

REFERENCES / READING LIST

The facts of death

Katherine Webber

- GMC treatment and care towards the end of life
<https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life>
- NICE End of Life Care for adults
<https://www.nice.org.uk/guidance/qs13>
- NICE Care of dying adults in the last days of life
<https://www.nice.org.uk/guidance/qs144/resources/care-of-dying-adults-in-the-last-days-of-life-pdf-75545479508677>
- End of life ambitions
<http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>
- Office of National Statistics deaths
<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths>
- One chance to get it right. Leadership Alliance
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf
- Department of Health. Choice in end of life care
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf
- Office National Statistics. VOICES survey
<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015>
- NHS Benchmarking. NACEL
<https://www.nhsbenchmarking.nhs.uk/nacel>

What is a “good death”

Andrew Davies

- Age Concern. Debate of the Age Health and Care Study Group. The future of health and care of older people: the best is yet to come. London: Age Concern; 1999.
- Davies A, Todd J, Bailey F, Gregory A, Waghorn M. Good concordance between patients and their non-professional carers about factors associated with a “good death” and other important end-of-life decisions. *BMJ Supportive & Palliative Care* 2016 [Epub ahead of publication]. <https://spcare.bmj.com/content/early/2016/05/17/bmjspcare-2015-001085>
- National Survey of Bereaved People (VOICES): England, 2015. Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015>
- Smith R. A good death. *BMJ* 2000; 320: 129-30. <https://www.bmj.com/content/320/7228/129>
- Steinhauser KE, Christakis N, Clipp EA et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; 284: 2476-82.
- Waghorn M, Young H, Davies A. Opinions of patients with cancer on the relative importance of place of death in the context of a “good death”. *BMJ Supportive & Palliative Care* https://spcare.bmj.com/content/1/3/310?int_source=trendmd&int_medium=trendmd&int_campaign=trendmd
- Wilson DM, Hewitt JA. A scoping literature review to assess the state of existing evidence on the “bad” death. *Palliative and Supportive Care* 2018; 16: 90-106.

Prognostication

Paddy Stone

- Whit et al. Systematic review of predictions of survival in palliative care: how accurate are clinicians and who are the experts? <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0161407>
- Provano et al. A new palliative prognostic score: a first step for the staging of terminally ill cancer patients. Italian Multicentre and Study Group on Palliative Care. *J Pain Symptom Manage* 1999 <https://www.ncbi.nlm.nih.gov/pubmed/10203875>
- Gwilliam et al. Development of prognosis in Palliative care Study (PiPS) predictor models to improve prognostication in advanced cancer: prospective cohort study. *BMJ* 2011. <https://www.bmj.com/content/343/bmj.d4920>

- Kalpakidou AK et al. The prognosis in palliative care study II (PiPS2). BMC Palliative Care 2018.
<https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-018-0352-y>
- Hui D et al. Clinical signs of impending death in cancer patients. Oncologist 2014.
<https://www.ncbi.nlm.nih.gov/pubmed/24760709>
- Benedetti D et al. International palliative care experts' view on phenomena indicating the last hours and days of life. Support Care Cancer 2013.
<https://www.ncbi.nlm.nih.gov/pubmed/23242388>
- White N et al. How do palliative care doctors recognise imminently dying patients? A judgement analysis. BMJ Open 2019 <https://bmjopen.bmj.com/content/8/11/e024996>
- Oostendorp L et al. Protocol for the ORaCIES study: an online randomised controlled trial to improve clinical estimates of survival using a training resource for medical students. BMJ Open <https://bmjopen.bmj.com/content/9/3/e025265>

Pain and other symptoms

Jo Thompson

- Dickman A and Schneider J (2016) *The Syringe Driver: Continuous Subcutaneous Infusions in Palliative Care*. 4th Edn. Oxford University Press.
- Graham F and Clark (2005) The syringe driver and the subcutaneous route in palliative: the inventor, the history and the implications. *Journal of Pain and Symptom Management* 29(1) 32-40.
- Hui D et al (2015) Symptom expression in the last seven days of life among cancer patients admitted to acute palliative care units. *Journal of Pain and Symptom Management* 50(4) 488-494.
- Klinkenberg M et al (2004) Symptom burden in the last week of life. *Journal of Pain and Symptom Management* 27(1) 5-13.
- National Institute for Health and Care Excellence (NICE) (2015) Care of dying adults in the last days of life (NG 31) available at <https://www.nice.org.uk/guidance/ng31> (accessed 1st March 2019). Website resource.
- Schmidt-Hansen M, Bennett MI, Arnold S, Bromham N, Hilgart JS. Oxycodone for cancer-related pain. Cochrane Database of Systematic Reviews 2017, Issue 8. Art. No.: CD003870. DOI: 10.1002/14651858.CD003870.pub6.

