. If anything it will increase, especially as our population ages and the ability to maintain our physiological corpus continues to improve. NHPCO policies should be consistent with respecting the morally sound and reasonable wishes of dying patients, which may include hastening death. <https://goo.gl/a82ekQ>

### Related

- *NURSING TIMES* | Online – 22 December 2016 – **‘Royal College of Nursing updates guidance on “I want to die” requests.’** The Royal College of Nursing has published revised guidelines for nurses and healthcare assistants on how to respond to requests from patients related to assisted suicide.<sup>1</sup> The guidance ... sets out the legal position for healthcare workers in such situations ... [and] ... provides practical examples of how to deal with difficult conversations and deliver good quality end-of-life care. <https://goo.gl/0MhLCa>

1. ‘When someone asks for your assistance to die: Royal College of Nursing guidance on responding to a request to hasten death,’ Royal College of Nursing, December 2016. <https://goo.gl/N0JS2S>

Cont.

Noted in Media Watch 24 October 2016, #484 (p.13):

- *PALLIATIVE MEDICINE* | Online – 19 October 2016 – ‘**Assessment of the wish to hasten death in patients with advanced disease: A systematic review of measurement instruments.**’ Of the seven instruments identified, the Desire for Death Rating Scale or the Schedule of Attitudes toward Hastened Death feature in 48 of the 50 articles reviewed. The Schedule of Attitudes toward Hastened Death is the most widely used and is the instrument whose psychometric properties have been most often analysed. <https://goo.gl/tgJmM4>

**N.B.** Additional articles on the desire to hastened death are noted in Media Watch 7 March 2016, #452 (pp.8-9)

### End-of-life care in Canada

#### **Utilisation of home-based physician, nurse and personal support worker services within a palliative care programme in Ontario, Canada: Trends over 2005-2015**

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 26 December 2016 – With health system restructuring in Canada and a general preference by care recipients and their families to receive palliative care (PC) at home, attention to home-based PC continues to increase. A multidisciplinary team of health professionals is the most common delivery model for home-based PC in Canada. However, little is known about the changing temporal trends in the propensity and intensity of home-based PC. The purpose of this study was to assess the propensity to use home-based PC services, and once used, the intensity of that use for three main service categories: 1) Physician visits; 2) Nurse visits; and, 3) Care by personal support workers (PSWs) over the last decade. Three prospective cohort data sets were used to track changes in service use over the period 2005 to 2015. Both the propensity and intensity to use home-based physician visits and PSWs increased over the last decade, while service propensity and the intensity of nurse visits decreased. Meanwhile, there was a general tendency for service propensity and intensity to increase as the end of life approached. These findings demonstrate temporal changes towards increased use of home-based PC and a shift to substitute care away from nursing to less expensive forms of care, specifically PSWs. These findings may provide a general idea of the types of services that are used more intensely and require more resources from multidisciplinary teams, as increased use of home-based PC has placed dramatic pressures on the budgets of local home and community care organisations. <https://goo.gl/4IZ79V>

#### **Related**

- *JOURNAL OF ACQUIRED IMMUNE DEFICIENCY SYNDROMES* | Online – 7 December 2016 – ‘**A population-based study of care at the end of life among people with HIV in Ontario from 2010 to 2013.**’ Aging and increasing co-morbidity is changing the end-of-life experience of people living with HIV (PLHIV) in the developed world. The authors quantified, at a population level, the receipt of health care services and associated costs across a comprehensive set of sectors among decedents with and without HIV. They observed 264,754 eligible deaths, 570 of whom had HIV. PLHIV were significantly younger than those without HIV... PLHIV spent a mean of 20.0 days in an acute care hospital in the last 90 days of life compared to 12.1 days for decedents without HIV; HIV was associated with 4.5 more acute care days. Mean cost of care in the last year were significantly higher among PLHIV (\$80,885.62 vs. \$53,869.77), mostly attributable to acute care costs. <https://goo.gl/tYnV7V>
- LAW COMMISSION OF ONTARIO | Online – Accessed 30 December 2016 – ‘**Understanding the relationship between suffering and capacity at the end of life: A pilot study.**’ The authors found that because decisions made at the end of life are highly consequential and made in a context in which intense emotions and a variety of factors interact with decision-making, existing mechanisms for capacity assessment may be inadequate or insufficient for this particular patient group in the circumstances of their condition. By merely relying on a legal cognitive capacity test, health care providers are unable to account for the entire intricate web encircling a patient at the end of their life. They also find it hard to assess how suffering can affect a patient’s decision-making ability. It appears that capacity assessments as they are currently conceived and conducted are not sufficiently capturing the complexity of decision making at the end-of-life. <https://goo.gl/nDbrwo>

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- LAW COMMISSION OF ONTARIO | Online – Accessed 30 December 2016 – ‘**Health care consent, advance care planning, and goals of care practice tools: The challenge to get it right.**’ The conclusion and recommendations section [of this report] summarizes that while informed consent is fundamental to patient-centred care, the various issues and challenges identified ... suggest that it is often neglected. Efforts that are meant to empower patients place little to no emphasis on health care consent and embed a model of advance care planning that is not aligned with Ontario legislation. As a result, patients’ rights to make informed decisions about their own care may be compromised. The conclusion [of the authors] is that a set of standardized practice tools would not be possible because tool development is so widespread, it has become an “industry.” Furthermore, there is no one set of “perfect” practice tools. There are different types of health practices and services so everyone sees need for variants on a tool as no one set of products would meet all needs.

