



Giving Voice for
people with dementia

givingvoiceuk.org/dementia

Message from the RCSLT Chief Executive – Kamini Gadhok MBE

Dementia is one of the biggest challenges facing the world today. The number of people with dementia worldwide is set to soar from 44 million to 76 million by 2030.

There are currently more than 800,000 people in the UK with dementia and this is set to rise to one million by 2021. The challenges to our health and social care services are immense and speech and language therapists have a vital part to play in the care of people with dementia.

The RCSLT has made dementia our top priority for 2014 and beyond. Too few people understand the role speech and language therapists have in helping individuals with dementia with communication, eating, drinking and swallowing difficulties, and the support they can provide to carers.

We aim to raise awareness of our role in dementia. Our task is to demonstrate to fellow health professionals, politicians and – most importantly – decision makers and budget holders that we have a vital place in supporting the care of people with dementia, so that our services are properly funded and used appropriately.

I look forward to your ongoing support for our Giving Voice for People with Dementia Campaign.

► Visit: <http://givingvoiceuk.org/dementia> to find out more about the campaign and the resources available

Our campaign asks:

The Royal College of Speech and Language Therapists calls upon governments, care commissioners, budget holders and care providers to:



1 Recognise the communication and eating, drinking and swallowing needs of people with dementia



2 Ensure people with dementia have access to the speech and language therapy services they need in hospitals, care homes and in their own homes



3 Set the highest standards for the education and training of health professionals, residential and home care staff to understand the communication difficulties experienced by people with dementia and their carers, and to ensure they have the professional speech and language therapy support they need



4 Provide education, support and training for health professionals, care home and agency staff to identify the early signs of eating, drinking and swallowing difficulties, and meet the nutritional needs of people with dementia

The vital role of SLTs in dementia

The role of speech and language therapists in the diagnosis and care of people with dementia is often overlooked. Consequently, very few communication services are commissioned for those who need them the most.

Dementia often results in communication problems for the person with dementia and with their carers, as well as eating, drinking and swallowing difficulties. Speech and language therapists have the specialist skills and knowledge to assess and provide support in all these areas. They work in a variety of settings including specialist memory services, community mental health teams, hospital wards, community services, learning disability services, care homes, day care and forensic services.

Communication problems are particularly challenging in the later stages of dementia. This is one of the most distressing experiences of dementia for family carers. Language impairment may be an initial presenting feature of the disease.

- ▶ Speech and language therapists are well placed to work with individuals and family carers throughout the course of dementia to identify communication difficulties and needs.
- ▶ By providing support, enabling understanding and recommending strategies, speech and language therapists are able to work with carers and people with dementia to help maintain their interpersonal relationships.
- ▶ They are uniquely qualified to assess an individual's ability to understand and to communicate that understanding to optimise a person's choice, degree of control and capacity to consent to treatment and care.
- ▶ Difficulties with eating, drinking and swallowing (dysphagia) are a recognised challenge for people with dementia, particularly in the later stages. Two-thirds of those with dementia in care homes were found to have dysphagia (Steele et al, 1997).
- ▶ The need to assess and manage eating and swallowing difficulties and identify potential aspiration is vital (NICE, 2006) particularly in those with advanced dementia (Logemann et al, 2008; Robbins et al, 2008).
- ▶ Dysphagia, if not managed, results in malnutrition and dehydration (Hudson, 2000) and is a causal factor in repeated chest infections and choking risk. A study of repeated hospitalisations for pneumonia in older people found swallowing dysfunction to be top of the list of hazardous variables (El Sohl et al, 2004).
- ▶ Dysphagia also has adverse effects on self-esteem, socialisation and enjoyment of life, as well as anxiety and panic at mealtimes.
- ▶ Studies demonstrate the important role of speech and language therapists in the assessment and management of dysphagia and in administering interventions and training staff.

Key dementia facts

- ▶ There are more than **800,000** people in the UK with dementia and this is set to rise to 1 million by 2021
- ▶ Dementia costs the economy **£23 billion** a year – more than cancer, stroke or heart disease combined
- ▶ There are **665,000** people with dementia in England, **88,000** in Scotland, **45,000** in Wales and **19,000** in Northern Ireland
- ▶ The chance of developing dementia increases with age – one in 14 over 65 years of age and one in six people over 80 has dementia
- ▶ More than **17,000** people under 65 years of age in the UK have early-onset or young-onset dementia
- ▶ Dementia affects all social groups and all ethnic groups
- ▶ The incidence of dementia in adults with learning difficulties is higher than in older adults in the general population
- ▶ The UK Government is committed to spend **£66 million** on dementia research by 2015 – but this is still only one eighth of what is spent on cancer research in the UK

HOW YOU CAN HELP

- ▶ Send us your story (we might be able to use this on our campaign website or as part of our media work).
Email: robin.matheou@rcslt.org
- ▶ Write to your MP, AM, MSP or MLA calling on governments to fund speech and language therapy services for people with dementia
- ▶ If you are a politician, a commissioner or a decision maker, please contact your local speech and language therapy service and find out more about what they can do for people with dementia and their families. You might be surprised.
- ▶ Visit: <http://givingvoiceuk.org/dementia> to find out more about the campaign and the resources available