

Royal College of Speech and Language Therapists briefing Westminster Hall Debate: Improving the lives of people living with dementia June 2019

1. Executive summary

The Royal College of Speech and Language Therapists welcome the "Hidden No More" report. We were delighted to see our evidence referenced that there are widespread differences in access to and support from speech and language therapy. People with dementia need access to speech and language therapy in order to live safely and live well. We believe that all people with dementia and their families should have access to high quality speech and language therapy when and where they need it.

2. Communication difficulties and dementia

Communication problems occur in <u>all</u> forms of dementia and in the later stages these become more challenging. Communication difficulties affect understanding and expression. People may experience word finding difficulties, struggle to focus on a topic of conversation or have difficulties understanding and using sentences.

Difficulties communicating with loved ones can cause huge distress. Families report communication difficulty as one of the most frequent and hardest to cope with experiences. Care staff also view communication problems as one of the greatest challenges in delivering good dementia care.

Communication difficulties can have a range of consequences:

- People with dementia are at risk of being unable to communicate that they are hungry or thirsty resulting in dehydration, malnutrition, and possible subsequent hospital admission.
- People are at risk of being unable to communicate that they are in pain.
- People with dementia can be excluded from all aspects of daily living that require communication, from managing their bills and banking, to shopping for food and using the telephone.
- People can be excluded from leisure activities and hobbies and struggle to maintain employment.

3. Choice, control, consent and dementia

People with dementia are often being excluded from care planning and decision-making processes due to a lack of understanding of communication difficulties amongst other professionals. People are often inaccurately assessed as being unable to make decisions. However, with the right communication support, people with dementia can make decisions on their treatment and care.

4. Eating, drinking and swallowing problems and dementia

Eating, drinking and swallowing problems (dysphagia) are a recognised challenge for people with dementia, especially in the later stages. If left unmanaged, these difficulties can result in choking, malnutrition, dehydration, pneumonia, admission to hospital and, in some instances, death.

5. Supporting people with dementia and those around them

People with dementia need access to speech and language therapy to maximise and maintain communication skills and independence for longer.

Speech and language therapists support people living with dementia and those caring for them in a number of ways:

- They assess speech, language and communication skills and support people to communicate for as long as possible with their loved ones, friends, and carers
- They provide a range of strategies to support conversation and interaction and to promote inclusion in social activities and community life
- They assess people's capacity for decision making and support people to express their wishes
 and feelings. Participation in decision-making is considered one of the most important
 communication-related activities of daily living that speech and language therapists work on.
- They also train other people, including family and health and care professionals, about the signs of communication difficulties in dementia and strategies to support and enhance communication.

6. Access to speech and language therapy

As highlighted in the Royal College of Speech and Language Therapists' evidence to the APPG inquiry into dementia as a disability, there are widespread differences in terms of access to and support from speech and language therapy. Our members highlight that:

- Provision across England and Wales is <u>patchy</u>. Speech and language therapy is frequently commissioned to only provide support for eating, drinking and swallowing needs (dysphagia) to people with dementia and not to provide support with communication difficulties.
- Many interventions have a strong evidence base and are effective for people with dementia including cognitive stimulation therapy, conversation training, word relearning therapies and group therapies. However, many people with dementia, who have speech, language and communication needs are not referred to speech and language therapy.
- A survey of over 100 SLTs reported concerns that referrers (medical professionals) did not refer people with dementia to speech and language therapy services, often because they did not understand the role of speech and language therapy.
- Our members report that the biggest barrier for people trying to access speech and language therapy is the restrictive service criteria.

7. Recommendations for improving the care of people with dementia

The Royal College of Speech and Language Therapists believe that all people with dementia and their families should have access to high quality speech and language therapy when and where they need it.

- Speech and language therapy needs to be provided to people with dementia to support communication, eating and drinking.
- Training to understand the communication and eating, drinking and swallowing needs of people with dementia should be provided to all health and care staff.

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