**N.B.** Access this and the Commission’s other reports in its initiative ‘Improving the last stages of life,’ at: <https://goo.gl/7PPU2y>.

**Related**

- *HEALTHCARE POLICY*, 2016;12(2):13-18. ‘**Doctors, lawyers and advance care planning: Time for innovation to work together to meet client needs.**’ Health organizations in Canada have invested considerable resources in strategies to improve knowledge and uptake of advance care planning (ACP). Yet barriers persist and many Canadians do not engage in the full range of ACP behaviours, including writing an advance directive and appointing a legally authorized decision-maker. This article advocates for greater collaboration between health and legal professionals to better support clients in ACP and presents a framework for action to build connections between these typically siloed professions. <https://goo.gl/ob17py>
- *QUÉBEC STUDIES*, 2016;62(2):71-93. ‘**Speak of the dead: Semantic domination and death taboos in Québec and France.**’ Mortuary linguistic products, such as obituaries, are carefully constructed using euphemism and metaphor to preserve cultural taboos on death and reinforce normative comprehensions of dying and grief. Because of the fundamentally metaphorical nature of both language and thought I argue that linguistic taboos not only reinforce social norms, but also place boundaries on our perceptions, conceptions, and reactions to the world in which we function. This study analyzes metaphorical phenomena in French language obituaries in Montreal and Paris in order to explore expressive, cultural, and conceptual gaps (or lack thereof) between Standard French and Québécois linguistic production and to examine the implications of these gaps in the comprehension and experience of dying and bereavement. <https://goo.gl/i6J58s>

**Involved in the business of death: The social work role in post-mortem care**

*HEALTH & SOCIAL WORK* | Online – 15 December 2016 – One way that hospitals address concerns about post-mortem care is through an office of decedent affairs (ODA). Many hospitals use this office to collect death paperwork, release bodies to funeral homes, perform autopsies, or increase rates of autopsies and organ and tissue donations. It is not common for an ODA to report to the Department of Social Work rather than the Department of Pathology. Few offices put the emphasis on post-mortem care for families or staff members. A comprehensive post-mortem program needs many different components, including support to families (e.g., viewing the dead, advising on next steps after a death, and providing bereavement support), consulting with and supporting multidisciplinary staffers, and coordinating with multiple medical center departments. This article examines a hospital’s use of social work principles and clinical training to provide leadership to an ODA and describes the key elements and advantages of a successful program. <https://goo.gl/ttl5Oj>



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## Sense of control in end-of-life decision-making

*JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 28 December 2016 – Participants in this study [i.e., community-dwelling adults aged 67 to 98 with a life expectancy of less than 1 year] generally delegated decisions to others, expressing their wishes by describing desired end-of-life outcomes and highlighting meaningful aspects of their lives. They did this in the belief that the delegate would make appropriate decisions on their behalf. In this way, participants were able to achieve a sense of control without being in control of decisions. Four themes emerged from the analysis that reflect the various approaches participants used to articulate their goals and maintain a sense of control: 1) Direct communication 2) Third-party analogies; 3) Adaptive denial; and, 4) Engaged avoidance. These findings challenge the prevailing view of personal autonomy. These older adults suggest a path to decision-making that focuses on priorities and goals, allowing them to take a more-passive approach to decision-making while still maintaining a sense of control. <https://goo.gl/xM1Nix>

### Related

- *CHEST* | Online – Accessed 27 December 2017 – ‘**Instability of willingness to accept life-sustaining treatments of patients with advanced chronic organ failure during one year.**’ The current findings show the complexity of preferences for end-of-life care and indicated once again that advance care planning is a continuous process between patients and physicians, in which preferences for specific situations were discussed and which needs to be regularly re-evaluated in order to deliver high-quality end-of-life care. <https://goo.gl/ioXeaG>
- *THE GERONTOLOGIST* | Online – 29 December 2016 – ‘**Considering the CPR decision through the lens of prospect theory in the context of advanced chronic illness.**’ It is common for people with advanced chronic illness to have many health care providers and many health care-related visits. It is also common, during those visits, to be asked whether attempts at CPR are desired, in the event of cardiac arrest. Although the question is common, the implications of a “yes” or a “no” may not be well understood. <https://goo.gl/P5Jxud>
- *HEC FORUM* | Online – 23 December 2016 – ‘**Licensing surrogate decision-makers.**’ Combined with the aging of society in most developed countries, an ever-growing number of patients will require surrogate decision-makers. While advance care planning by patients still capable of expressing their preferences about medical interventions and end-of-life care can improve the quality and accuracy of surrogate decisions, this is often not the case, not infrequently leading to demands for ineffective, inappropriate and prolonged interventions. <https://goo.gl/w4okim>

