

## Talking about dying: How to begin honest conversations about what lies ahead October 2018

## References

- 1 Clark D, Armstrong M, Allan A, Graham F, Carnon A, Isles C. Imminence of death among hospital inpatients: prevalent cohort study. *Palliat Med* 2014;28:474–9. https://doi.org/10.1177/0269216314526443
- 2 General Medical Council. Treatment and care towards the end of life: good practice in decision making. Glossary of terms. Manchester: GMC, 2010. www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life/glossary-of-terms [Accessed 29 August 2018].
- Royal College of General Practitioners and Royal College of Nursing. *Matters of life and death: Helping people to live well until they die.* General practice guidance for implementing the RCGP/RCN End of Life Care Patient Charter. London: RCGP, 2012. <a href="https://www.rcgp.org.uk/~/media/Files/CIRC/Matters%20of%20Life%20and%20Death%20FINAL.ashx">www.rcgp.org.uk/~/media/Files/CIRC/Matters%20of%20Life%20and%20Death%20FINAL.ashx</a> [Accessed 29 August 2018].
- 4 Thomas K, Clifford CM, de Silva D. National snapshot study of end of life care in the community for cancer and non-cancer patients. *BMJ Support Palliat Care* 2011;1:A5. https://doi.org/10.1136/bmjspcare-2011-000020.11
- 5 Department of Health. *The NHS Constitution for England*, 27 July 2015. London: DH, 2015. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/480482/NHS\_Constitution\_WEB.pdf [Accessed 29 August 2018].
- 6 National Palliative and End of Life Care Partnership. Ambitions for palliative and end of life care: a national framework for local action 2015–2020. http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf [Accessed 29 August 2018].
- 7 The Gold Standards Framework. *Advance care planning, 2013*. <u>www.goldstandardsframework.org.uk/advance-care-planning</u> [Accessed 29 August 2018].
- 8 Thomas K, Lobo B. Advance care planning in end of life care. Oxford: Oxford University Press, 2010.
- 9 Temel JS, Greer JA, Muzikansky A *et al*. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010;363:733–42. <a href="https://doi.org/10.1056/NEJMoa1000678">https://doi.org/10.1056/NEJMoa1000678</a>
- Howie L, Peppercorn J. Early palliative care in cancer treatment: rationale, evidence and clinical implications. Ther Adv Med Oncol 2013;5:318–23. <a href="https://doi.org/10.1177/1758834013500375">https://doi.org/10.1177/1758834013500375</a>
- Mullick A, Martin J, Sallnow L. An introduction to advance care planning in practice. BMJ 2013;347:f6064. https://doi.org/10.1136/bmj.f6064
- 12 Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Database Syst Rev 2013;6:CD007760. https://doi.org/10.1002/14651858.CD007760.pub2
- Dixon J, King D, Knapp M. Advance care planning in England: is there an association with place of death? Secondary analysis of data from the National Survey of Bereaved People. BMJ Support Palliat Care 2016 (epub ahead of print). https://doi.org/10.1136/bmispcare-2015-000971
- 214 Ziegler LE, Craigs CL, West RM et al. Is palliative care support associated with better quality end-of-life care indicators for patients with advanced cancer? A retrospective cohort study. BMJ Open 2018;8:e018284. <a href="https://doi.org/10.1136/bmjopen-2017-018284">https://doi.org/10.1136/bmjopen-2017-018284</a>
- 15 Royal College of Physicians. End of life care audit dying in hospital. National report for England 2016. London: RCP, 2016. www.rcplondon.ac.uk/projects/outputs/end-life-care-audit-dying-hospital-national-report-england-2016 [Accessed 29 August 2018].
- 16 Care Quality Commission. A different ending: Addressing inequalities in end of life care. London: CQC, 2016. www.cqc.org.uk/sites/default/files/20160505%20CQC\_EOLC\_OVERVIEW\_FINAL\_3.pdf [Accessed 29 August 2018].
- 17 Office for National Statistics. National Survey of Bereaved People (VOICES): England, 2015. Quality of care delivered in the last 3 months of life for adults who died in England. Newport: ONS, 2016.

  www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereaved peoplevoices/england2015 [Accessed 29 August 2018].
- Office for National Statistics. Deaths registered in England and Wales (Series DR): 2014. Table 12: Deaths registered by age, sex and selected underlying cause of death. Newport: ONS, 2015.
  www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredinenglandand walesseriesdr/2015-11-09/relateddata [Accessed 29 August 2018].

