



# **Speech and language therapy provision for people with dementia**

## **RCSLT Position Paper 2014**

## Foreword

This position paper, written by speech and language therapists who are experts in the field, highlights the speech and language therapy provision that should be available to ensure equity of access for people with dementia. It also highlights the key role that speech and language therapists have within multidisciplinary teams.

The paper intends to provide guidance on the provision of speech and language therapy services that meet the needs of people with dementia, their families and their carers.

Speech and language therapists have an increasingly recognised and well-documented role in providing services for people with dementia. However, there has been a lack of consistency in service development within the NHS and wide variability in service provision remains.

The Royal College of Speech and Language Therapists (RCSLT) has shown that in some areas specialist speech and language therapy services have been running well for more than 25 years – in these more established services, research activity contributes to the development of the evidence base.

The RCSLT recognises the need to improve access to speech and language therapy services for people with dementia and to also develop knowledge and skills within its membership. It supports clinical excellence networks (CENs), specialist advisers and has established a working group to promote the role of speech and language therapists in the care of people with dementia and their families.

Speech and language therapy services should be planned and resourced adequately, based on local demography and need. It is of concern that there remain many parts of the UK where people with specific communication or swallowing needs associated with their dementia are not able to access a specialist speech and language therapy service.

The RCSLT also believes that any person with a communication disorder or with dysphagia (eating, drinking and swallowing disorder, including those with a diagnosis of dementia) has a right to access a professional with expertise in these areas.

While not all speech and language therapists working with people with dementia will have the opportunity to work with a specialist team, they should still have the required level of knowledge and skills to respond to the specific challenges of assessing and managing this client group.

The first RCSLT Policy Position Paper on speech and language therapy provision for people with dementia (2005) focused on the lack of services and inequality and while service provision has improved since that paper's publication, inequality remains.

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## Contents

1 Executive summary	5
2 Purpose and Intention	8
3 Definition	9
4 Demographics	10
5 The need for speech and language therapy provision	12
6 Philosophy of care	14
7 The role of the speech and language therapist	15
8 The benefits of providing a speech and language therapy service	19
9 The risks of not providing a speech and language therapy service	23
10 Key recommendations	28
11 Further information	29
12 References	30

# **1 Executive summary**

Dementia affects approximately 800,000 people in the United Kingdom and is set to increase as the population grows older. There are real concerns about how service planners, commissioners and decision makers will meet this demand and, in particular, how they will address the needs of the rapidly growing population with dementia.

The benefits of providing a speech and language therapy service for people with dementia and their families include:

## **More effective assessment through:**

- Specific analysis of associated language disorders to inform differential diagnosis.
- Specialist assessment of any eating, drinking and swallowing problems.
- Assessment of individual's capacity to consent to treatment and care.

## **Preservation of independence by:**

- Providing specific programmes to maximise and maintain function.
- Providing an optimum environment for communication and eating and drinking.
- Enhancing function in the later stages of the condition.

## **Helping the person with dementia and those involved in their care by:**

- Providing support that enables carers to care – support which maximises knowledge, skill, self-efficacy and quality of life and minimises depression and anxiety.
- Providing specialist input to inform decision making around complex swallowing difficulties and non-oral feeding.
- Providing specific management strategies for people experiencing eating and swallowing difficulties.
- Providing specialist input to clinical networks for policy development, risk management, ethical decision-making, research and audit.
- Providing training in effective communication and management of eating and swallowing difficulties to promote good care.

## **Maintaining/developing relationships by:**

- Maintaining ongoing interpersonal relationships between individuals and carers
- Acting as advocate for people with communication disorder.
- Supporting the person with dementia to manage the everyday challenges they face with interactions in their community.

All of the above contribute to an improved quality of life and a reduction of hospital and care home admissions.

There are risks of not providing a speech and language therapy service for people with dementia and their families,

### **The risks to individuals**

- Decrease in quality of life, wellbeing, sense of personhood and quality of relationships for both the person with dementia and their carers.
- Delay in diagnosis and/or incorrect diagnosis.
- Barriers to accessing and communicating with other health and social care professionals.
- Social exclusion.
- Increased level of dependence at an earlier stage.
- Exclusion from decision making and service planning.
- Avoidable death due to malnutrition, choking and aspiration pneumonia.