## Medical futility: A contemporary review

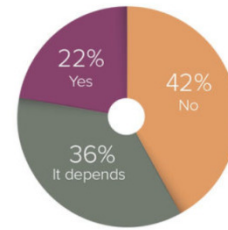
*JOURNAL OF CLINICAL ETHICS* | Online – Accessed 30 December 2016 – Although living in a pluralistic society presents one of the major reasons as to why, despite 30 years of intense discussion, no consensus has been made, the issue of medical futility will always be complex as it is, by nature, multifaceted, and numerous elements – including possible risks, evidence of the probability of benefit, the wishes of the patient (and family), professional standards, and cost – interact. Nevertheless, the global medical community has seen the development of two distinctly different approaches to medical futility: one in which the autonomy of patients is of paramount importance in the decision whether or not to pursue a treatment; and one in which beneficence and *primum non nocere* – first do no harm – are almost entirely the clinician’s prerogative, and whereby he/she has a duty to refuse any treatment for which the potential risks outweigh the potential benefits for the patient. Recently, however, there has been a rejection of this dichotomous view of medical futility and the apparent “power struggle” between physician and patient, and a positive movement towards a more collaborative decision-making process that highlights the necessity of communication, aiming to result in the obtainment of the best possible outcome for each patient as an individual. <https://goo.gl/2Rq13L>

Cont.

## Related

- *MEDSCAPE* | – 23 December 2016 – ‘**Medscape Ethics Report 2016: Life, death, and pain.**’ Every day, physicians grapple with wrenching life-and-death decisions. They often must weigh many factors (some conflicting), such as patient wishes, laws, right and wrong, one’s sense of duty... There are enough shades of gray such that the best course of action may not be obvious – and often there is no optimal course of action at all. *Medscape’s* Ethics Report premiered in 2010. Here, in its fourth report, more than 7,500 physicians from more than 25 specialties shared their often clashing views on issues about life, death, and patient suffering, with some notable shifts in attitude over the years. <https://goo.gl/L3ybuU>

Would you recommend life-sustaining therapy if you believed it would be futile?



- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 29 December 2016 – ‘**Racial differences persist in end-of-life care.**’ In multiple studies, black patients consistently received more aggressive intervention than did white patients. Over the years, U.S. studies have suggested that black patients tend to receive more aggressive medical intervention than white patients near the end of life. In 2016, a groundswell of research confirmed those earlier observations. <https://goo.gl/bRlm76>

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

#### **Dementia caregivers and live discharge from hospice: What happens when hospice leaves?**

*JOURNAL OF GERONTOLOGICAL SOCIAL WORK* | Online – 20 December 2016 – Hospice offers holistic support for individuals living with terminal illness and their caregivers. However, some individuals who enroll onto hospice services do not decline in health as quickly as determined by current regulations, termed a “live discharge.” Persons with dementia are among those who experience a live discharge due to the slow physical decline associated with the disease. When a live discharge occurs, it affects not only the patient but also the caregiver(s). There is very little data on the outcomes of persons who experience a live discharge and even less on their caretakers. Findings [of this study] emphasize the unique provisions covered under the Medicare Hospice benefit and the specific loss of services provided by the hospice team. Caregivers also made suggestions to improve the discharge process. <https://goo.gl/ZHvi0g>

#### **Related (U.K. perspective on end-of-life care for people living with dementia)**

- *BMJ OPEN* | Online – 21 December 2016 – ‘**Commissioning care for people with dementia at the end of life: A mixed-methods study.**’ A literature review generated three key themes: 1) Importance of joint commissioning; 2) Lack of clarity for the process; and, 3) Factors influencing commissioning. In exploring health professionals’ perceptions of the process, “uncertainty” was elicited as an overarching theme across the Clinical Commissioning Groups interviewed. Organisation of the process, lack of expertise, issues surrounding integration and the art of specification were considered important factors that contribute to the uncertainty surrounding the commissioning process. <https://goo.gl/GvAMv9>
- *JOURNAL OF CLINICAL NURSING* | Online – 20 December 2016 – ‘**Nursing home manager’s knowledge, attitudes and beliefs about advance care planning for people with dementia in long-term care settings: A cross-sectional survey.**’ Whilst nursing home managers recognise the potential benefits of advance care planning (ACP), barriers and challenges create a reluctance to facilitate. A gap between rhetoric and reality of implementation is evident, therefore long-term care settings must critically examine system, organisational and individual factors for failure to implement ACP for people with dementia. <https://goo.gl/633w1Z>

## **A matter of life and death: Controversy at the interface between clinical and legal decision-making in prolonged disorders of consciousness**

*JOURNAL OF MEDICAL ETHICS* | Online – 16 December 2016 – Best interests decision-making and end-of-life care for patients in permanent vegetative or minimally conscious states (VS/MCS) is a complex area of clinical and legal practice, which is poorly understood by most clinicians, lawyers and members of the public. In recent weeks, the Oxford Shrieval lecture by Mr. Justice Baker<sup>1</sup> ... and its subsequent reporting in the public press has sparked debate on the respective roles of clinicians, the Court of Protection and the Mental Capacity Act 2005 in decisions to withhold or withdraw life-sustaining treatments from patients with disorders of consciousness. The debate became polarised and confused by misquotation and inaccurate terminology, and highlighted a lack of knowledge about how patients in VS/MCS die in the absence of court approval. This article sets out the background and discussion and attempts to give a more accurate representation of the facts. In the spirit of transparency, the author presents a mortality review of all the patients in VS/MCS who have died under the care of his own unit in the last decade – with or without referral to the court, but always in accordance with the law. These data demonstrate that clinicians regularly undertake best interests decision-making in conjunction with families that may include life and death decisions (sometimes even the withdrawal or withholding of clinically assisted nutrition and hydration); and that these can be made within the current legal framework without necessarily involving the court in all cases. This is the first published case series of its kind. <https://goo.gl/UQcVVi>

