

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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Medical futility: Scroll down to [Specialist Publications](#) and ‘What matters in the debates taking place among doctors, nurses, patients, and family members in hospitals, courtrooms, legislatures, and Twitter chats around the world’ (p.12), in *Perspectives in Biology & Medicine*.

Canada

Dan’s Law for palliative care could die before election, supporters warn

ONTARIO | *The Windsor Star* – 4 March 2018 – The window is quickly closing for passage of a bill named for former Windsor autoworker Dan Duma who died fighting for the right to receive homecare in his final days. Bill 54, the Home-care & Community Service Amendment Act, colloquially known as Dan’s Law, received second reading in 2016 and was to be reviewed by the justice policy committee. “Dan’s Law has remained in purgatory ever since,” says Dr. Darren Cargill, who was Duma’s palliative care (PC) doctor. With the provincial election set for June, Cargill is ramping up his government lobbying, fearing the bill will die if it’s not passed before this legislative session ends. Duma and his wife, Ana, moved to Alberta to find work after GM’s Windsor transmission plant closed. There, Duma was diagnosed with liver cancer and was told he had only a short time left to live. During the Alberta wildfires of 2016, Duma was airlifted to Edmonton when the hospital in Fort McMurray

was evacuated. Duma and his wife decided to return to Windsor, where their two daughters live, for PC. But OHIP requires new residents to the province to wait three months for coverage. Under inter-provincial reciprocal billing agreements during that waiting period, new residents can be admitted to hospital for medical care, but they don’t qualify for home care or a bed in a hospice home. Dan’s Law proposes eliminating the waiting period for PC patients who move to Ontario after residing in another Canadian province. <https://goo.gl/wJxED9>

Specialist Publications

‘Palliative care in the home: A scoping review of study quality, primary outcomes, and thematic component analysis’ (p.7), in *BMC Palliative Care*.

Noted in Media Watch 21 November 2016 (#488, p.1):

- ONTARIO | *The Windsor Star* – 17 November 2016 – ‘Queen’s Park votes favourably on end-of-life **Dan’s Law.**’ Bill 54, to amend the Home Care & Community Services Amendment Act (1994), has passed second reading by the provincial parliament] Home care is currently not subject to Canada’s inter-provincial billing agreement. <https://goo.gl/NVLUTR>

N.B. Bill 54. Download/view at: <https://goo.gl/yBTBqU>

U.S.A.

House receives bill encouraging palliative care

KENTUCKY | *The Ohio County Monitor* (Beaver Dam) – 7 March 2018 – A measure designed to encourage the widespread adoption of palliative care (PC) to those who need it passed by a vote of 36-0 in the state Senate. Known as Senate Bill 149, the legislation would establish the Palliative Care Interdisciplinary Advisory Council within the Cabinet for Health & Family Services. The groups would make recommendations on how to improve and expand PC and educate patients about their options. Senate Bill 149 now goes to the House for consideration. <https://goo.gl/N5aB5x>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- WASHINGTON DC | WLJA News (Jasper, Georgia) – 7 March 2018 – **‘Dying vets cannot use life-ending drugs at many state homes.’** Veterans in government-run homes in many parts of the country that have legalized physician-assisted death, including Colorado, Vermont and Washington DC, are finding similar restrictions because assisted suicide goes against the policy of the U.S. Department of Veterans Affairs. Doctors can legally prescribe lethal medication for terminally ill patients in Oregon and Washington. Veteran homes in those states do not require the person be discharged to take the drugs, though staff cannot be involved, and no federal funds can be used. Montana’s state Supreme Court ruled in 2009 that doctors could use a patient’s request for life-ending medication as a defense against criminal charges. Regardless of state laws, the 1997 Assisted Suicide Funding Restriction Act passed by Congress prohibits the use of federal funds for assisted suicides... <https://goo.gl/Pyqvnv>
- HAWAII | Hawaii News Now (Honolulu) – 6 March 2018 – **‘House approves controversial medical aid-in-dying bill, sending it to Senate.’** After a robust debate, the full House approved a controversial medical aid-in-dying measure, sending the bill to the Senate. The House voted 39-12 to pass the measure... The measure, House Bill 239, allows a physician to prescribe life-ending medication to a terminally ill, but mentally-capable patient with less than six months to live. Under the bill, the patient must be able to take the medication themselves, only physicians can prescribe it (and not advance practice nurses) and it requires a mental health consultation. <https://goo.gl/3G5YEF>

Specialist Publications

‘Palliative care disincentives in chronic kidney disease: Changing policy to improve chronic kidney disease care’ (p.6), in *American Journal of Kidney Disease*.

‘Development of a home health-based palliative care program for patients with heart failure’ (p.7), in *Home Healthcare Now*.

‘End-of-life care for an undocumented Mexican immigrant: Resident perspective’ (p.9), in *Journal of Palliative Care*.

‘Challenges of dealing with financial concerns during life-threatening illness: Perspectives of health care practitioners’ (p.10), in *Journal of Social Work in End-of-Life & Palliative Care*.

‘Psychosocial standards of care for children with cancer and their families: A U.S. national survey of pediatric oncology social workers’ (p.13), in *Social Work in Health Care*.

‘Physician-assisted death psychiatric assessment: A standardized protocol to conform to the California End-of-Life Option Act’ (p.15), in *Psychosomatics*.

International

Appeal court upholds ruling on Alfie Evans life support

U.K. (England) | *The Guardian* (London) – 6 March 2018 – Three court of appeal judges ruled ... that doctors could stop treating Alfie Evans, who is in a semi-vegetative state due to a degenerative neurological condition. Upholding an earlier high court ruling that Alfie’s father has said was a “death penalty,” the appeal court judges said it was in the toddler’s best interests for doctors to remove his life-support treatment. The judge, Mrs. Justice King, said the latest medical evidence showed Alfie was “deeply comatose” and “to all intents and purposes unaware of his surroundings.” It remains unclear whether the parents will seek to challenge the appeal court ruling, which came a fortnight after the high court decided further treatment would harm Alfie’s “future dignity.” During legal pro-

ceeding ... judges have heard that the toddler’s condition is terminal and that his brain is “entirely beyond recovery.” Doctors have been unable to definitively diagnose Alfie’s condition, which MRI scans show has destroyed 70% of his brain matter. <https://goo.gl/2pmFj9>

Specialist Publications

‘Medical futility: What matters in the debates taking place among doctors, nurses, patients, and family members in hospitals, courtrooms, legislatures, and Twitter chats around the world’ (p.12), in *Perspectives in Biology & Medicine*.

