

## A National Conversation to inform a New Dementia Strategy for Scotland

As an individual with an interest in the lives of people living with dementia, and those providing care/support:

### 1. What does dementia mean to you and those around you?

The Royal College of Speech and Language Therapists (RCSLT) welcomes the opportunity to contribute to this national conversation to inform a New Dementia Strategy in Scotland. We are the professional body for speech and language therapists (SLTs), students and support workers in the UK. Our members work with people at all stages of life across a wide range of settings, from children and young people in community and education settings to adults in acute, primary, community and social care settings. We have worked closely with our members who work regularly with people with dementia to inform this response.

We believe, first and foremost, that it is important to recognise dementia as a condition that each person experiences in their own way. Speech and language therapists can offer support to people with dementia who have communication problems or difficulties eating, drinking and swallowing, however the extent and severity of these symptoms will vary from person to person. 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. Moreover, 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. This is why we need to ensure a human rights-based, person-centred approach to dementia care, where the person with dementia and their family supports are able to communicate their needs and have access to the services that meet them at that time. Every effort should be made to keep the person with dementia involved in their own care – communication skills being critical to fulfilling this commitment.

We also think it's important to acknowledge that people with dementia can benefit from a range of services that have varying levels of proximity to the person with dementia. While speech and language therapists do work one-to-one with people with dementia, they also empower those who are proximal to the person with dementia by, for example, providing family members and care home staff communication and/or swallowing strategies to support the person with dementia in a safe space with familiar faces. SLTs can also positively influence a multidisciplinary team supporting people with dementia, as they help other health professionals think differently about how they communicate with and understand the needs of the person. We think multidisciplinary teams need to be expanded in dementia care, and SLTs should be core members of these teams.

### 2. What supports work well for you?

Our members have shared a number of supports that strengthen a human rights-based, person-centred approach to dementia care. Establishing person and family-centred care at an early stage, with the person with dementia and their family having a meaningful involvement in care planning leads to better relationships and trust in support services.

Speech and language therapists facilitate post-diagnostic life story work, which deepens the understanding of those providing the person's care of the person's background and interests, enabling them to communicate and care for them in a person-centred way.

SLT services across Scotland have also been developing self management tools to ensure timely support in dementia care. [Swallowing Matters](#) was developed by the NHS Lanarkshire Speech and Language Therapy Adult Service in consultation with local care home staff and is a resource now used across other health boards to assist care home staff to identify how best to manage residents with eating and drinking difficulties. A similar toolkit, [Manual for Mealtimes](#), was developed by NHS Lothian and has allowed the SLT service to focus resource on high risk swallowing problems. The success of these swallowing self management tools have led SLT services to start developing similar models for communication self management to assist care home staff working with people with dementia.

### 3. What challenges need to be addressed?

We feel there is still a stigma attached to a dementia diagnosis, which leads to a number of challenges. Our members who regularly work with people and family members of people affected by dementia sometimes notice a reluctance to ask for help, either out of shame or denial at a dementia diagnosis. Some family members do not want to confirm a dementia diagnosis as they feel they would be letting that person down in some way. There are also some public perceptions of dementia – such as the assumption that dementia is only a mental condition – that put people off seeking help until the physical symptoms are severe. People with dementia have access to support services in Scotland, but if people don't understand the benefits, they will not be accessed. We believe there's a need for public health messaging around dementia, so people can understand what to expect and what support is available to them. Anyone can be affected by it themselves, or as the carer for a family member. Due to the scale of this public health campaign, we believe that an SLT should advise on the wording and messaging to ensure it is inclusive and accessible to everyone.

We also think the breadth of speech and language therapy needs to be better understood in the world of dementia care. There is a growing evidence base, but currently SLT involvement in dementia care in Scotland is minimal. Most health and care professionals working with people with dementia only call in an SLT if there are swallowing issues, and while this is an important part of our service, this often overlooks the importance of communication needs in people with dementia. Communication problems occur in all forms of dementia, and in the later stages these become more challenging.

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.

In our view, communication is a human right – without it, the person is not able to advocate for themselves or their care. It also plays a huge role in that person’s mental health and that of the family members around them. And it’s not just about the communication skills of the person with dementia – it’s also about the way everyone around them communicates with them. This is why we believe SLTs should be embedded in multidisciplinary teams in dementia care, to improve the communication environment around people with dementia as well as offering critical eating, drinking and swallowing support.

4. How would addressing these challenges change lives?

We hope that a sufficient public health campaign could change the current stigma attached to dementia and encourage people to seek support early. In our discussion with members, we did wonder if having dementia could be normalised – that the condition could be seen not as something scary or shameful, but as a challenging circumstance that society can adjust to accommodate. We believe people with dementia should keep their dignity and our respect. We can lead by example in keeping people involved in their care from the start, and hope that shifts in public understanding could lead to people with dementia living better lives in all aspects of society.

5. What do we need to build on/learn from what has been done before?

It’s clear that dementia care sits across a number of disciplines and services, making it difficult to provide a cohesive service to people with dementia. We think multidisciplinary dementia teams should be established across the country to ensure every person in Scotland with dementia is able to access the same level of person-centred care we strive for. We feel SLTs should be core members of these teams, as they provide the key to good communication across the team and in the community. However, it should be noted that in order for this to happen, we will need to increase the supply of SLTs and see investment in SLT services which have been historically underfunded compared to the level of need in Scotland.

In our view, we need to build on the work of the [5 Pillar Model of Post-Diagnostic Support](#). We understand that these have not been tested/evaluated since being developed in 2015. We’d also like to hear more about the outcomes from the demonstrator sites that were established, so that this knowledge can be shared across Scotland.

Finally, we believe that SLTs and our Allied Health Professional (AHP) colleagues play a critical role in dementia care, and it would be beneficial to have SLTs/AHPs involved in the drafting of this new dementia strategy.

6. What else would you like to tell us?