- Soares L et al (2018) Prevalence and intensity of dyspnea, pain, and agitation among people dying with late stage dementia compared with people dying with advanced cancer: a single centre preliminary study in Brazil. *Annals of Palliative Medicine* 7(4)437-443.
- Teunissen S et al (2007) Symptom prevalence in patients with incurable cancer: a systematic review. *Journal of Pain and Symptom Management* 34(1) 94-104.
- Twycross R et al (eds) (2017) Palliative Care Formulary 6th edn. Palliativedrugs.com.
- Vivat B et al (2019) Palliative care specialists in hospice and hospital/community teams predominantly use low doses of sedative medication at the end of life for patient comfort rather than sedation: Findings from focus groups and patient records for I-CAN-CARE. *Palliative Medicine* 1-11.

“Death rattle” and dyspnea

Charlotte Leach

- Abernethy *et al.* Randomized, double blind, placebo-controlled crossover trial of sustained release morphine for the management of refractory dyspnoea. *BMJ (Clinical Research Ed.)* 2003; 327(7414): 523-528
- Barnes *et al.* Opioids for the palliation of refractory breathlessness in adults with advanced disease and terminal illness. *Cochrane Database of Systematic Reviews* 2016. CD011008
- Bennett *et al.* Using anti-muscarinic drugs in the management of death rattle: evidence-based guidelines for palliative care. *Palliative Medicine* 2002;16:369-374
- Mercadante S. Death rattle: critical review and research agenda. *Supportive Care in Cancer* 2014;22:571-575
- Mularski et al. An Official American Thoracic Society Workshop Report: Assessment and Palliative Management of Dyspnoea Crisis. *Annals of the American Thoracic Society* 2013;10:s98-s106
- Smallwood *et al.* Management of refractory breathlessness with morphine in patients with chronic obstructive pulmonary disease. *Internal Medicine Journal* 2015;45:898-904
- Simon *et al.* Benzodiazepines for the relief of breathlessness in advanced malignant and non-malignant diseases in adults. *Cochrane Database of Systematic Reviews* 2011. CD007354
- Wee *et al.* Interventions for noisy breathing in patients near to death. *Cochrane Database of Systematic Reviews* 2008. CD005177

“Terminal agitation”

Andrew Davies

- Beller EM, van Driel ML, McGregor I et al. Palliative pharmacological sedation for terminally ill adults. Cochrane Database of Systematic Reviews 2015, Issue 1. Art. No.: CD010206. Website resource.
- Burry L, Mehta S, Perreault MM et al. Antipsychotics for treatment of delirium in hospitalised non-ICU patients. Cochrane Database of Systematic Reviews 2018, Issue 6. Art. No.: CD005594.
- Candy B, Jackson KC, Jones L et al Drug therapy for delirium in terminally ill adult patients. Cochrane Database of Systematic Reviews 2012, Issue 11. Art. No.: CD004770.
- Cherny NI, Radbruch L, Board of EAPC. European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. Palliative Medicine 2009; 23: 581-93.
- Hosker CM, Bennett MI. Delirium and agitation at the end of life. BMJ 2016; 353: i3085. Website resource.
- Juth N, Lindblad A, Lynoe A et al. European Association for Palliative Care (EAPC) framework for palliative sedation: an ethical discussion. BMC Palliative Care 2010; 9: 20. Website resource.
- Lonergan E, Luxenberg J, Areosa Sastre A. Benzodiazepines for delirium. Cochrane Database of Systematic Reviews 2009, Issue 4. Art. No.: CD006379.
- National Institute for Health and Care Excellence. Delirium: prevention, diagnosis and management. London: NICE; 2010. Website resource.
- Twycross R, Wilcock A, Howard P. Palliative Care Formulary, 6th edn. Nottingham: palliativedrugs.com; 2017.