1. 'A Matter of Life & Death,' Mr. Justice Baker, Oxford Shrieval Lecture 2016. <https://goo.gl/PiWeCJ>

Noted in Media Watch 31 October 2016, #485 (p.3):

- U.K. | *The Daily Mail* – 24 October 2016 – **'Don't obey orders in a living will, judge orders doctors: Ruling means patients in an unconscious state cannot die without the case going before a court.'** Living wills ... must no longer be obeyed by the medical profession, judges have ordered. They have declared that no one who is in a coma or an unconscious state should be allowed to die without the case first being considered by a court. The instructions set out by judges of the Court of Protection effectively strike down the 2005 Mental Capacity Act. <https://goo.gl/v6Vvu4>

## **Comprehensive and integrated palliative care for people with advanced chronic conditions: An update from several European initiatives and recommendations for policy**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 30 December 2016 – The number of people in their last years of life with advanced chronic conditions, palliative care (PC) needs and limited life prognosis due to different causes including multi-morbidity, organ failure, frailty, dementia, and cancer is rising. Such people represent more than 1% of the population. They are present in all care settings, cause around 75% of mortality, and may account for up to one third of total national health system spending. The response to their needs is usually late and largely based around institutional palliative care focused on cancer. There is a great need to identify these patients, and integrate an early palliative approach according to their individual needs in all settings, as suggested by the World Health Organization (WHO). Several tools have recently been developed in different European regions to identify patients with chronic conditions who might benefit from PC. Similarly, several models of integrated PC have been developed, some with a public health approach to promote access to all in need. The authors describe the characteristics of these initiatives, and suggest how to develop a comprehensive and integrated palliative approach in primary and hospital care, and to design public health and community-oriented practices to assess and respond to the needs in the whole population. Additionally, they report ethical challenges and prognostic issues raised, and emphasize the need for research to test the various tools and models to generate evidence about the benefits of these approaches to patients, their families and to the health system. <https://goo.gl/0plBX9>

## **Home-based palliative care for children with incurable cancer: Long-term perspectives of and impact on general practitioners**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 30 December 2016 – Although a large percentage of children with advanced-stage cancer die at home, remarkably little information is available regarding the experience of general practitioners (GPs) with respect to providing home-based palliative care (PC) to children with incurable cancer. A total of 112 GPs (78%) responded, and 91 GPs completed the questionnaire for 93 patients. The median interval between the child's death and completing the questionnaire was 7 years. The most prevalent symptoms reported in the patients were fatigue (67%) and pain (61%). Difficulties with communicating with (14%), coordinating with (11%), collaborating with (11%), and contacting (2%) fellow members of the multidisciplinary treatment team were rare. Hectic (7%) and shocking (5%) situations and panic (2%) around the child's death were rare. GPs reported feelings of sadness (61%) and/or powerlessness (43%) around the time of the patient's death, and they rated their own distress level as relatively high during the terminal phase... The majority of GPs (94%) reported that they ultimately came to terms with the child's death. In general, GPs appear to be satisfied with the quality of home-based PC that they provide pediatric patients with incurable cancer. Communication among health-care professionals is generally positive and is considered important. <https://goo.gl/TPioD7>

## **Pediatric cancer patients' important end-of-life issues, including quality of life: A survey of pediatric oncologists and nurses in Japan**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 21 December 2016 – A total of 157 pediatricians and 270 nurses participated in this study. Fifty-five items were refined to 35 "common and important" quality of life items. On factor analysis, 12 domains (containing 29 items) were identified: 1) Playing and learning; 2) Fulfilling wishes; 3) Spending time with family; 4) Receiving relief from physical and psychological suffering; 5) Making many wonderful memories; 6) Having a good relationship with the medical staff; 7) Having a peaceful death in the presence of family; 8) Spending time with a minimum of medical treatment; 9) Living one's life as usual; 10) Spending time in a calm hospital environment; 11) Being oneself; and, 12) Having a close family. Although the respondents in this study were medical care providers rather than the patients or their family members, findings should help medical staff provide better palliative care to Japanese pediatric cancer patients. <https://goo.gl/qGGfQz>

### **Related**

- *KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE*, 2016;19(4):283-291. 'Advances in hospice and palliative care in Japan: A review paper.' The numbers of PC units/inpatient hospices, hospital PC teams, and clinics with a home hospice function have been steadily increasing. The increasing numbers of physicians, nurses, and pharmacists have been certified as specialists in PC by national associations. Collaborative efforts have been made to standardize and disseminate educational programs and training opportunities in undergraduate, postgraduate, and continuing medical education. <https://goo.gl/dkkD4p>

