APPG on Hospice & End of Life Care

Inquiry into government funding for hospices

RCSLT response

August 2023

Executive summary

- Speech and language therapists (SLTs) can support people receiving palliative and end of life care, and their families, to have a good death, by supporting them with their communication, with eating, drinking and swallowing, and with decision-making.
- There are too few speech and language therapists working in hospices, and in other specialist palliative and end of life care teams.
- There is significant variation across the United Kingdom (UK) in accessing speech and language therapy posts based within specialist palliative care teams and hospices.
- Where there is no speech and language therapist, people who communicate differently or with difficulty and/or those with eating, drinking and swallowing difficulties can often have their needs go unidentified and unsupported.
- To ensure everyone who requires it has access to speech and language therapy at the end of their life, Government needs to ensure improved and consistent funding for speech and language therapy posts within hospices.

Background: the role of speech and language therapists in hospices

1. SLTs have a key role to play in supporting people at the end of their lives and their families. Working within a multi-disciplinary team (MDT), they can help to make sure that people who are dying and their families have a supportive experience throughout a difficult and sad time.
2. SLTs support people who are at the end of life with communication, with eating, drinking and swallowing, and with decision-making. These may be treated separately or together, based on the needs of the individual person and their families.
3. The role of SLTs is to support people's quality of life as they approach the end of their lives.
4. Currently, speech and language therapy services are under-developed, under-resourced and under-supported. The speech and language therapy role in palliative care is

frequently misunderstood or unrecognised at facility, regional, national and international levels.[1]

5. Examples of people speech and language therapists working in palliative and end of life care settings support include those with dementia, motor neurone disease, brain tumour, COPD, various cancers, including head and neck, and lung. In addition, almost 50% of people can experience difficulties with eating, drinking and swallowing in the last weeks of their lives.
6. For more on the role of speech and language therapy in palliative and end of life care, see our factsheet and clinical resources:
   https://www.rcslt.org/wp-content/uploads/2023/05/Supporting-a-good-end-of-life-factsheet.pdf
   https://www.rcslt.org/speech-and-language-therapy/clinical-information/end-of-life-care-overview/
7. For more on the role of SLT in advance care planning, see:
   https://speakforme.co.uk/podcast-episode-41

Current picture and variations of funding for hospice speech and language therapy services across the UK

1. Currently, there is no official data available on the number of speech and language therapists (SLTs) working in hospices/specialist palliative care services. Unofficially, it is estimated there are under 15 roles within the United Kingdom (UK). The vast majority of these are part-times roles. They are funded through a variety of means.
2. The dearth of provision is amplified when this number of posts is compared to the number of independent charitable hospices registered across the UK, 191.[2]
3. Northern Ireland has the most posts, with SLTs being included in community specialist palliative care allied health professional teams. This means that across the other three nations of the UK (England, Scotland, and Wales), SLTs are not typically members of specialist palliative care teams. This includes those working in a range of settings, for example hospices, and community services.
4. In the UK, the reality of practice is that SLTs offer consultation for palliative care patients, but are infrequently employed within palliative care teams. Contact may be limited to a single assessment and advice session.
5. Understanding of funding mechanisms and statutory requirements is limited amongst specialist palliative care SLTs. There has been no change in the number of specialist

[1] https://pubmed.ncbi.nlm.nih.gov/25762581/
[2] https://www.hospiceuk.org/publications-and-resources/hospice-accounts-report-2022#:~:text=This%20year%E2%80%99s%20report%20brings%20together%20information%20from%20the,of%20191%20independent%20charitable%20hospices%20in%20the%20UK

palliative care SLT roles since the introduction of the statutory requirement for the commissioning of palliative care. There is still a general feeling that the NHS provides part of the funding, but the rest remains through fundraising, donations and legacies, and different charities.