- 19 National Audit Office. End of life care. London: TSO, 2008. <a href="www.nao.org.uk/report/end-of-life-care/">www.nao.org.uk/report/end-of-life-care/</a> [Accessed 29 August 2018].
- 20 Office for National Statistics. National bereavement survey (VOICES), 2012. Newport: ONS, 2013. http://webarchive.nationalarchives.gov.uk/20160107054652/http://www.ons.gov.uk/ons/dcp171778\_317495.pdf [Accessed 29 August 2018].
- 21 Wright AA, Zhang B, Ray A *et al*. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;300:1665–73. https://doi.org/10.1001/jama.300.14.1665
- The Choice in End of Life Care Programme Board. What's important to me: a review of choice in end of life care. London: The Choice in End of Life Care Programme Board, 2015. <a href="https://www.gov.uk/government/publications/choice-in-end-of-life-care">www.gov.uk/government/publications/choice-in-end-of-life-care</a> [Accessed 29 August 2018].
- 23 Macmillan Cancer Support. Missed opportunities: Advance care planning report. London: Macmillan, 2018. www.macmillan.org.uk/ images/missed-opportunities-end-of-life-advance-care-planning tcm9-326204.pdf [Accessed 30 August 2018].
- 24 Brighton LJ, Bristowe K. Communication in palliative care: talking about the end of life, before the end of life. *Postgrad Med J* 2016;92:466–70. https://doi.org/10.1136/postgradmedj-2015-133368
- Etkind SN, Bone AE, Gomes B *et al.* How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Med* 2017;15:102. https://doi.org/10.1186/s12916-017-0860-2
- 26 Lyons P, Verne J. Pattern of hospital admission in the final year of life. BMJ Support Palliat Care 2011;1:81–2. https://doi.org/10.1136/bmjspcare-2011-000053.54
- 27 Harding R, Simms V, Calanzani N et al. If you had less than a year to live, would you want to know? A seven-country European population survey of public preferences for disclosure of poor prognosis. Psychooncology 2013;22:2298–305. https://doi.org/10.1002/pon.3283
- 28 Royal College of Physicians. Podcast: End of life care. London: RCP, 2018. https://ourfuturehealth.rcplondon.ac.uk/podcast/end-of-life-care/ [Accessed 29 August 2018].
- 29 Macmillan Cancer Support. *No regrets: How talking more openly about death could help people die well*. London: Macmillan, 2017. <a href="https://www.macmillan.org.uk/">www.macmillan.org.uk/</a> images/no-regrets-talking-about-death-report tcm9-311059.pdf [Accessed 29 August 2018].
- Brownlee S, Chalkidou K, Doust J *et al*. Evidence for overuse of medical services around the world. *Lancet* 2017;390:156–68. https://doi.org/10.1016/S0140-6736(16)32585-5
- 31 Henson LA, Gomes B, Koffman J, Daveson BA, Higginson IJ, Gao W. Factors associated with aggressive end of life cancer care. Support Care Cancer 2016;24:1079–89. https://doi.org/10.1007/s00520-015-2885-4
- 32 National Confidential Enquiry into Patient Outcome and Death. For better, for worse? A review of the care of patients who died within 30 days of receiving systemic anti-cancer therapy. London: NCEPOD, 2008. <a href="https://www.ncepod.org.uk/2008report3/Downloads/SACT">www.ncepod.org.uk/2008report3/Downloads/SACT</a> report.pdf [Accessed 30 August 2018].
- 33 Johnston SD, Tham TCK, Mason M. Death after PEG: results of the National Confidential Enquiry into patient outcome and death. *Gastrointest Endosc* 2008;68:223–7. https://doi.org/10.1016/j.gie.2007.10.019
- 34 Fulmer T, Escobedo M, Berman A, Koren MJ, Hernández S, Hult A. Physicians' views on advance care planning and end-of-life care conversations. *J Am Geriatr Soc* 2018;66:1201–5. https://doi.org/10.1111/jgs.15374
- 35 Sleeman KE. End-of-life communication: let's talk about death. J R Coll Physicians Edinb 2013;43:197–9. https://doi.org/10.4997/JRCPE.2013.302
- 36 Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. BMJ 2000;320:469–72. https://doi.org/10.1136/bmj.320.7233.469
- 37 Glare P, Virik K, Jones M *et al.* A systematic review of physicians' survival predictions in terminally ill cancer patients. *BMJ* 2003;327:195–8. https://doi.org/10.1136/bmj.327.7408.195
- Murray SA, Boyd K, Sheikh A. Palliative care in chronic illness. We need to move from prognostic paralysis to active total care. BMJ 2005;330:611–2. https://doi.org/10.1136/bmj.330.7492.611
- 39 Resuscitation Council (UK). Do not attempt CPR. Decisions relating to cardiopulmonary resuscitation. London: Resuscitation Council (UK), 2016. <a href="https://www.resus.org.uk/dnacpr/decisions-relating-to-cpr/">www.resus.org.uk/dnacpr/decisions-relating-to-cpr/</a> [Accessed 30 August 2018].
- 40 General Medical Council. Treatment and care towards the end of life: good practice in decision making. Cardiopulmonary resuscitation (CPR). Manchester: GMC, 2010. <a href="https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life/cardiopulmonary-resuscitation-cpr">www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life/cardiopulmonary-resuscitation-cpr</a> [Accessed 30 August 2018].
- 41 Northern England Strategic Clinical Networks. *Deciding right: your life, your choice. A guide to making individual care decisions in advance with children, young people and adults.* Newcastle upon Tyne: St Oswald's Hospice, 2015. <a href="www.necn.nhs.uk/wp-content/uploads/2014/05/Deciding-Right-v28-7May-20152.pdf">www.necn.nhs.uk/wp-content/uploads/2014/05/Deciding-Right-v28-7May-20152.pdf</a> [Accessed 30 August 2018].
- 42 Resuscitation Council (UK). *Post-resuscitation care*. London: Resuscitation Council (UK), 2016. <a href="www.resus.org.uk/resuscitation-guidelines/post-resuscitation-care/">www.resus.org.uk/resuscitation-care/</a> [Accessed 30 August 2018].
- 43 Girotra S, Nallamothu BK, Spertus JA *et al.* Trends in survival after in-hospital cardiac arrest. *N Engl J Med* 2012;367:1912–20. https://doi.org/10.1056/NEJMoa1109148