## **The appropriate provision of primary versus specialist palliative care to cancer patients: Oncologists' perspectives**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 20 December 2016 – Oncologists' perspectives about palliative care (PC) have not been adequately described qualitatively and may explain some of the gaps in the delivery of PC. The objective of this study was to characterize U.S. oncologists' perceptions of: primary and specialist PC; experiences interacting with PC specialists; and the optimal interface of PC and oncology in providing PC. Seven major themes emerged [from in-depth interviews with practicing oncologists]: 1) PC was perceived as appropriate throughout the disease trajectory, but due to resource constraints was largely provided at end of life; 2) Oncologists had three schools of thought on primary versus

Cont.



specialist PC; 3) There was an under-availability of outpatient PC; 4) Poor communication about prognosis and care plans created tension between providers; 5) PC was perceived as a “team of outsiders”; 6) PC had too narrow a focus of care; and, 7) Academic medical centers-based PC evidence did not generalize to community practices. Oncologists noted three ways to improve the interface between oncologists and PC providers: 1) A clear division of responsibility; 2) In-person collaboration; and, 3) Sharing of non-physician palliative team members. <https://goo.gl/qcRaQ3>

Noted in Media Watch 11 January 2016, #444 (p.9):

- *CLINICAL ONCOLOGY* | Online – 14 December 2015 – ‘**Prognosis, treatment benefit and goals of care: What do oncologists discuss with patients who have incurable cancer?**’ Across medical oncology providers [i.e., study participants] there was substantial variation in the frequency of discussing prognosis (range 33-90%), treatment intent (range 55-100%), and goals of care (range 0-17%). In total, 41% (93/222) of patients were seen by palliative care (PC); substantial medical oncology provider variation was observed (range 27-58%). Referral rates to PC did not increase over time (41-44%). In this cohort of ambulatory patients with an estimated life expectancy of 1 year or less, medical oncology documentation of prognosis, treatment benefit and goals of care was poor. <http://goo.gl/W7iooz>

#### Related

- *ANNALS OF ONCOLOGY* | Online – 19 December 2016 – ‘**Use of chemotherapy near the end of life: What factors matter?**’ Among hospitalized patients with cancer [i.e., study participants], young individuals, treated in comprehensive cancer centers or in high-volume centers without palliative care units were the most likely to receive chemotherapy near the end of life. We found no evident pattern between the expected chemo-sensitivity of different cancers and the probability for patients to receive chemotherapy close to death. <https://goo.gl/5Qq0DC>
- *TUMORI JOURNAL* | Online – 19 December 2016 – ‘**Position paper of the Italian Association of Medical Oncology on early palliative care in oncology practice (simultaneous care).**’ This article ... represents the position of Italian medical oncologists about simultaneous care and is the result of a 2-step project: a Web-based survey among medical oncologists and a consensus conference. The authors present the opinion of more than 600 oncologists who helped formulate these recommendations. This document covers 4 main aspects of simultaneous care: 1) Ethical, cultural, and relational aspects of cancer and implications for patient communication; 2) Training of medical oncologists in palliative medicine; 3) Research on the integration between cancer treatments and palliative care; and, 4) organizational and management models for the realization of simultaneous care. <https://goo.gl/L8mbpm>

#### Cracking open death: Death conversations in primary care

*JOURNAL OF PRIMARY HEALTH CARE* | Online – 21 December 2016 – A cultural silence on death has rendered both the medical and lay community insufficiently prepared for frank and meaningful engagement with the topic, exacerbated by restricted consultation timeframes. The ease of death conversations may be facilitated by taking a family-centred approach, using community organisations and settings, and harnessing conversation entry points provided by the media. Four core themes were identified [in this study]: “a need to talk about death”; “the role of the GP”; “broaching the topic”; and, “media.” Future research should aim to develop tailored resources and frameworks to support general GP’s meaningful engagement with the topic of death both within and outside of the end-of-life context. <https://goo.gl/IEVDpo>

#### Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 23 December 2016 – ‘**Teaching the art of difficult family conversations.**’ This train-the-educator workshop [discussed] addresses a critical need in both palliative care and general medicine by enhancing the educators’ skills in desiring and implanting a curriculum on communication skills of health care providers using experiential techniques with formative feedback. The authors hope that by outlining the implementation of this three-hour interactive format, future educators will adapt and utilize this workshop as it works best for their learners. <https://goo.gl/tf6vkj>

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- *PSYCHO-ONCOLOGY* | Online – 28 December 2016 – ‘**Caregiver, patient, and nurse visit communication patterns in cancer home hospice.**’ Few studies have examined the triadic communication between patients, spouse caregivers, and nurses in the home hospice setting. Thus, little is known about the types of communication patterns that unfold. Six visit communication patterns were identified and were defined largely by two dimensions: 1) Either the patient, the caregiver, or the patient and caregiver dyad interacting with the nurse; and, 2) The relatively high or low expression of distress during the visit. Time until death significantly predicted several clusters. <https://goo.gl/zrWvD0>

### **The effect of advance directive completion on hospital care among chronically homeless persons: A prospective cohort study**