N.B. News media coverage of the Alfie Evans case noted in the 26 February 2018 issue of Media Watch (#552, p.5).

Related

- U.K. (England) | *The Guardian* (London) – 7 March 2018 – **‘Isaiah Haastrup: Doctors to withdraw life support, parents say.’** The parents of Isaiah Haastrup, the profoundly brain-damaged baby at the centre of a right-to-live legal battle, have said doctors intend to withdraw life support, less than 24 hours after an 11th-hour appeal to European court judges failed. Kings College hospital in London, where Isaiah has been on life support since his birth one year ago, said it would not comment on the proposed timing of the baby’s extubation, citing patient confidentiality. The European court of human rights ruled as inadmissible an appeal by Isaiah’s parents against a high court judgment that it was in their son’s best interests that life-sustaining treatment be withdrawn. <https://goo.gl/6YsQTF>

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

Six-month limit for terminally ill benefits claimants “unfair”

U.K. (Northern Ireland) | *The Belfast Telegraph* – 5 March 2018 – People with terminal illnesses could face agonising waits for payments, a major charity has warned. Marie Curie’s head of policy and public affairs Joan McEwan told the *Belfast Telegraph* that as legislation currently stands, it may “exclude many legitimate claimants from applying under the special rules.” These include a condition requiring a diagnosis that the applicant has no more than six months to live. While claimants under the special rules can expect to have their claims cleared within two weeks, other claims take an average of more than three months. Information obtained by the charity following a freedom of information request found that of the 550 local Personal Independence Payment (PIP) claims awarded under the special

rules for terminal illness at 31 August 2017, more than 90% were awarded to cancer patients, when the disease accounts for less than a third of deaths in Northern Ireland. “This suggests that a large number of people with other terminal illnesses are not accessing PIP under the special rules. <https://goo.gl/w9N8Rq>

Specialist Publications

‘Experience adjusted life years and critical medical allocations within the British context: Which patient should live?’ (p.11), in *Medicine, Health Care & Philosophy*.

Misinterpreted do-not-resuscitate orders can be deadly

ISRAEL | *The Jerusalem Post* – 4 March 2018 – Patients who arrive at an intensive care unit (ICU) with a do-not-resuscitate (DNR) order face a significantly higher risk of dying within 28 days than those who come to an ICU without a DNR order, according to researchers at Ben-Gurion University, Soroka University Medical Center ... and their colleagues in the U.S., Australia and Singapore. The risk was particularly high for women, patients attached to respirators, those with cancer and surgical patients. The researchers carried out a retrospective analysis of patients in five ICUs...¹ They suggest that doctors misinterpret DNR orders more broadly than they were often intended – to mean fewer treatments and medicines – where the original

order was a particular directive not to attempt cardiopulmonary resuscitation in specific circumstances. Novack and his colleagues believe the problem may lie with doctors confusing DNR orders and patients' desires to end-of-life care, leading the doctors to be less inclined to intervene in life-threatening situations. <https://goo.gl/sHrs85>

Specialist Publications

'Resuscitation decisions at the end of life: Medical views and the juridification of practice' (p.9), in *Journal of Medical Ethics*.

1. 'Quantifying the mortality impact of do-not-resuscitate orders in the ICU,' *Critical Care Medicine*, 2017; 45(6):1019-1027. **Abstract:** <https://goo.gl/npkuyq>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- INDIA | Aljazeera – 9 March 2018 – **'India's Supreme Court allows "passive euthanasia."** In its decision, the country's highest court permitted its citizens to draft a "living will" that specifies that life support not be given in the case of coma. Passive euthanasia allows the withdrawal of medical treatment with the intention to hasten the death of a terminally-ill patient. The five-member court, *however*, said that individuals are only allowed to draft a living will while he or she is in "normal state of health and mind," *The Hindustan Times* reported. The decision was in response to a petition by a non-government organisation, which argued that a person with terminal illness should be given the right to refuse being placed on life support. <https://goo.gl/dT8DTz>
- THE NETHERLANDS | Dutch News (Amsterdam) – 7 March 2018 – **'More euthanasia in The Netherlands, nearly all cases in line with the rules.'** The number of people helped to die under Dutch euthanasia legislation rose 8% last year to 6,585... Of them, 99.8% were carried out carefully and in line with the guidelines... In almost 90% of cases, the patient was suffering from cancer, heart and artery disease or diseases of the nervous system, such as Parkinson and MS. Three patients were in the advanced stage of dementia and 166 were in earlier stages. In 83 cases, the patient was suffering from severe psychiatric issues, a trend which has raised questions among psychiatrists... Twelve cases were labeled by the monitoring committee as not being carefully carried out – these were mainly problems with medical care or not having an independent second opinion. <https://goo.gl/Bc86mr>



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>

Specialist Publications

Reappraising “the good death” for populations in the age of ageing

AGE & AGEING | Online – 6 March 2018 – This is the second of paired commentaries in *Age and Ageing*, the journal of the British Geriatrics Society, and the *Journal of the American Geriatrics Society*.¹ The aim is to address issues of current significance and to foster dialogue and increased understanding between academics and clinicians working in comparative international settings. Both commentaries address the urgent need to improve palliative care (PC) for older people, with a critique of some stereotypes surrounding PC and the “good death.” The companion commentary ... is grounded in authors’ experience as academic clinicians. In the present paper, the authors offer a perspective on the outcome and wider consequences of misalignment between current U.K. policy and aspirations for end-of-life care in relation to epidemiological trends and patient experience of death and dying. **Abstract:** <https://goo.gl/G8xBSt>

1. ‘Should we bury “the good death”?’ *Journal of the American Geriatrics Society*, published online 6 March 2018. **Access options:** <https://goo.gl/mLt9WV>

