

**F**or some time now, there has been public debate about the challenges arising from the increased demand for care due to an ageing population. There are real concerns about how service planners and commissioners will meet this demand and, in particular, how they will address the needs of the rapidly growing population with dementia.

### Dementia explained

For the uninitiated, dementia describes a collection of symptoms that result in a slow, gradual decline in memory, reasoning and communication skills. Alzheimer's disease, caused by changes to the structure of the brain and a deficiency in neurotransmitting chemicals, is the most commonly diagnosed type of dementia and affects around 417,000 people in the UK (Dementia UK, 2013). Vascular dementia, related to a stroke or to small vessel disease, is the second most common form of dementia and affects more than 110,000 people (NHS Choices, 2013). There are other less common forms of the condition, including fronto-temporal dementia and dementia with Lewy bodies. Some individuals have mixed dementia – where they present with elements of vascular dementia and Alzheimer's disease.

While dementia is often perceived as affecting older people, according to Alzheimer's UK, more than 17,000 people aged under 65 years in the UK are affected, and this is likely to be an underestimate. People with learning disabilities may also experience a higher risk of dementia because of premature ageing. For example, by their fifties, approximately half of people with Down syndrome will exhibit some features associated with Alzheimer's disease (Down's Syndrome Association).

### Communication problems

Although the symptoms can vary according to the individual, difficulties with language and communication occur in all forms of dementia. Some people can experience problems expressing themselves, talking and understanding conversations. They typically exhibit word-confusion, can use the wrong words for common items or mix words up. Reading and understanding written text can also be a problem.

These difficulties obviously cause great distress to the individuals concerned and their relatives and carers. The person

# It's time to talk about dementia

With May's 'Dementia Awareness Week' focusing on 'talking', Claire Moser introduces the RCSLT's forthcoming dementia campaign

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with dementia might know something is wrong and may be worried about the changes they are noticing in themselves. According to Alzheimer's Research UK (2012), 77% of people with dementia feel anxious or depressed. The progressive nature of dementia often means families cannot identify the day they first noticed something was wrong. They are more likely to become gradually aware that their relative is experiencing what might be dementia before they seek medical intervention.

As the condition progresses, dementia will eventually lead to dysphagia (Easterling and Robbins, 2008). This can be due to behavioural changes, sensory or motor problems (or a combination of all three) (ASHA, 2013).

### Dementia statistics

We have already touched on the extent of the problem, but the dementia figures are quite astounding. According to Alzheimer's Research UK (2012):

- An estimated 25 million people in the UK know a close friend or family member with dementia.
- More than 800,000 people in the UK have dementia and epidemiologists expect this number to double in the next 30 years.
- By the year 2021, there will be more than a million people with dementia.
- One in three people aged over 65 will have dementia by the time they die.

In addition to the huge personal impact, dementia has on individuals and their families, there are huge financial costs associated with the condition. Alzheimer's Research UK says dementia cost the UK more than £23 billion in 2012, and estimates that the value of work carried out by carers was around £8 billion.

### Commissioning dementia services

While SLTs do not need reminding that many people with dementia have a communication difficulty and eating, drinking and swallowing problems, unfortunately many of the providers and commissioners of dementia services do.

The Alzheimer's Society (2010) reports that people with dementia recognise 'relationships or someone to talk to' as their top priority for 10 key quality-of-life indicators, closely followed by the "ability to communicate" – highlighting the importance of communication within daily life and relationship building.

In April 2013, the National Institute for Health and Care Excellence published its quality standard for supporting people to live well with dementia. Among the statements that describe high-quality care are that:

- People with dementia are involved in making choices and decisions about their care and support.
  - They can continue to meet their friends and family and can make new relationships.
  - They have the opportunity to be involved in and influence the design, planning, evaluation and delivery of services.
- However, an RCSLT mapping exercise of UK speech and language therapy provision shows that local decision makers have commissioned very few communication services for people with dementia. This highlights the fact that many individuals and their families are not receiving the

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speech and language therapy they need to help them cope with and adapt to the communication problems they face. There is obviously a great deal to do to raise awareness amongst the planners and commissioners of services of the importance of communication in dementia.

On the plus side, decision makers do seem to understand the importance of eating, drinking and swallowing problems in people with dementia, and the fact that the failure to intervene appropriately will result in malnutrition, choking, aspiration, chest infections and associated repeat admissions to hospital.