*JOURNAL OF URBAN HEALTH* | Online – 27 December 2016 – The objective of this study was to determine if homeless individuals who complete an advance directive (AD) through a shelter-based intervention are more likely to have information from their AD documented and used during subsequent hospitalizations. The AD included preferences for life-sustaining treatments, resuscitation, and substitute decision maker(s). A total of 205 homeless men from a homeless shelter for men in Toronto, Canada, were enrolled in the study and offered an opportunity to complete an AD with the guidance of a trained counselor... During the 1-year follow-up period, 38 participants who completed an AD and 37 participants who did not complete an AD had at least one hospitalization... Participants who completed an AD were significantly more likely to have documentation or use of an AD in hospital, compared to participants who did not complete an AD... Homeless men who complete an AD through a shelter-based intervention are more likely to have their detailed care preferences documented or used during subsequent hospitalizations. <https://goo.gl/NzLvHN>

#### **Related**

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 30 December 2016 – ‘**Homeless individuals approaching the end of life: Symptoms and attitudes.**’ Homeless individuals often have unique experiences at the end of life (EOL). Eligibility required a serious medical condition and for the patient’s medical provider to answer “no” to the question “Would you be surprised if this patient were not alive in one year?” Interviews explored symptoms using the Memorial Symptom Assessment Survey. Symptoms were compared to those of relevant comparator groups in other studies. Homeless individuals may experience a high frequency of pain and other symptoms as they approach the end of life. Care for such individuals may require a tailored approach. <https://goo.gl/szzW4u>

**N.B.** Additional articles on end-of-life care for the homeless are noted in Media Watch 5 December 2016, 8 August 2016, #474 (p.12), and 14 March 2016, #453 (pp.14-15).

### **Intimacy issues in palliative care: How to ask**

*MEDSCAPE* | Online – 23 December 2016 – In a quality improvement project, Kelemen and colleagues describe the growing consensus about the need to address intimacy concerns in patients with serious illness or near the end of life.<sup>1</sup> The pilot project was very simple and involved asking the following questions: How much has your illness affected intimacy? How has your illness affected your relationships? Patients were then queried about whether they were ever asked about intimacy during their hospital stay, and whether they found the intimacy discussion helpful. This study included 57 patients in inpatient palliative care (PC) programs. The mean patient age was 58 years, and the sample had good gender inclusion of 59.6% men and 40.4% women. The population was 68% African American, and the major diagnosis was heart failure. Patients reported that their illness had affected their intimacy, with 35% reporting a significant impact and 21% a moderate impact, although 14% reported little impact and 28% said there was no impact. An important point from this project was that providers from any discipline on the PC team could ask about intimacy. However, the vast majority (96%) of the patients reported that no one had asked about intimacy concerns, yet 56% reported that their illness had significantly or moderately affected intimacy. <https://goo.gl/xpzPfd>

1. ‘Screening for intimacy concerns in a palliative care population: Findings from a pilot study,’ *Journal of Palliative Medicine*, published online 5 May 2016. [Noted in Media Watch 16 May 2016, #462 (p.12) with selected articles listed on sexuality and intimacy in terminal illness.] <http://goo.gl/2rTFZH>

## After the ICU: Caregiver well-being

*MEDSCAPE* | Online – 21 December 2016 – Patients who survive long stays in the ICU, such as those who receive prolonged mechanical ventilation, will most often require continued assistance from a caregiver more than a year after ICU discharge. The effects of this responsibility on the family caregivers are not well known, but may include such negative consequences as poor health-related quality of life, emotional distress, a subjective sense of burden, and symptoms of posttraumatic stress disorder. Cameron and colleagues recently studied 280 caregivers of patients who had received 7 or more days of mechanical ventilation in an ICU to determine which patient and caregiver characteristics were associated with caregiver health outcomes up to a year after patient discharge from an ICU.<sup>1</sup> A large proportion of caregivers (67% initially and 43% at 1 year) reported high levels of depressive symptoms, which declined over time in 84% of the caregivers. <https://goo.gl/QpUjYC>

1. 'One-year outcomes in caregivers of critically ill patients,' *New England Journal of Medicine*, 2016; 374(21):1831-1841. [Noted in Media Watch 30 May 2016, #464 (p.1)] <http://goo.gl/ums18m>

### Related

- *MEDICAL ETHICS ADVISOR* | Online – 1 January 2017 – '**Better communication with family in ICU reduces intensity of end-of-life care: Simple interventions may reduce the prolongation of dying.**' Having palliative care physicians facilitate communication on high-risk patients in the ICU reduces intensity of end-of-life care and decreases hospital length of stay, according to recent studies. To improve communication with the family of critically ill patients: 1) Encourage bedside clinicians to lead conversations on goals of care; 2) Give family a point person to get updated information from; and, 3) Address conflicting information given by providers. <https://goo.gl/RuLTjM>

## A training program for spiritual care

*MEDSCAPE* | Online – 20 December 2016 – Those in the field of palliative care (PC) have voiced significant concerns in recent years about workforce shortages, including a dearth of specialists, and the need to train generalists to meet a burgeoning need for providers. Almost all of this literature has been related to specialist PC physician shortages, but a recent article makes an important contribution to the literature by sharing an example of training to prepare interprofessional clinicians as generalists in spiritual care.<sup>1</sup> The investigators conducted training to prepare 115 clinicians across several disciplines to have generalist knowledge in spiritual care. This education approach was very appropriate, given extensive literature documenting how ill-prepared most clinicians are in spiritual care. <https://goo.gl/7E47ZH>

