

## **Major Conditions Strategy Submissions: palliative care**

### **June 2023**

**Question: How can we improve access to palliative and end of life care?**

#### **Role of speech and language therapy**

- The best possible communication is essential for a person who is in their last year or days of life, to help them to maintain relationships and to communicate effectively.
- Speech and language therapists identify and support those with communication difficulties to engage in future care planning conversations and allow them to make decisions about their preferred place of care, to refuse treatment and management of affairs.
- Swallowing abilities may change significantly and rapidly, especially in the last weeks or days of life. Speech and language therapy input helps to eliminate risk and supports a person to continue eating and drinking with acknowledged risks of aspiration, to have a modified diet or fluids or have clinically assisted nutrition and hydration, for example, tube feeding.

#### **The issues**

- There is a lack of public and health professional's understanding and engagement with palliative care and advance care planning. This results in these conversations not being approached early on, or at diagnosis for those with a life limiting condition.
- Multidisciplinary team lack confidence and skills to have these conversations and in general managing patients at the end of life. They lack confidence to approach end of life conversations.
- Speech and language therapy posts based within specialist palliative care teams and hospices are few and far between. Where there is no speech and language therapist those with communication difficulties often go unidentified and then are not facilitated to be involved in future care planning conversations.

- Multidisciplinary team lack knowledge and understanding of the speech and language therapy role and how it can help.
- Regional variation in access to professionals and in accessing specialist palliative care services.
- Many people will access some kind of palliative or end of life care, but timing and quality is variable.
- Referral processes and criteria are different in regions.

### **How can we improve access to services?**

- Need to remove the fear and uncertainty around the terms 'palliative', 'end of life' and 'advance care planning' with professionals and the public to ensure referrals are discussed and consented to.
- A clearer understanding of terminology and myth busting about the added value of palliative care would help.
- Need to upskill the whole multidisciplinary team in generalist palliative and end of life care.
- Provide education and training for the multidisciplinary team about how to support in conversations about future care and to discuss dying with people.
- Begin conversations with families around anticipated deterioration at the time of diagnosis, rather than accessing palliative care in a crisis.
- Empower service users/families to engage in informed decisions about their care.
- Ensure the resources are in places for specialist palliative or end of life care for those who need it, for example access to hospice beds.
- 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. Speech and language therapists need to be considered as a core member of Specialist Palliative Care teams and need to be based within the teams in hospices and community teams.
- Conversations about future care needs to be considered a specialist part of the speech and language therapy role which required education/training and capacity within our job roles.