Risks of inadequate funding for speech and language therapy services in hospices

1. The best possible communication is essential for people who are in the final days, weeks or year of life. Difficulties with communication can impact upon the hospice team's ability to provide symptom control and supportive psychosocial care. They can also diminish people's ability to take part in end-of-life care decision-making and support, and maintain their relationships with family and friends.
2. There is evidence that other medical clinicians tend to underestimate the cognitive abilities and mental capacity of people who communicate differently or with difficulty.
3. Swallowing abilities deteriorate significantly and rapidly, especially in people's last weeks or days of life. Swallowing difficulties can result in discomfort for people, their families, and the caregivers around them. They can make taking medication more difficult.
4. The lack of - and variation in - access to speech and language therapy services in hospices across the UK risks inequity in support for people at the end of their lives and their families.
5. There is also a risk to people not being able to exercise their fundamental human rights, in relation to communication, and eating and drinking.
6. Additionally, there is a risk that the goals of the recent World Health Organisation policy brief on integrating rehabilitation into palliative care[3] will not be met for people who communicate differently or with difficulty, and/or having difficulties with eating, drinking and swallowing. The WHO policy brief states that rehabilitation within palliative care empowers people with incurable health conditions to actively manage their condition, reduce symptoms and enables individuals to stay independent and socially active. SLTs can support that, allowing people to enjoy the best possible quality of life right up until the end of their life. Current provision of SLT services within hospices and palliative care does not reflect Ambition 2 of ambitions for palliative and end of life care – that each person gets fair access to care.
7. Ultimately, and most fundamentally, the risks of inadequate funding for speech and language therapy services in hospices is that people who are dying and their families will have a less good death.

[3] https://apps.who.int/iris/handle/10665/366505

Recommendations for making things better

1. There needs to be more recognition of the role of SLTs in providing palliative and end of life care, including in hospices.
2. 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 Government funding to provide access to speech and language therapy in hospices.

Perspective: Speech and language therapy in Rehabilitative Palliative Care

Eleanor Davies, Palliative Care Speech and Language Therapist, St Joseph's Hospice

Rehabilitative Palliative Care: a challenge for the 21st century, 2015

- The ability to communicate ones needs, thoughts, feelings and wishes is central to a person's sense of wellbeing and quality of life. It enables patients to be active participants in goal setting within the wider rehabilitation process, expressing their needs, wishes and priorities and contributing to personalised advance care plans. When communication is compromised, significant frustration and distress can result for both patients and their caregivers.
- Speech and language therapists (SLTs) are skilled in assessing, diagnosing and advising on a wide variety of communication difficulties. Particularly when working with patients with life-limiting and rapidly progressing conditions, it is essential that intervention begins at an early stage in order to plan and prepare for any deterioration in communication abilities.
- FF was referred to speech and language therapy shortly after her initial diagnosis of motor neurone disease. At this stage, she was still able to communicate well with only a mild dysarthria (speech difficulty); however, the various options for alternative communication aids were discussed in anticipation of a decline in her speech function. As her speech gradually deteriorated, she started using a light writer (text to speech communication device) to support her communication and she was referred for an early assessment of an eye-gaze communication system. Utilising this advanced system FF was able to continue to use this to communicate with her husband and friends until shortly before her death.
- Eating and drinking also plays a key role in Rehabilitative Palliative Care in order to maximise not only nutritional intake but to optimise energy to participate in activities that add quality of life. Difficulties in swallowing (dysphagia) can result from various medical conditions and are frequently seen in patients as they approach the palliative stage of illness. SLTs are able to provide an expert opinion in the assessment, diagnosis and management of dysphagia, giving advice and guidance on dietary

modifications and compensatory strategies with the aim of maximising a patient's comfort and reducing any distressing symptoms which may arise.

- SLTs provide specialist expertise and leadership to the hospice multidisciplinary team, to support patients and families in challenging decisions around alternative feeding and/or acknowledged risk feeding. Supporting people's wishes to eat and drink where there is a significant risk of aspiration or choking can be extremely worrying for staff, and yet may provide critical quality to people's lives. Empowering staff to be aware of, and work supportively alongside, risk is a challenging element of Rehabilitative Palliative Care where SLTs offer leadership and guidance on how to constructively manage the risk while enabling patients' autonomous choice.
- Speech and language therapy roles are extremely rare in hospices and subsequently patients and families are deprived of dedicated SLT expertise to optimise communication and swallowing function essential to quality of life.
- To provide comprehensive Rehabilitative Palliative Care, specialist speech and language therapy must be available to all patients receiving hospice support.

For more information

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