1. 'Efficacy of training interprofessional spiritual care generalists,' *Journal of Palliative Medicine*, 2016; 19(8):814-821. <https://goo.gl/wMgyza>

## Palliative sedation: The position statement of the Italian National Committee for Bioethics

*MINERVA ANESTESIOLOGICA* | Online – 22 December 2016 – In January 2016 the Italian National Bioethics Committee published a position statement, 'Deep and continuous palliative sedation in the imminence of death,' related to the use of sedation and analgesia for relief from pain and psychological distress in dying patients. The Committee, in this statement, points out the clinical and ethical appropriateness of palliative sedation as a therapeutic procedure. As a result, palliative sedation has to be considered today useful, scientifically safe and reliable, and acknowledged as an integral part of good clinical practice. At the same time, the position statement, once and for all, makes clear that palliative sedation cannot and must not be equated with the practice of euthanasia. Thus, this document should be known by health professionals caring for dying patients not only in palliative as well as in intensive care settings, but it should be also considered as a milestone aimed to encourage and ease a widespread implementation of this procedure in all health care settings. <https://goo.gl/NLynP4>

Cont.

Noted in Media Watch 11 July 2016, #470 (p.13):

- *CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE* | Online – 1 July 2016 – ‘**A systematic literature review on the ethics of palliative sedation: An update (2016).**’ In a 2010 review of palliative sedation, the following areas were identified as lacking in consensus: 1) Inconsistent terminology; 2) Its use in non-physical suffering; 3) The ongoing experience of distress; and, 4) Concern that the practice of palliative sedation may hasten death. This review looks at the literature over the past 6 years and provides an update on these outstanding concerns. <http://goo.gl/qWxPqk>

Noted in Media Watch 12 May 2014, #357 (p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 May 2014 – ‘**Palliative sedation: Analysis of international guidelines and position statements.**’ Guidelines, etc., have been published by the American College of Physicians-American Society of Internal Medicine (2000), Hospice & Palliative Nurses Association (2003), American Academy of Hospice & Palliative Medicine (2006), American Medical Association (2008), Royal Dutch Medical Association (2009), European Association for Palliative Care (2009), National Hospice & Palliative Care Organization (2010), and National Comprehensive Cancer Network (2012). <http://goo.gl/luY00q>

### **Supporting family caregivers of older Americans**

*NEW ENGLAND JOURNAL OF MEDICINE* | Online – 29 December 2016 – Every day, millions of older Americans (those 65 years of age or older) manage basic health and functioning needs with the help of family caregivers. These family caregivers (defined as relatives, partners, friends, or neighbors who provide help because of a personal relationship rather than financial compensation) may arrange and attend medical appointments, participate in routine and high-stakes treatment decisions, coordinate care and services, help with daily tasks such as dressing and bathing, manage medicines, obtain and oversee the use of medical equipment, handle bills and banking, and ensure that older adults’ needs for food and shelter are met. The availability and adequacy of support provided by family caregivers has important consequences for older Americans’ quality of life, the services they use, and the quality and costs of care they receive.<sup>1</sup> According to the Congressional Budget Office, family caregivers are responsible for producing 80% of the total estimated economic value of community-based long-term services and supports for older adults.<sup>2</sup> <https://goo.gl/ozlaQ6>

1. ‘Retooling for an Aging America: Building the Health Care Workforce: A National Conference on Advancing Physician Competence in Care of Older Adults,’ 2009. [Noted in Media Watch 24 August 2009, #111 (p.6)] <https://goo.gl/ksmr8W>
2. ‘Rising Demand for Long-Term Services and Supports for Elderly People,’ Congressional Budget Office, June 2013. [Noted in Media Watch 8 July 2016, #313 (p.3)] <https://goo.gl/z2lvMt>

### **Rural long-term care nurses’ knowledge of palliative care**

*ONLINE JOURNAL OF RURAL NURSING & HEALTH CARE*, 2016;16(2):141-167. Regardless of the location, rural nurses care for patients and their families across the trajectory of an illness and into death in long-term care (LTC) facilities. The rural nurses [i.e., participating registered nurses and licensed practical nurses in three rural LTC facilities in south-central Kentucky] lacked knowledge of palliative care (PC) using the Palliative Care Knowledge Test (PCKT). Although the study sample scored below 50%, registered nurses were more knowledgeable than licensed practical nurses on many of the items on the test. The total years practiced in LTC did not affect the knowledge on the PCKT. Nurses cannot practice what they do not know. Nurses who lack knowledge about the philosophy and principles of PC may lower the quality of end-of-life care for patients in LTC. An evaluation of the knowledge level of nurses for PC is an important first step in instituting an educational intervention. <https://goo.gl/fwFXmW>