Related

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 8 March 2018 – “**All of a sudden, a lot less still makes it worthwhile to be alive**”: **Palliative care patients’ views on life.**’ Results [of this study] support the idea that many people facing terminal illness continue to focus on living and remain within their biographies and the contexts of their lives, even if their functional status declines. Patients and relatives appreciated that interviews [that they participated in] were provided as kind of a legacy. Yet, more robust research is needed to decide whether such interviews yield any therapeutic effect. **Abstract:** <https://goo.gl/enu3ZQ>

Palliative care patients’ quality of dying and circumstances of death: Comparison of informal caregivers’ and healthcare professionals’ estimates

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 8 March 2018 – Patient-reported outcomes are usually considered to be the gold standard assessment. However, for the assessment of quality of dying and death, ratings of informal caregivers (ICGs) or health-care professionals (HCPs) must be considered for ethical and methodological reasons. The findings [of this study] appear to show a high satisfaction with quality of dying and death as rated by ICGs and HCPs, but the authors suspect this might be indicative of a methodological challenge, that is, a ceiling effect in both assessments. Single low scoring items may provide important clues for improvement in end-of-life care. Although descriptive data show comparable mean values and standard deviations, the actual congruence of ratings is low. Replacing one rating by another cannot be recommended. **Abstract:** <https://goo.gl/AF8ciC>

Noted in Media Watch 1 January 2018 (#544, p.13):

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 18 December 2017 – ‘**Informal caregivers’ views on the division of responsibilities between themselves and professionals: A scoping review.**’ Professionals are assumed to adequately address the needs and wishes of informal caregivers, but little is known about informal caregivers’ views on the division of care responsibilities. Based on the opinion of informal caregivers, the authors conclude that professionals do not seem to explicitly take into account the views of informal caregivers about the division of responsibilities during their collaboration with them. **Full text:** <https://goo.gl/RrffNC>



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 beginning on p.16.

Palliative care disincentives in chronic kidney disease: Changing policy to improve chronic kidney disease care

AMERICAN JOURNAL OF KIDNEY DISEASE | Online – 3 March 2018 – The dominant health delivery model for advanced chronic kidney disease (CKD) and end-stage renal disease (ESRD) in the U.S., which focuses on provision of dialysis, is ill-equipped to address many of the needs of seriously ill patients. Although palliative care (PC) may address some of these gaps in care, its integration into advanced CKD care has been suboptimal due to several health system barriers. These barriers include uneven access to specialty PC services, underdeveloped models of care for seriously ill patients with advanced CKD, and misaligned policy incentives. This article reviews policies that affect the delivery of PC for this population, discusses reforms that could address disincentives to PC, identifies quality measurement issues for PC for individuals with advanced CKD and ESRD, and considers potential pitfalls in the implementation of new models of integrated PC. **Abstract:** <https://goo.gl/MhbCFP>

N.B. Additional articles on palliative and end-of-life care for people living with chronic kidney disease noted in the 15 January 2018 issue of Media Watch (#546, p.10).

Prison hospice care: Life and death behind bars

AMERICAN JOURNAL OF PSYCHIATRY (Residents' Journal), 2018;13(3):3. Hospice care is a unique field that enables psychiatrists to use their skill set to improve the quality of life and experience of death for terminally ill patients and their families. Prison hospice is an expanding specialty that should be considered by physicians who are interested in the legal system, hospice care, and care for vulnerable populations. An increase in both the U.S. prison population and average inmate age has burdened the correctional system with caring for chronically and terminally ill incarcerated persons. One response to this problem was the Sentencing Reform Act of 1984, which provided the option of compassionate release for dying inmates. However, this policy has been largely ineffective, with release of few incarcerated persons and with some inmates dying in prison during the long petition process. Prison hospice programs offer an alternative to compassionate release and provide both inmate volunteers and psychiatrists with the unique opportunity to care for individuals in the criminal justice system. **Full text:** <https://goo.gl/PESs5X>

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 (last updated 1 February 2018) can be downloaded/view at Palliative Care Network-e: <https://goo.gl/YLckx6>

End-of-life care in Australia

No one said he was dying: Families' experiences of end-of-life care in an acute setting

AUSTRALIAN JOURNAL OF ADVANCED NURSING, 2018;35(3):21-31. This study identified key actions for nurses and doctors in providing a best practice approach to caring for the dying person. Firstly, allowing families time to prepare for their loved ones death by identifying that the person is dying and family as soon as possible. Families need to be involved in the conversations, and have information, including prognosis, explained to them. Clinicians should be sensitive, use plain language and avoid euphemisms, with follow up to ensure the family understands. Secondly, there is potential for ambiguity and uncertainty at the end of life. Clinicians should explain the prognosis and that the dying process varies between individuals. This must be honestly and openly acknowledged, and discussed with patients, substitute decision makers, families and carers. Finally, families of people who are dying also need care from the treating team, both during the dying process and following the death. There is a need to ensure there is support for the family with their grief responses and to identify those that are at risk of complicated grief. In order to address these priorities all members of the interdisciplinary team should receive education and training to prepare them for having conversations about end-of-life care. **To access the full text, click on the journal contents page and scroll down to the article:** <https://goo.gl/KRWT1c>

End-of-life care in Norway

Teamwork in primary palliative care: General practitioners' and specialised oncology nurses' complementary competencies

BMC HEALTH SERVICES RESEARCH | Online – 7 March 2018 – The complementary competencies and autonomous roles of a specialised nurse and a general practitioner (GP) represented a good match for primary palliative care (PC). GPs could be valid co-workers for oncology nurses (ONs) by making maximum use of their generalist competencies. By prioritizing PC as much as medical emergencies, as suggested by some [study] participants, and by applying their previous knowledge of the patient, GPs could give ONs much of the crucial support they need. If GPs also gave priority to courses in PC, that would add value to their expertise. A business model where primary health care is mainly funded per capita could lead to more sustainable practices with several professions sharing patient care. Attention to different professional cultures of working and learning has implications for quality improvement efforts. It is worth noting that some GPs' surgeries act as communities of practice with common goals and standards. This form of collective organization for learning and quality improvement could be a way forward for the GP profession, and a way to overcome undesirable variations in competence and practice. **Full text:** <https://goo.gl/UT5iqf>