### **The risks to organisations**

- Unnecessary admission and readmission to hospital and care homes.
- Behaviour that challenges not managed effectively.
- Needs of vulnerable adults not met.
- Inequity of service provision and lack of adequate supervision resulting in poor standards of care.

### **Key recommendations**

- There should be access to speech and language therapy services for people with dementia. Commissioners, decision makers and service providers, who are aware of the needs of their local population, should ensure there is access to speech and language therapy services to meet those needs.
- Speech and language therapy services should provide equal access to intervention for communication and for swallowing disorders.
- Speech and language therapy services should be adequately resourced to provide quality care for people with dementia.
- Speech and language therapy services for people with dementia should be provided within an integrated multidisciplinary context to ensure the philosophy and goals of intervention are shared and consistent.
- "Cost per case" arrangements or service level agreements with minimal levels of provision for SLT are unlikely to provide a service of the quality and expertise that people with dementia require.
- Communication and swallowing are the responsibility of the whole team – the role of the speech and language therapist is to empower and educate others as well as providing direct specialist input as appropriate.
- Early speech and language therapy intervention is crucial so that people with dementia and their carers have their needs met in a timely way.

## **2 Purpose and intention**

What has become evident in the process of consultation with the profession for the purposes of writing this paper is the overwhelming passion, energy and commitment for people with dementia to be included as valued members of society, and the core role SLTs have in enabling inclusion.

This paper aims to offer guidance to SLTs and speech and language therapy managers in order to influence commissioning arrangements and it is hoped the paper will also be useful for other organisations committed to supporting the rights of people with dementia. It includes:

- Key strategic and policy drivers influencing practice.
- Values embedded within speech and language therapy practice.
- Role and scope of speech and language therapy practice.
- The value of a speech and language therapist as a member of the interdisciplinary team
- Advice on service models and structures.
- Evolving roles and workforce issues for the profession.
- Questions for future consideration and discussion.
- Key research and evidence base.

### 3 Definition

The term 'dementia' describes a set of symptoms, which include loss of memory, mood changes, and problems with communication and reasoning. These symptoms occur when the brain is affected by certain diseases, including Alzheimer's disease and the damage caused by vascular changes. Dementia is progressive, which means the symptoms will gradually get worse. How fast dementia progresses will depend on the individual person and what type of dementia they have. Each person is unique and will experience dementia in their own way.

The World Health Organisation's ICD-10 (2010) definition of dementia includes: "disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement".

There are over 100 different forms of dementia. Alzheimer's disease is the most common form of dementia. The estimated distribution is as follows:

- Alzheimer's disease (AD) 62%
- Vascular dementia (VaD) 17%
- Mixed dementia (AD and VaD) 10%
- Dementia with Lewy bodies 4%
- Fronto temporal dementia (FTD) 2%
- Other dementias 3%

(Alzheimer's Society, 2013a)

## 4 Demographics

Dementia is one of the most severe and devastating disorders we face. There are approximately 800,000 people with dementia in the UK and this figure is predicted to rise to more than one million by 2021 (Alzheimer's Society, 2013a)

Key data for the UK, provided by Knapp et al (2007) include the following:

- The national cost of dementia is currently about £17 billion per year but this is estimated to treble to over £50 billion per year (Comas-Herrera et al, 2007).
- It affects men and women in all social groups.
- People from all ethnic groups are affected by dementia.

Matthews et al (2013) report that between 1991 and 2011 the number of people with dementia in care homes increased from 56% to 70%.

At any one time, a quarter of acute hospital beds are in use by people with dementia (Royal College of Psychiatrists, 2013) and in a study by the Alzheimer's Society, 97% of nursing staff and nurse managers reported that they always or sometimes care for someone with dementia (Alzheimer's Society, 2009).

There is an increased risk of developing dementia in later life for those who have experienced a traumatic brain injury (Shively et al, 2012).