**N.B.** To access the full text, click on ‘Full Text: PDF.’

## Development and validation of the Palliative Care Knowledge Scale

*PALLIATIVE & SUPPORTIVE CARE* | Online – 27 December 2016 – An initial item pool of 38 true/false questions was developed based on extensive qualitative and quantitative pilot research. The preliminary items were tested with a community sample of 614 adults aged 18-89 years as well as 30 palliative care (PC) professionals. The factor structure, reliability, stability, internal consistency, and validity of the 13-item Palliative Care Knowledge Scale (PaCKS) were assessed. The results indicate that the PaCKS meets or exceeds the standards for psychometric scale development. Prior to this study, there were no psychometrically evaluated scales with which to assess knowledge of PC. The study developed the PaCKS, which is valid for assessing knowledge about palliative services in the general population. With the successful development of this instrument, new research exploring how knowledge about PC influences access and utilization of the service is possible. Prior research in PC access and utilization has not assessed knowledge of PC, though many studies have suggested that knowledge deficits contribute to underutilization of these services. <https://goo.gl/3Fi3zH>

### Assisted (or facilitated) death

Representative sample of recent journal articles:

- *JOURNAL OF AMERICAN PHYSICIANS & SURGEONS*, 2016;21(4):98-101. ‘**Physician-assisted suicide and euthanasia: The destruction of morals, ethics, and medicine.**’ Physician-assisted suicide and euthanasia are destroying the long-standing core ethical principle that physicians should not harm or kill patients. Trust in physicians and in the patient-doctor relationship is being irreparably harmed by these pro-death initiatives. Ethical physicians must make their stand and refuse to participate in physician-assisted suicide or euthanasia, irrespective of what the law allows or demands. <https://goo.gl/OAxMFx>

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### 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

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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.
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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.
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### Something Missed or Overlooked?

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

- *JOURNAL OF MEDICAL ETHICS* | Online – 28 December 2016 – ‘**Organ donation after medical assistance in dying or cessation of life-sustaining treatment requested by conscious patients: The Canadian context.**’ The availability of medical assistance in dying (MAID) has many implications, including the possibility of combining this practice with organ donation through the controlled donation after cardiac death (cDCD) protocol. cDCD most often occurs in cases where the patient has a severe neurological injury but does not meet all the criteria for brain death. The donation is subsequent to the decision to withdraw life-sustaining treatment (LST). Cases where patients are conscious prior to the withdrawal of LST are unusual, and have raised doubts as to the acceptability of removing organs from individuals who are not neurologically impaired and who have voluntarily chosen to die. These cases can be compared with likely scenarios in which patients will request both MAID and organ donation. In both instances, patients will be conscious and competent. Organ donation in such contexts raises ethical issues regarding respect for autonomy, societal pressure, conscientious objections and the dead-donor rule. untries and examine the ethical issues associated with cDCD in conscious patients who choose to die. <https://goo.gl/W65P1E>
- *PARLIAMENTARY AFFAIRS* | Online – 26 December 2016 – ‘**Political parties and MPs’ morality policy voting behaviour: Evidence from Germany.**’ This article investigates the impact of party membership on MPs’ morality policy voting behaviour, going beyond the common dichotomy of left and right parties and differentiating the preferences of other party families (e.g. Christian democrats, Liberals and Greens) regarding abortion, stem-cell research and euthanasia. They argue that parties generally face a “self-determination vs. protection of life” trade-off. In the case of embryo research, however, a party’s economic preferences and its position towards the freedom of research come into play, too. Exploring eight free votes in Germany after 1990, our analysis identifies party membership as the key determinant, supporting the claim that parties are groups of people who share common values. <https://goo.gl/b9piU9>
- *PASTORAL PSYCHOLOGY* | Online – 10 December 2016 – ‘**The moral deliberations of 15 clergy on suicide and assisted death: A qualitative study.**’ It is important to understand under what conditions clergy have moral objections to suicide, ending futile medical treatment, physician-assisted suicide, and euthanasia. Fifteen Catholic, Jewish and Protestant clergy completed semi-structured interviews. Analysis generated eight themes: 1) Sanctity of life; 2) Preservation of the natural course of life; 3) Pastoral care; 4) Support of the faith community; 5) Referral to professional services; 6) End-of-life decision in community; 7) Consultation with medical professionals; and, 8) A shift to a hopeful narrative. Respondents consistently endorsed the priority of pastoral care, demonstrating a deep concern for the well-being of suffering congregants. Every respondent objected to suicide. <https://goo.gl/tMFz0K>
- *ZEITSCHRIFT FÜR GERONTOLOGIE UND GERIATRIE* | Online – 13 December 2016 – ‘**Factors which influence the position towards euthanasia: Results of a representative survey among older people in Germany.**’ Assisted death was supported by 74.2% of the [1,068] respondents and assisted suicide by 80.4%. Support decreased with increasing strength of religious faith and a non-German country of origin. Of the participants 53.3% were worried about being a burden to their family, especially people with a limited state of health. People who shared this concern showed significantly more support for both types of euthanasia. More than 40% feared that people with severe and incurable illnesses would be more likely to be forced into a premature death (slippery slope argument). This concern was associated with a decreasing support of euthanasia. <https://goo.gl/gus0PH>

N.B. German language article.

### [Media Watch: Online](#)

#### **International**

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

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

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

PALLIMED: <http://goo.gl/7mrgMQ> [Scroll down to ‘Aggregators’ and Barry Ashpole and Media Watch]

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**Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: [HTTP://GOO.GL/JNHVMB](http://goo.gl/JNHVMB)

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

**Canada**

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <https://goo.gl/IOSNC7>

**Europe**

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

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1l9K>

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

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