Noted in Media Watch 29 August 2016, #477 (p.6):

- *BMC PALLIATIVE CARE* | Online – 24 August 2016 – '**Patients' perceptions of palliative care quality in hospice inpatient care, hospice day care, palliative units in nursing homes, and home care: A cross-sectional study.**' In Norway, palliative care (PC) is provided by a public healthcare system in primary or community care (CC), and specialist healthcare (SH) contexts (tertiary and secondary care). CC and SH provide non-specialized PC as an integrated part of the services, in addition specialized PC services are offered. **Full text:** <http://goo.gl/sENwle>

Palliative care in the home: A scoping review of study quality, primary outcomes, and thematic component analysis

BMC PALLIATIVE CARE | Online – 7 March 2018 – Fifty-three studies formed the final data set. The literature varied extensively. Five themes were identified: 1) Accessibility of healthcare; 2) Caregiver support; 3) Individualized patient centered care; 4) Multidisciplinary care provision; and, 5) Quality improvement. Primary outcomes were resource use, symptom burden, quality of life, satisfaction, caregiver distress, place of death, cost analysis, or described experiences. The majority of studies were of moderate or unclear quality. There is robust literature of varying quality, assessing different components of palliative care (PC) in the home interventions, and measuring different outcomes. To be meaningful to patients, these interventions need to be consistently evaluated with outcomes that matter to patients. Future research could focus on reaching a consensus for outcomes to evaluate PC in the home interventions. **Full text:** <https://goo.gl/Rs81hA>

Related

- *HOME HEALTHCARE NOW*, 2018;36(2):84-92. '**Development of a home health-based palliative care program for patients with heart failure.**' Current research suggests that the utilization of palliative care (PC) and an interdisciplinary team approach to the care of patients with heart failure improves the quality of life and decreases utilization of healthcare resources at the end of life. This performance improvement project examined the knowledge of a home healthcare inter-disciplinary team's knowledge about PC in patients with heart failure, the 30-day readmission rate for patients enrolled in a home-based PC program, and documentation of advanced directives in a home healthcare organization. **Abstract:** <https://goo.gl/MPSc72>

Aligning policy objectives and payment design in palliative care

BMC PALLIATIVE CARE | Online – 7 March 2017 – There is a gap between needs for and supply of palliative care (PC) in many countries. PC services are beginning to move beyond their cancer care origins to address needs more broadly defined, which increases the gap between this now more broadly defined need and supply. Although PC is still a small proportion of health budgets, growing provision will place a challenge on funders. Some resources may be released through improved efficiency in cost per visit, or in terms of a more efficient care path to death – fewer emergency department visits or reduced use of intensive care unit beds as examples – but additional resources may still be required. If PC is to become a universally accessible service, new approaches to funding, based on the experience of funding reforms in other parts of the health system, need to be adopted. However, the funding models used in acute inpatient care need to be adapted to take account of the unique nature of policy objectives for PC. As PC policies are redeveloped, funders should give explicit consideration to adopting new funding approaches as canvassed here to ensure funding policy and aspirational service objectives are aligned. Because policy objectives and contexts are country dependent, PC funding models will also differ across nations, but hopefully will still allow for cross-national learning. **Full text:** <https://goo.gl/ZWD428>

Outcomes, experiences and palliative care in major stroke: A multicentre, mixed-method, longitudinal study

CANADIAN MEDICAL ASSOCIATION JOURNAL, 2018;190(9):E238-E246. Case fatality after total anterior circulation stroke is high. The authors' objective was to describe the experiences and needs of patients and caregivers, and to explore whether, and how, palliative care (PC) should be integrated into stroke care. They conducted 99 interviews with 34 patients and their informal and professional caregivers and identified several major themes: patients and caregivers faced death or a life not worth living; those who survived felt grief for a former life; professionals focused on physical rehabilitation rather than preparation for death or limited recovery; future planning was challenging; and, "palliative care" had connotations of treatment withdrawal and imminent death. Major stroke brings likelihood of death but little preparation. Realistic planning with patients and informal caregivers should be offered, raising the possibility of death or survival with disability. Practising the principles of PC is needed, but the term "palliative care" should be avoided or reframed. **Full text:** <https://goo.gl/dP8Ht4>

Noted in Media Watch 11 December 2017 (#542, p.14):

- *NEUROLOGY TODAY*, 2017;17(23):14-15. 'What accounts for disparities in the use of palliative stroke care? It may not be what you think.' A new analysis suggests it might be the systems in place in hospitals serving minority populations – and not the belief systems of individual patients – that account for racial disparities in care.¹ **Full text of expert commentary:** <https://goo.gl/SX82Md>

1. 'Racial differences in palliative care use after stroke in majority-white, minority-serving, and racially integrated U.S. hospitals,' *Critical Care Medicine*, 2017;45(12):2046-2054. **Abstract:** <https://goo.gl/NujFLJ>

Child's play: The role of play in mitigating the fear of death among pediatric palliative care team patients, families, and caregivers

JOURNAL OF LOSS & TRAUMA | Online – 2 March 2018 – The authors examine the role of play as seriously ill children involved with a hospital based palliative care (PC) team live out what may be the remainder of their lives. They question the function that play has, if any, in mitigating the fear of death among dying children and their caregivers. The authors explore formal and informal manners of therapeutic play among children and adults occurring in moments of terrible stress, pain and the looming threat of death. They draw on playful representations of death from popular culture and from extended field research conducted with a pediatric PC team in a large regional children's hospital caring for seriously ill children and their families, as patients, families and caretakers struggle to make sense of their suffering, fear and loss. **Abstract:** <https://goo.gl/NCZTEz>

Cont.

