End-of-life care – influencing

Introduction

This page contains information and resources to:

- influence your local decision-makers and budget holders;
- and raise awareness of the role of speech and language therapy in end of life care.

There are also resources to support you to:

- demonstrate the value of your service;
- and develop your leadership skills.

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

- **Guidance**
- **Learning**
- **Evidence and research**
- **Contacts**

Please note: the resources in this section are provided for informational purposes only. No endorsement is expressed or implied unless otherwise indicated, and while we make every effort to ensure this page is up-to-date and relevant, we cannot take responsibility for resources maintained by external providers.

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

Influencing stakeholders

General

- Visit our **local influencing pages** to find information and resources that will help you demonstrate to your local stakeholders how you:
    - deliver their objectives;
    - improve outcomes for them;
    - improve outcomes for people who benefit from speech and language therapy.
- **Leadership resources**
- **Measuring outcomes**
- **Evidence-based practice**

End-of-life care information

- **RCSLT position statement for end-of-life care**
  This position statement is aimed at commissioners and includes key recommendations, benefits of including speech and language therapy in end-of-life care services, and risks of not including speech and language therapy in end-of-life care services.
- **National guidance**
  This list of national guidance can help you build a business case for influencing stakeholders in end-of-life care services.
- Statistics
  These statistics provide an overview of how many people receive end-of-life care, where people die, and concerns for families/carers.

Campaigning to raise awareness

The role of SLTs in end-oflife care is still poorly understood, so raising awareness is important as an ongoing commitment alongside service development.

General

- RCSLT guidance on **raising awareness**
- The RCSLT's **Giving Voice** pages provide tips for demonstrating how speech and language therapy makes a difference to individuals and the broader society across the UK.
- RCSLT guidance on using **social media**.

"How people die remains in the memory of those who live on" is a quotation by Dame Cicely Saunders (1989) that underpins a need for high-quality end-of-life care, as does the standard for those dying of ‘One chance to get it right’ (2014), a review to improve the care of people who are dying and their families.

It means patient-centred care involves good communication, ongoing assessment and coordination between services, with family-focused support that is tailored to any set of circumstances – cultural, social, psychological, and spiritual (NICE Quality Standards End of Life Care for Adults 2011).

Statistics

This data helps to understand the environment, changing trends and requirements for future service development and workforce training.

How many people receive end-of-life care at any one time?

Adults:

- Typically 1% will be in their last year of life (Dying Matters 2014).
- Two-thirds of adult deaths are in people aged over 75 years.
- Of the third who are under 75 years, there are more deaths in the age ranges 35-64 and 65-74.

(Office for National Statistics 2017)

Infants, children and young people:

- There is a rising national prevalence of life-limiting conditions in children in England (Fraser et al 2012), reportedly a doubling of estimates from data gathered from 2000 to 2010.
- Around 6,000 infants, children and young people between 0 and 19 years die in the UK every year (Wolfe et al 2014).
- Approximately 40% of deaths for those under 15 years are neonatal deaths (Nasir 2016).
- Almost 50,000 children and young people aged 19 or under in the UK are living with life-limiting conditions:
    - more than 300 conditions are classed as life-limiting or life-threatening for children, including those with disabilities and complex health- and social-care needs;
    - for those children and their families, palliative and end-of-life care begins at diagnosis.

(Wolfe at al 2014)

Where do people die?

The settings for place of death can be:

- hospital;
- home;
- residential setting (schools, care/nursing homes, prisons);
- hospice.

Public Health England (2018) profiled the proportions of deaths by setting:

- Almost half of all deaths occur in hospital.

- Nearly a quarter of deaths occur in people’s own home.
- Approximately a fifth of deaths occur in residential settings.
- Just over 5% of deaths occur in a hospice.

Learning disability and mortality

- Average age at death of people with learning disabilities was 59 for males and 56 for females
- More than a quarter (28%) of deaths were of people aged under 50 years
- People with profound or multiple disabilities had an average age of death of 41 years
- Those with mild or moderate learning disabilities had an average age at death of 63 years.

(The Learning Disabilities Mortality Review Annual Report 2017)

Concerns people have when a loved one is dying

- Over 4 in 10 (44%) of those who had questions or worries wanted to know what physical or mental changes they should expect when someone close to them was near death
- Whether to bring up difficult issues with their dying family member or friend before the end of their life (21%)
- How to make them more comfortable (58%)
- Whether they should die in a more comforting environment than a hospital ward (18%)
- The last words they should say to them (40%)
- Who should be there in the final moments (36%)

(Sue Ryder Care 2018)

Public health and end-of-life care

Public health may have different meanings depending on the context.

Public health in end-of-life care is around social efforts to improve health in life-threatening or life-limiting illnesses, care giving and bereavement (National Council for Palliative Care 2013).

It also takes account of:

- Understanding the limits to service provision.
- Recognising that ‘health’ is not about simply addressing illness and disease but also the promotion of health and well-being.
- Recognising and acting on the fact that ‘health is everyone’s responsibility’.
- Understanding that ageing, caring and dying take a long time and bereavement lasts forever.
- Recognising and tackling the social epidemiology of ageing, dying, caregiving and loss (Kellehear 2015).

SLTs have a key role in supporting people at the end of their life with communication, eating and drinking, and making decisions about their care.

SLTs also support families and carers in making the experience less stressful by involving them in decisions for the person receiving end-of-life care, and having conversations about death and dying, as well as signposting them to supporting resources that can help with grieving.

References

Dying Matters. *Identifying End of Life Patients* [online], 2014

Endoflifecare-intelligence.org.uk. *What We Know Now* 2014 [online], 2014

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

Kellehear A. Compassionate City Charter, 2015

National Council for Palliative Care. *Public Health Approaches to Palliative Care: A Toolkit*, 2013

Nice.org.uk. *Overview: End of Life Care for Adults*. NICE Quality Standards [online], 2011

***One Chance to Get it Right*: *improving people's experience of care in the last few days and hours of life* [online], 2014**

Ons.gov.uk. Child and Infant Mortality in England and Wales. Office for National Statistics. [online], 2016

Ons.gov.uk. Deaths. Office for National Statistics [online], 2017

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

Saunders C, Baines M. *Living with Dying: the management of terminal disease.* Oxford: Oxford University Press, 1989.

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

The Learning Disabilities Mortality Review Annual Report. University of Bristol, [online], 2017

Wolfe I, Macfarlane A, Donkin A, Marmot M, Viner R, College R, National Children's Bureau, For A. *Why Children Die: death in infants, children and young people in the UK*. London: Royal College Of Paediatrics And Child Health, May, 2014.