- Davison SN, Simpson C. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. BMJ 2006;333:886. https://doi.org/10.1136/bmj.38965.626250.55
- 45 Association for Palliative Medicine. *The use of opioids*. APM position statement. Fareham: APM, 2018. https://apmonline.org/wp-content/uploads/2018/07/apm-opioid-statement-june-2018-2.pdf [Accessed 30 August 2018].
- 46 Boland JW, Ziegler L, Boland EG, McDermid K, Bennett MI. Is regular systemic opioid analgesia associated with shorter survival in adult patients with cancer? A systematic literature review. *Pain* 2015;156:2152–63. https://doi.org/10.1097/j.pain.0000000000000306
- 47 Maltoni M, Scarpi E, Rosati M *et al*. Palliative sedation in end-of-life care and survival: a systematic review. *J Clin Oncol* 2012;30:1378–83. https://doi.org/10.1200/JCO.2011.37.3795
- 48 Association for Palliative Medicine. *APM position on using sedating medication at the end of life*. APM position statement. Fareham: APM, 2009. https://apmonline.org/wp-content/uploads/2018/03/Sedation\_0902.pdf [Accessed 30 August 2018].
- 49 NHS Scotland. Scottish Palliative Care Guidelines. Severe uncontrolled distress. Edinburgh: NHS Scotland, 2014. www.palliativecareguidelines.scot.nhs.uk/guidelines/end-of-life-care/severe-uncontrolled-distress.aspx [Accessed 30 August 2018].
- 50 Twycross R, Wilcock A, Howard P (eds). Palliative Care Formulary, 6th edn. London: Pharmaceutical Press, 2017. www.palliativedrugs.com/palliative-care-formulary.html [Accessed 30 August 2018].
- 51 Association for Palliative Medicine. *APM position on the double effect (DE)*. APM position statement. Fareham: APM, 2009. https://apmonline.org/wp-content/uploads/2018/03/Double\_Effect\_0902.pdf
- 52 General Medical Council. *Treatment and care towards the end of life: good practice in decision making*. Manchester: GMC, 2010. <a href="https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life">www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life</a> [Accessed 30 August 2018].
- 53 Association for Palliative Medicine. APM position statement on the provision of clinically assisted hydration at the end of life. APM position statement. Fareham: APM, 2017. <a href="https://apmonline.org/news-events/apm-position-statements/">https://apmonline.org/news-events/apm-position-statements/</a> [Accessed 30 August 2018].
- 54 Dale J, Petrova M, Munday D, Koistinen-Harris J, Lall R, Thomas K. A national facilitation project to improve primary palliative care: impact of the Gold Standards Framework on process and self-ratings of quality. *Qual Saf Health Care* 2009;18:174–80. https://doi.org/10.1136/qshc.2007.024836
- Highet G, Crawford D, Murray SA, Boyd K. Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. BMJ Support Palliat Care 2014;4:285–90. https://doi.org/10.1136/bmjspcare-2013-000488
- 56 Bernacki R, Hutchings M, Vick J *et al.* Development of the Serious Illness Care Program: a randomised controlled trial of a palliative care communication intervention. *BMJ Open* 2015;5:e009032. https://doi.org/10.1136/bmjopen-2015-009032
- 57 The Serious Illness Care Programme UK. *Better conversations, better care*. Wirral: The Clatterbridge Cancer Centre NHS Foundation Trust, 2018. <a href="http://betterconversations.org.uk/about/">http://betterconversations.org.uk/about/</a> [Accessed 30 August 2018].
- 58 Tweedie J, Hordern J, Dacre J. Advancing medical professionalism. London: RCP, 2018. <a href="https://www.rcplondon.ac.uk/advancing-professionalism">www.rcplondon.ac.uk/advancing-professionalism</a> [Available soon].
- 59 Future Hospital Commission. Future hospital: caring for medical patients. A report from the Future Hospital Commission to the Royal College of Physicians. London: RCP, 2013. <a href="https://www.rcplondon.ac.uk/projects/outputs/future-hospital-commission">www.rcplondon.ac.uk/projects/outputs/future-hospital-commission</a> [Accessed 30 August 2018].
- Resuscitation Council (UK). ReSPECT: Recommended summary plan for emergency care and treatment. London: Resuscitation Council (UK), 2018. <a href="https://www.respectprocess.org.uk/">www.respectprocess.org.uk/</a> [Accessed 30 August 2018].