Noted in Media Watch 13 October 2014 (#379, p.14):

- *CHILDREN* | Online – 1 October 2014 – ‘**The role of play in children’s palliative care.**’ Providing time and opportunities to play can be overlooked or considered to be of little importance or relevance when the focus of the adult carers is the amelioration of clinical symptoms of the illness and on lessening the psychological impact the illness may have on the child. This paper outlines the role and the value of play as an integral component in the provision of palliative care for children with chronic, life-threatening and life-limiting conditions. **Abstract:** <https://goo.gl/iFMnWp>

Resuscitation decisions at the end of life: Medical views and the juridification of practice

JOURNAL OF MEDICAL ETHICS | Online – 9 March 2018 – Concerns about decision making related to resuscitation have led to two important challenges in the courts resulting in new legal precedents for decision-making practice. Systematic research investigating the experiences of doctors involved in decisions about resuscitation in light of the recent changes in law remains lacking. The data presented in this paper were collected as part of a wider research study of end-of-life care in an acute hospital setting. Discussions and decision making about resuscitation present many challenges for those involved on acute medical wards. The data highlight the potential for multiple interpretations of legal precedents, creating misunderstandings that may impact patient care in less positive ways. This paper provides unique insights into how doctors respond to the changing medico-legal culture and the subsequent effects on patient care. It demonstrates how the juridification of medical practice can occur. It highlights the potential benefit of a structure to support clinicians, patients and relatives in discussing and navigating decisions around care at the end of life in line with the patient’s wishes and preferences. Recommendations for future research are made and legal ramifications are discussed. **Abstract:** <https://goo.gl/WEAvL6>

Case study

End-of-life care for an undocumented Mexican immigrant: Resident perspective

JOURNAL OF PALLIATIVE CARE | Online – 7 March 2018 – Undocumented immigrants account for 14.6% of the uninsured population in the U.S. Decisions about end-of-life treatment are often difficult to reach in the best of situations. The authors present a 43-year-old undocumented Mexican female immigrant with metastatic sarcomatoid squamous cell cervical cancer and discuss the barriers that she faced during her treatment. Limited English proficiency, living below the poverty line, low level of education, and lack access to Medicare, Medicaid, or other insurance coverage under the Affordable Care Act are major causes of decreased health-care access and service utilization by the immigrant population. Latinos are less likely to be referred to hospice by oncologists, and nearly a third of hospice agencies offer limited or no services to undocumented immigrants. Undocumented immigrants with terminal diagnoses generally do not have access to comprehensive or multidisciplinary follow-up treatment. Instead, one of their few options is to return to their home countries without any long-term treatment. This article discusses the many barriers and proposes areas for reform. **Abstract:** <https://goo.gl/dAwVBC>

Noted in Media Watch 5 March 2018 (#553, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 25 February 2018 – ‘**End-of-life care for unauthorized immigrants in the U.S.**’ The notion of patients’ rights is based on the Universal Declaration of Human Rights, which recognizes inherent human dignity and the equal and unalienable rights of all members of the human family to be universally protected irrespective of race, color, gender, language, religion, political or other opinion, national or social origin, property, birth, or other status. These fundamental human rights become particularly important to seriously ill patients as they are vulnerable due to the limitations imposed by their illness(es). **Abstract:** <https://goo.gl/KwuA8E>

N.B. Additional articles on unauthorized/undocumented immigrants in the U.S. in the context of palliative and end-of-life care noted in the 18 December 2017 issue of Media Watch (#543, p.3).

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

Challenges of dealing with financial concerns during life-threatening illness: Perspectives of health care practitioners

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 5 March 2018 – The costs of serious medical illness and end-of-life care are often a heavy burden for patients and families. Twenty-six practitioners, including social workers, managers/administrators, supervisors, and case managers from five health care settings, participated in qualitative semi-structured interviews about financial challenges patients encountered. Seven practitioners took part in a focus group. Practitioners described interacting micro, meso, and macro influences on the financial well-being and challenges patients encountered. Micro level influences involved patient characteristics, such as their demographic profile and/or health status that set them up for financial aptitude or challenges. Macro level influences involved the larger health care/safety net system, which provided valuable resources for some patients, but not others. Practitioners also discussed the meso level of influence, the local setting where they worked to match available resources with patients' individual needs given the constraints emerging from the micro and macro levels. Practitioners described how they navigated the interplay of these three areas to meet patients' needs and cope with financial challenges. Implications for practice point to directly addressing the kind of financial concerns that patients and families facing financial burden from serious medical illness have, and identifying ways to bridge knowledge and resource access gaps at the individual, organizational, and societal levels. **Abstract:** <https://goo.gl/ejXwq9>

Comfort at the crossroads: Service, therapy and emotional support animals in the ICU and at the end-of-life

JOURNAL OF TRAUMA & ACUTE CARE SURGERY | Online – 8 March 2018 – The U.S. has witnessed a vast increase in animals in therapeutic roles. These roles include Service as defined by the American Disabilities Act (ADA) as well as other animal types that are not covered under the ADA provisions. Such animal roles are designated as therapy animals and emotional support animals (ESA). Understanding the legal and regulatory requirements that govern how each animal type accesses healthcare facilities is essential in planning for their presence. Since only service animals are required to be given access to facilities, individual institutions must plan for how to accommodate their presence throughout different phases of care. Additionally, plans to incorporate Therapy animals, if so desired, should be articulated including requirements for training, health and certification prior to patient space access. ESA are not required to be granted facility access but are increasingly prevalent in public spaces and should drive healthcare facility policy generation to address allowing or prohibiting access. Finally, anticipated conflict between individual rights that cross along animal presence lines should be anticipated and proactively addressed instead of responding to conflict only after it has arisen. **Abstract:** <https://goo.gl/ge6zrv>

The Lancet Commission on Palliative Care & Pain Relief: Findings, recommendations, and future directions

THE LANCET GLOBAL HEALTH, 2018;6(Supplement 1):S5-S6. The burden of serious health-related suffering is huge and could in large part be alleviated with palliative care (PC) and pain relief. About 25.5 million of 56.2 million people who died in 2015 experienced serious health-related suffering, and another 35.5 million experienced serious health-related suffering due to life-threatening and life-limiting conditions. A disproportionate number (more than 80%) of these 61 million individuals live in low-income and middle-income countries with severely limited access to any PC, even oral morphine for pain relief. Furthermore, nearly 2.5 million children worldwide die in need of PC and pain relief, and more than 90% of paediatric deaths associated with serious health-related suffering are avoidable. These are a few of the most salient findings of the report of the *Lancet* Commission on Global Access to Palliative Care & Pain Relief.¹ **Full text:** <https://goo.gl/PhbGZw>

1. 'Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage,' *The Lancet*, published online 12 October 2017. [Noted in the 16 October 2017 issue of *Media Watch* (#534, p.14)] **Full text:** <https://goo.gl/i7r9M1>

Experience adjusted life years and critical medical allocations within the British context: Which patient should live?

