

End-of-life care - evidence

Introduction

Here you will find a summary of evidence and research relating to end-of-life care and the role of speech and language therapy.

Visit the RCSLT Research Centre for information and resources to support your evidence-based practice, ways to enhance your continuing professional development (CPD), information about clinical academic careers, resources to help you get involved in research, and much more.

For more end-of-life care information, see also:

- Public page
- Guidance
- Learning
- Influencing and campaigning
- Contacts

Please **contact us** if you have any suggestions or feedback on these pages.



Finding evidence

Access research articles through our <u>RCSLT Journals Collection</u>, and more resources to support using evidence-based practice in our <u>Research Centre</u>



Cochrane Reviews

Cochrane Reviews are systematic reviews of primary research in human health care and health policy, internationally recognised as the highest standard in evidence-based health care. Search the **Cochrane Database of Systematic Reviews**.

Good P, Richard R, Syrmis W, Jenkins-Marsh S, Stephens, J. Medically assisted hydration for adult palliative care patients. Cochrane Database of Systematic Reviews [online] 2014)



Research papers, articles and books

Alsolamy S. Islamic views on artificial nutrition and hydration in terminally ill patients. *Bioethics* 2012; 28(2), 96–99.

Barriguinha C, Mourão MT, Martins JC. The speech therapist in palliative care: perspective of patients, families and/or informal caregivers and professional team involved. *Revista Portuguesa de Terapia da Fala* 2015; 4,15–20.

Bogaardt H, Veerbeek L, Kelly K, Van der Heide A, Van Zuylen L, Speyer R. Swallowing problems at the end of the palliative phase: incidence and severity in 164 unsedated patients. *Dysphagia* 2014; 30(2), 145–151.

Boundy EO, Dastjerdi R, Spiegelman D, Fawzi WW, Missmer SA, Lieberman E, Kajeepeta S, Wall S, Chan GJ. Kangaroo mother care and neonatal outcomes: a meta-analysis. Pediatrics [online] 2016; 137(1), e20152238

Bowen P, Mansfield A, King H. Using subcutaneous fluids in end-of-life care. *Nursing Times* [online] 2014

Chahda L, Mathisen BA, Carey LB. The role of speech-language pathologists in adult palliative care. International Journal of Speech-Language Pathology [online] 2017; 19(1), 58-68

Clark D, Armstrong M, Allan A, Graham F, Carnon A, Isles C. Imminence of death among hospital inpatients: prevalent cohort study. Palliative Medicine [online] 2014; 28(6), 474–479

Eckman S, Roe J. Speech and language therapists in palliative care: what do we have to offer? International Journal of Palliative Nursing, 2005; 11(4), 179–181.

Fraser L, Miller M, Hain R, Norman P, Aldridge J, McKinney P, Parslow R. Rising national prevalence of life-limiting conditions in children in England – White Rose Research Online. Whiterose.ac.uk. [online] 2012

Gardiner C, Harrison M, Ryan T, Jones, A. Provision of palliative and end-of-life care in stroke units: a qualitative study. *Palliative Medicine* 2013; 27(9), 855–860.

Good, P, Richard R, Syrmis W, Jenkins-Marsh S, Stephens J. Medically assisted hydration for adult palliative care patients. *Cochrane Database of Systematic Reviews* [online] 2014

Griffith R. Withdrawing or withholding life-sustaining clinically-assisted nutrition and hydration. *British Journal of Community Nursing* 2017; 22(12), 615–617.



Hawksley R, Ludlow F, Buttimer H, Bloch S. Communication disorders in palliative care: investigating the views, attitudes and beliefs of speech and language therapists. *International Journal of Palliative Nursing*, 2017; 23(11), 543–551.

Hughes JC, Jolley D, Jordan A, Sampson EL. Palliative care in dementia: issues and evidence.

Advances in Psychiatric Treatment, [online] 2007; 13(4), 251–260

Humel P, Cronin J. Home care of the high risk infant. *Advances in Neonatal Care* 2004; 4(6), pp.354–364.

Jones S, Howard L, Thornicroft G. (). 'Diagnostic overshadowing': worse physical health care for people with mental illness. *Acta Psychiatrica Scandinavica* [online] 2008; 118(3), 169–171

Kambarami RA. *Kangaroo Care Method (Mother-Baby Skin to Skin Care): a guide for health workers.* Harare: Uz, Dept. Of Paediatrics And Child Health, 1996.

Kelly K, Cumming S, Corry A, Gilsenan K, Tamone C, Vella K, Bogaardt H. The role of speech-language pathologists in palliative care: where are we now? A review of the literature. *Progress in Palliative Care* 2016; 24(6), 315–323.

Kenner C, Mcgrath JM. National Association of Neonatal Nurses. *Developmental Care of Newborns & Infants: a guide for health professionals*. Glenview, II: National Association Of Neonatal Nurses, 2010.