While dementia is often perceived as affecting older people, there are more than 17,000 younger people with dementia in the UK. However, this number is likely to be an underestimate, and the true figure may be up to three times higher (Alzheimer's Society, 2013b).

Dementia generally affects people with learning disabilities in similar ways to the rest of the population, but there are some important differences.

- The incidence of dementia in older adults with learning disabilities is up to five times higher than older adults in the general population (Strydom et al, 2013). The increased risk for Alzheimer's disease in people with Down syndrome has been well established (Strydom et al, 2013).
- People with Down syndrome often show different symptoms in the early stages of dementia. They are less likely to receive a correct or early diagnosis of dementia and may not be able to understand the diagnosis and may experience a more rapid progression of dementia (Alzheimer's Society, 2013c).

## **National context**

Position papers seek to capture the most up-to-date evidence base and best practice principles for a given clinical area. This will be common to all parts of the United Kingdom, and indeed beyond. But the context for delivering services in that clinical area may vary between England, Scotland, Wales and Northern Ireland due to legislative, regulatory, national and local policy differences.

To ensure that a position paper has a longer shelf-life, an up-to-date summary of relevant laws, regulations; policies and guidance can be accessed on the RCSLT dementia webpage.

This ensures that position statements are relevant to the whole of the UK, and the context can be updated as soon as it changes. Where it is unavoidable relevant documents have been referenced within the main text (always for all four nations). Local context should also be researched when considering taking forward recommendations from a position paper.

### **NICE Clinical Guideline 42 (2006)**

This guideline makes specific recommendations, within the NHS in England and Wales, on Alzheimer's disease, dementia with Lewy bodies, frontotemporal dementia, vascular dementia and mixed dementias, as well as recommendations that apply to all types of dementia. It recommends that:

- Health and social care staff should identify the specific needs of people with dementia and their carers arising from ill health, physical disability, sensory impairment, communication difficulties, problems with nutrition, poor oral health and learning disabilities.
- Good communication between care providers and people with dementia and their families and carers is essential, so that people with dementia receive the information and support they require.
- Health and social care staff should encourage people with dementia to eat and drink by mouth for as long as possible. Specialist assessment and advice concerning swallowing and feeding in dementia should be available.

In 2011, the Department of Health, Social Services and Public Safety (DHSSPS) in Northern Ireland advised that the guidance contained in the NICE guideline is valid for Northern Ireland and endorsed it for implementation in health and social care (HSC).

## **SIGN Clinical Guideline 86 (2006)**

The first Scottish Intercollegiate Guidelines Network (SIGN) guideline on interventions for the management of behavioural and psychological aspects of dementia (SIGN 22) was published in February 1998. The original guideline addressed assessment, non-drug interventions, neuroleptic drugs, use of other drugs and consent.

This revised guideline (2006) expands and updates the evidence base supporting the recommendations and incorporates advice on new treatments. The guideline considers investigations and interventions in which direct benefit to the patient can be demonstrated. It covers all stages of dementia excluding mild cognitive impairment. The guideline does not address palliative care in advanced disease, risk or prevention.

## **5 The need for speech and language therapy provision**

Dementia causes:

- Communication difficulty for the person with dementia.
- Communication difficulty for carers.
- Eating, drinking and swallowing difficulties.

Speech and language therapists (SLTs) have the specialist knowledge and skills to directly assess and manage these problems.

Communication problems occur in all forms of dementia and in the later stages these problems become increasingly challenging ( Bourgeois, 2010). Particular patterns of communication change are associated with different types of dementia and are therefore an important part of differential diagnosis (Gorno-Tempini et al, 2011). Language impairment may be an initial presenting feature of the disease, particularly in frontotemporal dementia (FTD): progressive non-fluent aphasia (PNFA), logopenic variant of progressive aphasia and semantic dementia (SD).

Communication difficulty has been described as one of the most frequent and hardest to cope with experiences for family carers (Egan et al 2010; Braun et al, 2010). It is important to remember that many carers report moments of great joy, pleasure and humour from their life as a carer (Searson et al, 2008) with effective communication and relationships playing an integral part in this experience.