**The RCSLT dementia campaign**

The RCSLT will soon be launching a major campaign seeking to have an impact at national and local levels. We aim to:

- Raise the profile of the communication and eating, drinking and swallowing needs of people with dementia.
- Showcase the contribution of speech and language therapy in dementia care.
- Put speech and language therapy on national and local dementia agendas.
- Raise awareness of the skills needed to support people with dementia.



**Speech and language therapy and dementia**

**What would you say to someone who asks you why they should commission a speech and language therapy service in dementia? Here's a summary you can use:**

- 1** Specific analysis of language disorder by an SLT can play a key role in the diagnosis of different types of dementia and makes a vital contribution to early diagnosis (and therefore early intervention) and ongoing monitoring of changes over time.
- 2** The SLT can identify the strengths and needs of an individual with dementia and clarify to others what they can expect in terms of the individual's communication abilities.
- 3** SLTs also have the skills to assess the capacity of the individual with dementia to consent to treatment and take part in decisions around their care.
- 4** SLTs can help maintain the interpersonal relationships between individuals and their family/caregivers by analysing the success of the communication strategies used and providing targeted advice to improve/maintain these strategies.
- 5** By working directly with people with dementia and their families, SLTs can maximise an individual's function, maintain sense of identity, reduce stress on caregivers, manage family/carer's expectations, and adapt intervention as the dementia progresses.
- 6** SLTs can advise on how to enhance the communication environment, whether this is in the individual's home or in the acute hospital/care home setting. This can help reduce the causes of challenging behaviours.
- 7** By assessing eating, drinking and swallowing problems (dysphagia) and providing suitable strategies, SLTs can maintain eating and drinking, and reduce the risk of malnutrition and serious problems, such as choking and aspiration chest infections and support families and the wider team in managing end of life issues.
- 8** SLTs can inform the decision-making process regarding non-oral feeding and can contribute information regarding the safety and efficiency of oral intake.
- 9** SLTs can support and train other health and social care professionals to manage communication eating, drinking and swallowing problems to improve quality of life and independence.



## “The theme of Dementia Awareness Week’ is ‘talking’ It’s an ideal opportunity for SLTs to get involved”

The timing of our campaign reflects the recognition that action is necessary to deal with the challenges presented by an expanding dementia population. Across the UK, the respective governments have already committed money to raise awareness and each has produced a dementia strategy to explain how they plan to improve the care and support to people with dementia (see below). At the local level, many commissioners and planners are investing in services for older people.

Through our campaign, we will be calling for:

- Commissioners and budget holders to review their access to, and provision of, speech and language therapy for people with dementia.
- Relevant health professionals, care home and home care staff to understand the impact of communication difficulties in dementia and to ensure they have the knowledge and skills to provide people with appropriate communication support.
- People with dementia to have timely access to speech and language therapy to support their needs.
- Hospital wards and care homes to have access to speech and language therapy services to support people with dementia.

- Health professionals, care home, agency and home care staff to be able to identify the early signs of eating, drinking and swallowing difficulties, and to know when to refer to speech and language therapy, so that people with dementia can meet their nutritional needs safely and appropriately.

### Time to talk

‘Dementia Awareness Week’ will take place across England, Wales and Northern Ireland from 19–25 May, 2013. With ‘talking’ as this year’s theme, it is an ideal opportunity for RCSLT members to get involved in this timely initiative. Visit: [www.alzheimers.org.uk/remembertheperson](http://www.alzheimers.org.uk/remembertheperson)

We will be using the Giving Voice brand and we want you to campaign whether you offer a dementia service or not. This is a great chance to exercise your influencing skills further. During 2013, we will develop specific web resources for you to use, will develop a parliamentary briefing for you to discuss with your local politicians and publish a revised version of the RCSLT position paper on dementia. Let us know your thoughts and sign up to take part in campaigning activities. Email: [dementia@rslt.org](mailto:dementia@rslt.org) ■

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### References & resources

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 RCSLT Giving Voice Campaign: <http://givingvoiceuk.org>

### The UK national dementia strategies

England: ‘Living well with dementia’: <http://tinyurl.com/clcclnz>  
 Scotland: ‘Dementia strategy Scotland’: <http://tinyurl.com/d8bhwhl>  
 Wales: ‘National Dementia Vision for Wales’: <http://tinyurl.com/bq6lqn6>  
 Northern Ireland: ‘Improving Dementia Services in Northern Ireland - A Regional Strategy’: <http://tinyurl.com/cbdwn5n>