Krikheli L, Mathisen BA, Carey LB. Speech-language pathology in paediatric palliative care: A scoping review of role and practice. *International Journal of Speech-Language Pathology*, 2017; 20(5), 541–553.

Lambert H. The allied health care professional's role in assisting medical decision making at the end of life. *Topics in Language Disorders* [online] 2012; 32(2),119–136

Levy A, Dominguez-Gasson L, Brown E, Frederick C. Managing dysphagia in the adult approaching end of life. *ASHA Leader* 2004; 9(13),1.

Luckett T, Reid KLP. Speech and Language Therapy in Palliative Care [online]. Oup.com, 2015

Mason J, Scior K. (). 'Diagnostic overshadowing' amongst clinicians working with people with intellectual disabilities in the UK. Journal of Applied Research in Intellectual Disabilities [online] 2004; 17(2), 85-90

Mathisen B, Yates P, Crofts P. Palliative care curriculum for speech-language pathology students. *International Journal of Language & Communication Disorders* 2011; 46(3), 273–285.

Mckenzie K. Feeding Decisions at the End-of-Life: Law, Ethics and Emotions [online] 2018



Moloney J, Walshe M. Managing and supporting quality of life issues in dysphagia: a survey of clinical practice patterns and perspectives in the UK, Ireland and South Africa. *International Journal of Language & Communication Disorders* 2018; 54(1), 41–49.

Murphy J. Communication strategies of people with ALS and their partners. *Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders* 2004a; 5(2),121–126.

Murphy J. 'I prefer contact this close': perceptions of AAC by people with motor neurone disease and their communication partners. *Augmentative and Alternative Communication* 2004b; 20(4), 259–271.

Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. *BMJ* 2005; 330(7498),1007–1011.

Nancarrow SA, Booth A, Ariss S, Smith T, Enderby P, Roots A. Ten principles of good interdisciplinary team work. *Human Resources for Health* 2013; 11(1).

Nationalvoices.org.uk. A Narrative for Person-Centred Coordinated Care. National Voices [online], 2013

Newman K. Speech and language therapy techniques in end-of-life care. *End of Life Journal* 2009; 3(1), 8–14.

O'Reilly AC, Walshe M. Perspectives on the role of the speech and language therapist in palliative care: an international survey. *Palliative Medicine* 2015; 29(8), 756–761.

Parravicini E. Neonatal palliative care. Current Opinion in Pediatrics 2017; 29(2), 135-140.

Pascoe A, Breen LJ, Cocks N. What is needed to prepare speech pathologists to work in adult palliative care? *International Journal of Language & Communication Disorders* 2018; 53(3), 542–549.

Pollens RD. Integrating speech-language pathology services in palliative end-of-life care. *Topics in Language Disorders* 2018; 32(2),137–148.

Public Health England. End of Life Care Profiles: February 2018 update. [online]. GOV.UK, 2018

Robinson L, Dickinson C, Bamford C, Clark A, Hughes J, Exley C. A qualitative study: professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but' *Palliative Medicine* 2012; 27(5), 401–408.

Roe J, Leslie P. Beginning of the end? Ending the therapeutic relationship in palliative care.

International Journal of Speech-Language Pathology [online] 2010

Salt N, Robertson SJ. A hidden client group? Communication impairment in hospice patients.

International Journal of Language & Communication Disorders [online] 1998; 33(S1), 96–101



Saunders C, Baines M. *Living with Dying: the Management of Terminal Disease*. Oxford: Oxford University Press, 1989.

Sinuff T, Dodek P, You JJ, Barwich D, Tayler C, Downar J, Hartwick M, Frank C, Stelfox HT, Heyland DK. Improving end-of-life communication and decision-making: the development of a conceptual framework and quality indicators. *Journal of Pain and Symptom Management* 2015; 49(6), 070–1080.

Soileau K, Elster N. The hospice patient's right to oral care. *Journal of Palliative Care* 2018; 33(2), 65–69.

Sue Ryder Care. New Research Reveals the Biggest Concerns People Have When a Loved One is Dying [online]. Sue Ryder, 2018

Taylor H. Legal and ethical issues in end of life care: implications for primary health care. *Primary Health Care* (2015; 25(5), 34–41.

<u>The Brain Tumour Charity. Losing Myself. The Brain Tumour Charity [online], 2013</u> Toner MA, Shadden BB. End of life. *Topics in Language Disorders* 2012; 32(2), 111–118.

Tuffrey-Wijne I, Hogg J, Curfs L. End-of-life and palliative care for people with intellectual disabilities who have cancer or other life-limiting illness: a review of the literature and available resources. *Journal of Applied Research in Intellectual Disabilities*, 2007; 20(4), 331–344.



Research priorities

The RCSLT, in collaboration with the <u>National Institute of Health Research (NIHR)</u>, is working on a project to determine the top priorities for new research in speech and language therapy. Read about <u>our research priorities</u>.