Communication difficulty can be exhausting for the person with dementia and affects their identity and relationships (Bryden, 2005)

Difficulties with eating, drinking and swallowing are a recognised challenge for people with dementia, particularly in the later stages. Sixty-eight percent of those with dementia in homes for the aged were found to have dysphagia (Steele et al, 1997). The need to assess and manage eating and swallowing difficulties and identify potential aspiration is important (NICE 2006), particularly in those with more advanced dementia (Logemann et al 2008; Robbins et al 2008).

Studies demonstrate the important role of SLTs in the assessment and management of dysphagia and in administering interventions and training staff (RCSLT 2009). Multidisciplinary consideration of eating, drinking and swallowing needs is an integral part of a comprehensive end of life approach (Royal College of Physicians 2010).

The Resource Manual for Commissioning and Planning Services for SLCN (Speech, Language and Communications Needs) (RCSLT, 2013) supports RCSLT members to communicate with commissioners by including a synthesis of the research evidence relating to the impact of speech, language therapy. The review was based on systematic searching and expert review. The document includes:

- Incidence and prevalence figures.
- Range of interventions available.
- Effectiveness of interventions available.
- Relative cost effectiveness of those interventions (where evidence exists).
- A prioritisation process which manages health gain across the population as a whole.

## 6 Philosophy of care

The current policy agenda is clear in that services should be designed around the needs and individual choices of patients and their families.

This philosophy was encompassed within the work of Kitwood (1997) and has been developed and expanded by a number of researchers and practitioners. The notion of personhood with its emphasis on preserved ability and wellbeing encourages the belief that all people with dementia, at all stages, have something to communicate. More recently, emphasis has shifted from person-centred to relationship-centred care to highlight the need to support both the person with dementia and those who care for them (Nolan et al, 2004).

Gorska et al (2013), when assessing the service-related needs of older people with dementia, identified the need for increased access to non-pharmacological interventions, including speech and language therapy, as an essential element of high quality care to support identity and social engagement.

James (2011) argues that behaviour that challenges is often an attempt by the person to make sense of the environment or communicate an unmet need. Through careful communication with the person, the caregiver can take steps to understand the hidden meaning concealed by the confusion and therefore take steps to reduce the incidence of behaviour that challenges.

It can clearly be seen that optimising the communication skills of both the person with dementia and carer is a central theme to providing high-quality relationship-centred care. Assessment and treatment should be individualised, should draw from the broad range of approaches available and should take account of the increasingly well-documented evidence regarding patterns of language breakdown in different forms of dementia (Snowden, 2003).

It is therefore essential that all people with dementia and their carers are able to access speech and language therapy if this agenda and philosophy is to be met locally.

## **7 The role of the speech and language therapist**

Speech and language therapists (SLTs) work in a variety of settings to contribute to the care of people with dementia, including specialist memory services, community mental health teams, hospital wards, community services, learning disability services, care homes, day care, and forensic services.

The role encompasses the following (but will be dependent on skill mix, with some aspects requiring specialist skills and others that can be provided by speech and language therapy assistants under supervision):

### **Assessment to inform differential diagnosis**

- In those who present with a prominent language disorder; for example, frontotemporal dementia, primary progressive aphasia and language presentation of Alzheimer's disease.
- In those who present with prominent speech difficulties (dysarthria); for example, cognitive difficulties associated with Parkinson disease, dementia with Lewy Bodies, vascular dementia, Huntington disease, motor neurone disease, progressive supranuclear palsy, cortico-basal degeneration and multiple systems atrophy.
- Work with other professionals to ensure that the extent of the speech and language impairment is taken into account during administration and interpretation of cognitive assessments.

### **Assessments to outline needs and inform interventions**

Identify:

- The nature and severity of the language/speech disorder and its impact on communication.
- The profile of skills and difficulties with communication and the resulting challenges and risks for the individual with dementia and their carers in everyday life.
- The contribution that unmet communication needs make to behaviour that challenges.
- The psychological and social impact of the communication difficulty on the person with dementia and their carers.
- The communication network (including, people and places) to maximise communication opportunities.
- The capacity for decision making in those who are experiencing significant language disorder including strategies to facilitate this.
- The likely progression of the language disorder to enable health and social care interventions to be delivered in a timely and effective manner.