MEDICINE, HEALTH CARE & PHILOSOPHY | Online – 1 March 2018 – Medical resource allocation is a controversial topic, because in the end it prioritises some peoples' medical problems over those of others. This is less controversial when there is a clear clinical reason for such a prioritisation, but when such a reason is not available people might perceive it as deeming certain individuals more important than others. This article looks at the role of social utility in medical resource allocation, in a situation where the clinical outcome would be identical if either person received the treatment. This situation is explored with a focus on the U.K., but its conclusions have wider applications to any system where healthcare is taxpayer funded. **Abstract (w. list of references):** <https://goo.gl/CxYQxX>

Noted in Media Watch 1 January 2018 (#544, p.18):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 December 2017 – ‘**Distributive justice: An ethical priority in global palliative care.**’ The ethical principle of distributive justice underpins questions of resource allocation at a fundamental level. Resource allocation in the absence of cultural humility or a genuine willingness to understand decision making priorities in a given culture can contribute to inequity and may have harmful consequences. **Abstract:** <https://goo.gl/3ws9CQ>

N.B. Selected articles on the allocation of limited healthcare resources noted in the 26 February 2018 issue of Media Watch (#552, pp.12-13).

The “end of life” of people with disabilities living in institutions: A conceptual construction in palliative care medicine

MÉDECINE PALLIATIVE | Online – 9 March 2018 – Technical and scientific progress in medicine has significantly lengthened the life expectancy of people with disabilities. Gradually the associations caring for them have developed a number of nursing facilities to support them as they age. The loss of independence due to disability (or multiple disabilities) is compounded by problems of ageing and disease, requiring competent medical intervention and inevitably leading to an increase in deaths. Although the sector has been able to inspire a truly remarkable “support culture,” these associations still have problems accompanying the people they support until their natural end. In response to those difficulties, the French national end-of-life (EoL) observatory recommends that “EoL support and palliative care (PC) should be a priority in staff training for professionals working in nursing homes and skilled nursing homes caring for people with disabilities.” The authors, on the other hand, argue that the idea that training in PC or EoL management would help those institutions is mere illusion. **Abstract:** <https://goo.gl/UKNSA7>

N.B. French language article.

Barriers to advance care planning in end-stage renal disease: Who is to blame, and what can be done?

THE NEW BIOETHICS | Online – 7 March 2018 – Patients with end-stage renal disease experience significant mortality and morbidity, including cognitive decline. Advance care planning has been emphasized as a responsibility and priority of physicians caring for patients with chronic kidney disease in order to align with patient values before decision-making capacity is lost and to avoid suffering. This emphasis has proven ineffective, as illustrated in the case of a patient treated in the authors' hospital. Is this ineffectiveness a consequence of failure in the courtroom or the clinic? Through the authors' own experience they affirm what has been written before: that legal precedent favors intensive treatment in virtually all cases without “clear and convincing evidence” of a patient's previously declared wishes to the contrary. Equally clear is that more than 20 years of support in the clinical literature suggesting ACP early in the course of disease can address challenges in the legal system for those lacking capacity. However, many physicians fail to recognize the need for ACP in a timely manner and lack the necessary training to provide it. **Abstract:** <https://goo.gl/gZjQbc>

Cont.

Related

- *COLLEGIAN* | Online – Accessed 7 March 2018 – ‘**End-of-life care for older people in sub-acute care: A retrospective clinical audit.**’ The lack of pre-hospital advance care planning and delayed or ambiguous communication about goals-of-care can result in sub-optimal end-of-life care (EoLC). The likelihood of patient decline and death should be anticipated in the frail older population receiving care in sub-acute care settings. The delay in recognising and acknowledging that a patient may be declining towards death results in delays to re-evaluation of care and the opportunity to commence appropriate EoLC to patients. **Full text:** <https://goo.gl/JAtxD5>
- *JOURNAL OF MEDICAL ETHICS* | Online – 9 March 2018 – ‘**Making medical decisions for an incompetent older adult when both a proxy and an advance directive are available: Which is more likely to reflect the older adult’s preferences?**’ Eighty per cent of the older adults [i.e., study participants] completed the directive. Choices they made in the directive were more in line with the preferences they stated during the interview than were their proxies’ guesses at their answers. However, concordance was relatively low, with percentages of agreement ranging from 43% to 83% across scenarios. **Abstract:** <https://goo.gl/9K9W2w>

Anticipatory grief, proactive coping, social support, and growth: Exploring positive experiences of preparing for loss

OMEGA – JOURNAL OF DEATH & DYING | Online – 8 March 2018 – Prominent theories on the grieving process tend to begin after a death or other loss has occurred. Many individuals experience anticipatory grief prior to the physical death. Participants in this study consisted of 120 adults who were anticipating the death of a loved one due to terminal illness. The purpose of this investigation was to assess the relationship between the positive disposition of proactive coping and two forms of growth. Both personal and posttraumatic growth were present to a significant degree, and proactive coping illustrated unique predictive power in personal growth. Social support was a significant mediator of proactive coping and growth and was determined to be an outcome of the assertive nature of this disposition. Implications for helping professionals who serve anticipatory grievers as well as directions for future research are discussed. **Abstract:** <https://goo.gl/7MqMZR>

Special issue on medical futility

What matters in the debates taking place among doctors, nurses, patients, and family members in hospitals, courtrooms, legislatures, and Twitter chats around the world