Hydration and nutrition

Chris Farnham

- GMC Guidance <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life>
- Davies AN et al. A cluster randomised feasibility trial of clinically assisted hydration in cancer patients in the last days of life. Palliat Med 2018. <https://www.ncbi.nlm.nih.gov/pubmed/29343167>

- Good, P., Richard, R., Syrmis, W., Jenkins-Marsh, S., & Stephens, J. (1996). Medically assisted nutrition for adult palliative care patient. *Cochrane Database of Systematic Reviews* <http://doi.org/10.1002/14651858.CD006274.pub3>
- Good, P., Cavenagh, J., Mather, M., & Ravenscroft, P. (2008). Medically assisted nutrition for palliative care in adult patients. *Cochrane Database of Systematic Reviews (Online)*, (4), CD006274. <http://doi.org/10.1002/14651858>

Post mortem

Antonia Field-Smith

- A Code of Practice for the Diagnosis and Confirmation of Death (AOMRC): http://www.aomrc.org.uk/wp-content/uploads/2016/04/Code_Practice_Confirmation_Diagnosis_Death_1008-4.pdf
- Hospice UK publications: <https://www.hospiceuk.org/what-we-offer/publications>
- Guidance for completing MCCD and cremation forms: https://www.gro.gov.uk/Images/medcert_July_2010.pdf
<https://www.gov.uk/government/publications/medical-practitioners-guidance-on-completing-cremation-forms>
- Medical examiner reforms: <https://www.gov.uk/government/publications/changes-to-the-death-certification-process/an-overview-of-the-death-certification-reforms>
- Guide to Coroner Services: https://www.coronersociety.org.uk/_img/pics/pdf_1503323588.pdf
- National Guidance on Learning from Deaths: <https://www.england.nhs.uk/wp-content/uploads/2017/03/nqb-national-guidance-learning-from-deaths.pdf>
- Using the structured judgement review method: a guide for reviewers: https://www.rcplondon.ac.uk/sites/default/files/media/Documents/NMCRR%20guide%20England_0.pdf

Communication skills

Kath Webber

- Moore, P. M., Rivera, S., Bravo-Soto, G. A., Olivares, C., & Lawrie, T. A. (2018). Communication skills training for healthcare professionals working with people who have cancer. *Cochrane Database of Systematic Reviews*, 17(3), 209–124. <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD003751.pub4/epdf/full>
- Caswell, G. (2015). Communication between family carers and health professionals about end-of-life care for older people in the acute hospital setting: a qualitative study. *BMC Palliative Care*, 1–14. <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-015-0032-0>
- The Point of Care. Enabling compassionate care in acute hospital settings. Jenny Firth-Cozens, Jocelyn Cornwell. <https://www.pointofcarefoundation.org.uk/>
- LJ Fallowfield, VA Jenkins, HA Beveridge Truth may hurt but deceit hurts more: communication in palliative care *Palliative Medicine* 2002; 16: 297-303
- Fallowfield, L., Jenkins, V., Farewell, V., & Solis-Trapala, I. (2003). Enduring impact of communication skills training: results of a 12-month follow-up. *British Journal of Cancer*, 89(8), 1445–1449. <http://doi.org/10.1038/sj.bjc.6601309>
- Anne-Mei The, Tony Hak, Gerard Koëter, Gerrit van der Wal. Collusion in doctor-patient communication about imminent death: an ethnographic study *BMJ* 2000;321:1376–81
- Johnson, S. B., Butow, P. N., Bell, M. L., Detering, K., Clayton, J. M., Silvester, W., et al. (2018). A randomised controlled trial of an advance care planning intervention for patients with incurable cancer. *British Journal of Cancer*, 1–9. <http://doi.org/10.1038/s41416-018-0303-7>

Ethical and legal issues

Craig Gannon

- Royal College of Nursing Guidance <http://rcnendoflife.org.uk/the-patient-journey/ethics/>
- Thorns A. Ethical and legal issues in end-of-life. *Clinical Medicine*. <http://www.clinmed.rcpjournals.org/content/10/3/282>

- Beauchamp TL. Methods and principles in biomedical ethics. Journal of Medical Ethics
<https://jme.bmj.com/content/29/5/269>
- Rodriguez-Prat A et al. Patient perspectives of dignity, autonomy, and control at the end of life. Systematic review and meta-ethnography. PLoS One. 2016.
<https://www.ncbi.nlm.nih.gov/pubmed/27010323>
- Bester J, Kodish E. Cardiopulmonary resuscitation, informed consent, and rescue: what provides moral justification for the provision of CPR?
<https://www.ncbi.nlm.nih.gov/pubmed/30896446>