## **Interventions for people with dementia and their carers**

- Direct intervention with the person with dementia to provide specific programmes to maintain and maximise communication function; for example, personalised communication and memory strategies (including communication passports and life story work).
- Work with formal and informal carers to implement personalised communication strategies.
- Provide advice on changes necessary to reduce the increased risks identified for the person with communication impairment, so they are able to function as safely and independently as possible within their community.
- Facilitation of the use of communication strategies in all environments, within the home and in the wider community.
- Help for the person and their family carers to manage stress resulting from communication difficulties.
- Group intervention to maximise retained communication skills and provide a supportive environment for socialisation; for example, Sonas groups, cognitive stimulation therapy, and reminiscence.
- Contribution to post-diagnostic services for people with dementia and their carers; for example, sessions on communication within information and support groups.
- Incorporating the individual's specific communication requirements into the multidisciplinary team care plan.
- Facilitating people with dementia to have equal access to services promoting rehabilitation and enablement.
- Advocate for an individual with complex communication needs arising from their dementia
- Working with the multidisciplinary team to disseminate information in an accessible format.

## **Assessment and management of eating, drinking and swallowing difficulties**

- Identifying the nature and severity of any eating, drinking and swallowing disorder and the impact this has on enjoyment of food and mealtimes.
- Assessing the risk of aspiration and choking.
- Contributing to a holistic assessment of mealtime difficulties, eg mood, behaviour, the care environment, physical and sensory issues.
- Making recommendations for the management of swallowing difficulties.
- Advising, supporting and training carers in effective ways to promote safe swallowing, reduce risk of aspiration and enable nutrition and hydration needs to be met.
- Contributing to future planning of eating and drinking needs, including when tube feeding and end of life issues are under discussion. This would also include continued feeding (risk feeding) when aspiration is an acknowledged risk.
- Planning, reviewing and monitoring to prevent unnecessary admission to hospital.
- Enabling family carers to have full understanding and involvement in the decision making process at end of life and offer support as required.

## **Training**

To provide training to family carers and a range of health, social care and voluntary sector staff, students and the wider community about:

- Communication difficulties in dementia and strategies to support and enhance communication.
- Recognition and management of atypical dementias where the primary symptoms are with language and communication rather than memory, eg primary progressive aphasia and its variants.
- Management of eating, drinking and swallowing difficulties in dementia.
- The role of speech and language therapy in dementia.

To provide support, advice and supervision to speech and language therapists working in other specialities, about the needs of people with dementia.

## **Research and development**

Speech and language therapists are engaged in a variety of projects to:

- Identify gaps in the evidence base.
- Carry out research activities.
- Promote best practice in service provision.
- Develop appropriate care pathways.

**Visit: [www.rcslt.org](http://www.rcslt.org) for examples and case studies**

## **8 The benefits of providing a speech and language therapy service**

Speech and language therapists can support people with dementia, their carers and the wider health and social care team in a variety of ways:

- **Specific analysis of language disorder to inform differential diagnosis**

There has long been recognition that different causes of dementia lead to different patterns of cognitive decline (Neary and Snowden, 2003). Neuropsychological assessment has an important contribution to make to differential diagnosis of dementia. Assessment across a range of cognitive domains including language is required to distinguish these different patterns of impairment. Detailed language profiling is particularly important in assessing frontotemporal dementia and the progressive aphasia (Gorno-Tempini et al, 2011; Snowden, 2003). Speech and language therapists are qualified to carry out such assessments and therefore have a crucial role to play when language symptoms are prominent; for example, frontotemporal dementia, progressive aphasia, language presentations of Alzheimer's disease and corticobasal degeneration.

Examination of motor speech difficulties (dysarthria) by the SLTs may be important in conditions affecting motor and subcortical areas; for example, cognitive difficulties associated with Parkinson disease, dementia with Lewy Bodies, vascular dementia, Huntington disease.