PERSPECTIVES IN BIOLOGY & MEDICINE, 2018;60(3). In the summer of 2017, much of the world was riveted by the case of Charlie Gard, a baby in London whose parents wanted an experimental treatment and whose doctors thought that further treatment would be futile. The case worked its way through the British courts and, eventually, was even heard by the European Court of Human Rights. Many ethical issues resolve over time. Discussions about disagreements lead to discovery of common ground. That doesn’t seem to be the case with the issue of medical futility and, particularly, with the appropriateness of unilateral decisions by doctors to withdraw life support over the objections of patients or family members. Thirty years of debate and discussion, thousands of articles, and numerous court cases seem to have sharpened, rather than softened, disagreements. States have different laws regarding these issues. Some permit unilateral treatment withdrawal. Others strengthen the power of patients and families to resist such unilateral choices. Hospitals have policies, but the policies differ. **Journal contents page:** <https://goo.gl/EMhL6B>



N.B. Selected articles/reports on the Charlie Gard case are noted in the 25 September and 13 November 2017 issues of *Media Watch* (#531, p.11 and #538, p.8, respectively). The November 2017 issue of the *American Journal of Bioethics*, noted in the latter issue of the weekly report, focuses on the medical decision-making process in pediatrics. **Journal contents page:** <https://goo.gl/yQE2Lk>

Psychosocial standards of care for children with cancer and their families: A U.S. national survey of pediatric oncology social workers

SOCIAL WORK IN HEALTH CARE, 2018;57(4): 221-249. In 2015, an interdisciplinary group of psychosocial experts developed 'The Standards of Psychosocial Care for Children with Cancer & Their Families.' In total, 107 social workers from 81 cancer institutions participated in a 25-item online survey that mirrored the 15 Standards for Psychosocial Care. Social work participants reported that psychosocial support is being provided at most cancer centers surveyed, primarily by social workers and child life specialists, addressing adaptation to the cancer diagnosis, treatment, and transitions into survivorship or end-of-life care and bereavement. While social workers reported offering comprehensive services throughout the cancer trajectory, many of the 2015 Standards are not being systematically implemented. Areas for improvement include funding for psychosocial support staff and programs, incorporation of standardized assessment measures, assessment for financial burden throughout treatment and beyond, consistent access to psychology and psychiatry, integrated care for parents and siblings, and more inclusion of palliative care services from time of diagnosis.

Abstract: <https://goo.gl/ZtbgFA>

Is all suffering equal or is time to address existential suffering

PEDIATRIC CRITICAL CARE MEDICINE, 2018; 19(3):275-276. Suffering is often defined as a state of pain, distress or hardship. At the end of life (EoL) our goal as critical care clinicians is to reduce suffering, and we focus most often on pain and symptom management. Although pain and symptom management is important, existential suffering is real and pervasive at the EoL and is often neglected. Existential suffering has been described in the palliative care literature as feelings of dread, powerlessness, solitude and loss of control that occurs when faced with terminal illness. It is suffering with no clear connection to physical pain and can often manifest as questioning one's spiritual connections or identity as a parent. Patients and parents of dying patients describe it as being groundless, "shaken to the core" and feelings of extreme hopelessness. By ignoring existential suffering ... are we missing an opportunity to connect with parents and to help guide them through the grieving process. **First page view:** <https://goo.gl/EgqbiR>

N.B. 'The Standards for Psychosocial Care for Children With Cancer and Their Families' is the focus of the December 2015 issue of *Pediatric Blood & Cancer*. [Noted in the 4 January 2016 issue of Media Watch (#443, p.15)] **Contents page:** <https://goo.gl/L5eoYT>

Related

- *BJA EDUCATION* | Online – 2 March 2018 – '**Current recommendations for paediatric resuscitation.**' The European paediatric resuscitation guidelines 2000 have since undergone a number of sequential changes, during updates in 2005, 2010, and 2015. During this time, survival to return of spontaneous circulation has increased to 77% and survival to hospital discharge to 44%, for in-hospital cardiac arrests. This article reviews the current (2015) guidelines for healthcare professionals. It also highlights evidence behind key changes undertaken since the year 2000. **Full text:** <https://goo.gl/zyYay8>
- *CHIPPS E-JOURNAL*, 2018;No.50;42-45. '**Early integration of pediatric palliative care into pediatric oncology practice: The time is now.**' Pediatric palliative care (PPC) is a field which should be embedded into pediatric oncology. Not because the guidelines recommend it, but because children who are referred to PPC services suffer less. Reinforcing the stigma that palliative care teams should only see patients with significantly limited life expectancy or those actively dying dismisses the known benefits to patients and families that the PPC service can provide throughout the illness trajectory.

N.B. This article and latest issue of the e-journal of the Children's Project on Palliative/Hospice Services (CHiPPS) can be accessed in its entirety at the National Hospice & Palliative Care Organization website. **Downloaded/view at:** <https://goo.gl/yuNGd5>

Disruption or innovation? A qualitative descriptive study on the use of electronic patient-physician communication in patients with advanced cancer

SUPPORTIVE CARE IN CANCER | Online – 4 March 2018 – The authors evaluated an electronic web-based tool which assembles the patient, their caregivers, and their healthcare providers in a virtual space for team-based communication. They identified five themes relating participants' perspectives on electronic communication to their experience of care: 1) Apparent gaps in care; 2) Uncertainty in defining the circle of care; 3) Relational aspects of communication; 4) Incongruence between technology and social norms of patient-physician communication; and, 5) Appreciation but apprehension about the team-based communication tool for improving the experience of care. The potential of tools for electronic communication to bring together a team of healthcare providers with the patient and caregivers is significant, but may pose new challenges to existing team structure and interpersonal dynamics. Patients and physicians were worried about the impact that electronic communication may have on the patient-physician relationship. **Abstract (w. list of references):** <https://goo.gl/SKTSJu>

