

# Supporting a good end of life

**Speech and language therapists (SLTs) can play an important role in supporting people at the end of their lives, including supporting their families and friends and the other professionals working with them. By helping people who have communication and eating, drinking and swallowing difficulties, SLTs can help them maintain their relationships and live as well as possible, right up to the end of their lives.**

Currently there are very few speech and language therapy posts based within specialist palliative care teams and hospices. To ensure everyone who requires it has fair access to speech and language therapy at the end of their life there needs to be more consistent funding for these types of posts.

## What is end of life care?

End of life care is defined as the approach taken to people in the last year of their life. This includes their last days and hours. It should address physical, emotional, social, and spiritual aspects. Person-centred care is essential to ensure individuals get high quality care at the end of their life centred around what matters to the person.<sup>1</sup>



## What is the role of speech and language therapists in end of life care?

SLTs work with adults who are at the end of life across a variety of settings. These include hospitals, hospices, people's own homes, outpatient clinics and residential/nursing homes.

Typically, one per cent of the adult population will be in the last year of their life at any one time. Communication and eating, drinking and swallowing difficulties may be experienced by those with cancer, progressive neurological conditions, dementia, frailty, organ failure, learning disabilities, or after sudden events, for example, a road traffic accident or stroke.

Any speech and language therapy input should be modified as a person's health deteriorates. It is essential that SLTs support families and carers to enable a person to enjoy eating and drinking, and to support communication and connection. It is important to respect faith, culture, sexual orientation, physical and learning abilities, individual circumstances, personal values, and preferences so the care can be truly person-centred.

SLTs can offer a unique skill set which can contribute to high quality end of life care.



## Supporting communication at the end of life

People may experience communication difficulties secondary to their condition or related to the symptoms of dying, for example fluctuating consciousness, breathlessness, effects of medications, and delirium.

SLTs should work with those receiving end of life care and their families and carers to maximise communication potential. This may involve the use of augmentative and alternative communication (AAC), conversation partner training, and communication

strategies for the dying person, family members or the multi-disciplinary team (MDT) around them, as well as modification to the environment.

Enabling dying people to communicate effectively can support them to take part in important conversations with their loved ones as well as advance care planning, allowing them to make decisions about their preferred place of care and end of life, advance directives to refuse treatment, management of affairs, amongst other things.

SLTs may also support people to make decisions about day-to-day life such as the care they receive, activities they want to partake in, what food they would like to eat and what they would like to drink.

By supporting communication, person-centred goal setting can be achieved through people identifying their priorities and what matters to them in their last year of life.<sup>2</sup>

### David's story

David was in his late 50s when he was diagnosed with Motor Neurone Disease. David's first symptoms were speech changes. Early involvement from a speech and language therapist meant that he was soon set up with AAC to support his communication. Alongside the wider MDT, David's SLT supported him in using his AAC to express his wishes around future treatment options, for example to decline the use of a feeding tube. As David's wishes were established with the MDT and his family early on, during the disease progression his SLT input around eating and drinking was tailored to meet these wishes and he continued to eat and drink (including his favourite lemonade), right up until his death.

## Supporting eating, drinking and swallowing at the end of life

SLTs can provide assessment and diagnosis of eating, drinking and swallowing difficulties (dysphagia) for people reaching the end of their life.

As with communication, swallowing abilities may change significantly and rapidly, especially in the last weeks or days of life.

Risks associated with eating, drinking and swallowing difficulties are aspiration (food and/or drink entering the lungs), malnutrition, dehydration and choking. They may also include an inability to take medication, hunger, thirst, loss of dignity or quality of life. These risks may potentially impact on prognosis and treatment options.

Often the primary focus of speech and language therapy will not be solely on eliminating the risks, but ensuring eating and drinking is as pleasurable as possible and supporting the person's wishes. Some people may make an informed decision to continue eating and drinking what they like until they die. Others may be more comfortable having a modified diet or fluids or using strategies or compensatory techniques to increase comfort and reduce distress. The use of clinically assisted nutrition and hydration, for example, tube feeding, can pose a range of ethical issues towards the end of life – a MDT approach can support appropriate use of such feeding and also the stopping of its use.

Regardless of the options or lack of options available, it is important to involve the dying person in the decision and their families and carers should the person lack capacity to make the decision themselves.

### Betty's story

Betty was 94. She had dementia and had been admitted to hospital with a chest infection. She also had a background of COPD, stroke and diabetes. She had had multiple hospital admissions in the last year with chest and urine infections. Betty had been on a modified diet since her last admission to hospital but continued to have repeated chest infections and was now showing overt signs of aspiration when eating and drinking. Her medical team decided that Betty was reaching the end of her life and management turned to keeping her comfortable. Betty's daughter previously visited her daily in her nursing home to support with mealtimes. Betty would always have a cup of tea when her daughter visited.

As Betty's condition declined her daughter struggled to come to terms with the fact Betty was accepting only minimal amounts of food and drink. The SLT and MDT worked together with Betty's daughter to provide her with education about the dying process and eating and drinking. Advice was given around strategies to support Betty to eat and drink the small amounts she wanted to reduce any distressing symptoms. As Betty's death approached, her daughter was given information and support around mouth care which enable her to do something meaningful for her mother's final days.



Hunger and thirst naturally decrease at the end of life. This is normal, and part of the dying process. Digestive and metabolic processes change and organ systems do not function in the same way. Often the body cannot cope with significant nutrition and hydration input. This can lead to other distressing symptoms and increased discomfort.

SLTs, alongside other MDT colleagues, can support dying people to eat and drink as desired for comfort, determined by appetite, thirst, tolerance and level of alertness. They can also support families and carers to come to terms with the dying person's lack of eating and drinking.

Individualised 'tastes for pleasure' may be used when a person isn't able to eat and drink much but may still enjoy a taste of their favourite flavours – this could be their favourite cup of tea or prosecco. As well as a small amount of pleasure for the person at the end of their life, it helps create positive memories for those left behind and generates meaningful discussion between families and care providers about the dying person's life and things they enjoyed.<sup>3</sup>

## Supporting mouth care at the end of life

At the end of life, the lack of eating and drinking by their loved one can be frustrating and distressing for relatives. At this time, mouth care is more important than ever. Mouth care involves maintaining a clean and comfortable mouth and preventing oral infection. It can include cleaning teeth, dentures, tongue, gums and palate and maintaining healthy oral mucosa. This can help optimise people's quality of life, increases comfort, and enhances dignity. The mouth has been described as the last area of the body that relatives can be involved in caring for in someone's last days and hours of life. This can provide an alternative focus for relatives to feel useful and connected.<sup>4</sup>

## Acknowledgements

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## References

- 1 For more on end of life care see:  
<https://www.rcslt.org/speech-and-language-therapy/clinical-information/end-of-life-care-overview/>
- 2 For more information on goal-setting see:  
<https://www.magonlinelibrary.com/doi/abs/10.12968/ijpn.2018.24.3.115>
- 3 For an example of giving end of life patients taste for pleasure see:  
<https://www.sath.nhs.uk/staff-blog/giving-our-end-of-life-patients-taste-for-pleasure/>
- 4 For more information on mouth care at the end of life see:  
<https://www.nature.com/articles/s41407-020-0255-7>