Exploring symptom meaning: Perspectives of palliative care physicians

SUPPORTIVE CARE IN CANCER | Online – 3 March 2018 – Exploring symptom meaning can serve to provide information, alleviate anxiety, and facilitate individualised care, but only when patients present cues or are open to discuss symptom-related concerns. However, various barriers hinder such dialogue in consultations. Greater awareness of symptom meaning and its influence may facilitate physicians exploring symptom meaning more with patients in the future. Six key themes were identified [in this study]: 1) Definitions of symptom meaning (causal meanings, functional impact, existential impact, and cascade of meanings); 2) Meanings are personal (demographic, culture, spiritual, and family differences); 3) Eliciting meanings requires subtlety and trust (following the patient's cues); 4) Discussing meaning can be hard (for the patient and health professional); 5) Therapeutic (assuaging fears, feeling listened to and valued, increased sense of control, and reduced symptom distress); and, 6) Enhances clinicians' practice and work satisfaction (provision of more tailored care, reassurance through the provision of information, and strengthening of doctor-patient relationship). **Full text:** <https://goo.gl/vMk8Zi>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BMC MEDICAL ETHICS* | Online – 6 March 2018 – ‘**Euthanasia and assisted suicide for people with an intellectual disability and/or autism spectrum disorder: An examination of nine relevant euthanasia cases in the Netherlands (2012-2016).**’ Autonomy and decisional capacity are highly complex for patients with intellectual disabilities and difficult to assess; capacity tests in these cases did not appear sufficiently stringent. Assessment of suffering is particularly difficult for patients who have experienced life-long disability. The sometimes brief time frames and limited number of physician-patient meetings may not be sufficient to make a decision as serious as euthanasia and assisted suicide (EAS). The Dutch EAS due care criteria are not easily applied to people with intellectual disabilities and/or autism spectrum disorder, and do not appear to act as adequate safeguards. **Full text:** <https://goo.gl/d1AYyi>
- *CHRISTIAN BIOETHICS*, 2018;24(1):38-58. “‘**I am my brother’s keeper**’”: **Communitarian obligations to the dying person.**’ Contemporary arguments concerning the permissibility of physician-assisted suicide (PAS), or suicide in general, often rehearse classical arguments over whether individual persons have a fundamental right based on autonomy to determine their own death, or whether the community has a legitimate interest in individual members' welfare that would prohibit suicide. The author explicates historical arguments pertaining to PAS aligned with these poles. He contends that an ethical indictment of PAS entails moral duties on the part of one's community to provide effective means of ameliorating physical and existential suffering. **Abstract:** <https://goo.gl/cVsrGT>

N.B. The focus of the current issue of *Christian Bioethics* is physician-assisted suicide and voluntary euthanasia. **Journal contents page:** <https://goo.gl/a2HDgr>

Cont.

- *JOURNAL OF MEDICAL ETHICS* | Online – 2 March 2018 – ‘**Advance euthanasia directives: A controversial case and its ethical implications.**’ Authorising euthanasia and assisted suicide with advance euthanasia directives (AEDs) is permitted, yet debated, in The Netherlands. The authors focus on a recent controversial case in which a Dutch woman with Alzheimer’s disease was euthanised based on her AED.¹ A Dutch euthanasia review committee found that the physician performing the euthanasia failed to follow due care requirements for euthanasia and assisted suicide. This case is notable because it is the first case to trigger a criminal investigation since the 2002 Dutch euthanasia law was enacted.. **Abstract:** <https://goo.gl/7Fxf9r>
 1. ‘Advance euthanasia directives are problematic, but Mrs. A is a misleading case,’ *Journal of Medical Ethics*, published online 26 February 2018. **Introductory paragraphs:** <https://goo.gl/o5zqa3>
- *NEW ENGLAND JOURNAL OF MEDICINE*, 2018;378(10):883-885. ‘**Physician-assisted death for psychiatric patients – misguided public policy.**’ Physicians in the Netherlands and Belgium have helped a small but growing number of patients with mental illness but no terminal condition to end their lives. In some U.S. states, attempts to extend physician-assisted death to psychiatric patients appear inevitable. **Introduction:** <https://goo.gl/gKy36K>
- *NEW ENGLAND JOURNAL OF MEDICINE*, 2018;378(10):885-887. ‘**Physician-assisted suicide and psychiatric illness.**’ In exceptional cases, suicide might be considered a rational choice of a competent person, even in the presence of psychiatric illness. But unless a truly rigorous prospective review system is in place for such cases, countries should not legalize the practice. **Introduction:** <https://goo.gl/CYBK8r>
- *PSYCHOSOMATICS* | Online – 2 March 2018 – ‘**Physician-assisted death psychiatric assessment: A standardized protocol to conform to the California End-of-Life Option Act.**’ A committee at University of California, San Francisco Medical Center (UCSFMC) developed a clinical protocol informed by the law with an additional local expectation of an evaluation by a psychiatrist or clinical psychologist. The consultation-liaison psychiatry group at the university developed a standard protocol for the psychiatric assessment for use by clinicians performing these assessments. Attention to the cognitive, mood, and decisional capacity status pertinent to choosing physician-assisted death (PAD) is required under the clinical guidance document. Case vignettes of six early patients evaluated for PAD are presented. **Abstract:** <https://goo.gl/qJceuv>

Worth Repeating

The troubles of telling: Managing communication about the end of life

QUALITATIVE HEALTH RESEARCH | Online – 27 January 2014 – Communication about palliative care (PC) represents one of the most difficult interpersonal aspects of medicine. Delivering the “terminal” diagnosis has traditionally been the focus of research, yet transitions to specialist PC are equally critical clinical moments. The authors focus on twenty medical specialists’ strategies for engaging patients around referral to specialist PC. Their aim was to develop an understanding of the logics that underpin their communication strategies when negotiating this transition. The authors draw on qualitative interviews to explore their accounts of deciding whether and when to engage in referral discussions; the role of uncertainty and the need for hope in shaping communication; and, their perceptions of how patient biographies might shape their approaches to, and communication about, the end of life. They argue that communication is embedded in social relations of hope, justice, and uncertainty, as well as being shaped by patient biographies. [Noted in the 3 February 2014 issue of *Media Watch* (#343, p.12)] **Abstract (w. list of references):** <https://goo.gl/hvEwTn>

Palliative Care Network

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>

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Asia

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

Cont.

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[January/February 2018 issue (Scroll down to 'Paediatric palliative care; the patient's voice']

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

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

South America



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

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