Speech and language therapists have a key role in the recognition of different types of dementia (Snowden and Griffiths, 2000) and make a vital contribution in a multidisciplinary assessment to early diagnosis (Garrard and Hodges, 1999). They are also able to monitor the course of the dementia including changes to language skills and communication as a result of pharmacological intervention.

- **Specialist assessment of eating, drinking and swallowing (dysphagia)**

When dysphagia occurs as a feature of dementia, difficulties presented at mealtimes are often complex and will include feeding, positioning, behavioural and psychological problems (Steele et al, 1997). It is known that the correct specialist advice and management increases independence, helps to maintain eating skills and can reduce the risk of undernutrition, dehydration and aspiration. Multidisciplinary team working is essential in managing people with oral feeding difficulties and SLTs are key team members (Royal College of Physicians, 2010).

- **Provision of specific programmes to maximise and maintain function**

There is a growing body of evidence to justify that intervention with people who have dementia and their carers improves communication (Enderby et al, 2013.)

Communication in primary progressive aphasia can be maintained and enhanced by specific interventions (Carthery-Goulart et al, 2013). Examples include communication passports, augmentative and alternative communication tools, life story work and Talking Mats. (Bourgeois, 2009; Murphy and Oliver, 2013; Savitch and Stokes, 2011)

- **Enabling carers to care by providing support which maximises knowledge, skill, self-efficacy and quality of life and minimises depression and anxiety**

How much and for how long a family member provides care is strongly correlated to the extent of the person's dementia, the carer's experience of burden and depression and in particular their experience of behaviour that challenges and communication difficulties (Searson et al, 2008).

The best evidence for psychosocial carer support encourages the use of intensive one to one individualised therapy following home based assessment. Typically, this should combine an element of knowledge and skills training with individualised behaviour management (Selwood et al, 2007; Gallagher-Thompson and Coon, 2007; Vernooij-Dassen, 2011). The most likely outcome from this form of intervention appears to be a reduction in carer reported depression (Thompson et al, 2007).

Speech and language therapists are well placed and resourced to work individually and in groups with family carers throughout the course of the illness specifically to identify changing difficulties and needs in relation to communication. They also have a role in referring on for specialist psychological input as required.

- **Reduce stress and burden on carers by providing specific management strategies for people experiencing eating and swallowing difficulties**

Mealtime difficulties such as food refusals, difficulty eating certain food textures and coughing/choking when eating, can be challenging and stressful for carers. Intervention for dysphagia focuses on care practice, environmental modification, adaptation of equipment and texture modification of food and drinks. These modifications reduce the impact of the dysphagia, improve nutritional intake and reduce stress and burden on care givers (Biernacki and Barratt, 2001).

- **Maintenance of an ongoing interpersonal relationship between the person with dementia and carers**

People with dementia and their carers are at risk of significant changes in the quantity and quality of interaction between themselves and others.

They are also at risk of losing communication partners as informal support from family and friends often diminishes (Bourgeois, 2010).

By providing support, enabling understanding and recommending specific strategies SLTs are able to work with carers and people with dementia to help maintain their interpersonal relationships. When enabled with resources eg life story book and opportunities, such as Alzheimer's café groups, as well as a better understanding of why and how someone with dementia may communicate both the carer and the person with dementia are more likely to experience successful interactions.

- **Maintenance of function in later stages of the disease**

Work by Le Dorze et al (2000) suggests that viewing carers as communication partners who can take on a greater share of the communicative burden as deterioration progresses is a positive way to encourage communication by direct intervention. Speech and language therapists can advise on adapting existing provision to enable the inclusion of people with advanced dementia in activities and to help staff achieve effective communication with them (Powell, 2000).

- **Enable carers and other professionals to provide the optimum environment for communication and eating and drinking**

The environment of people with dementia is a crucial determinant of their wellbeing. Speech and language therapists can advise on how to enhance the communication environment by passive enrichment and improvement of active interaction between people and their physical and social surroundings (Lubinski, 1995).

Adapting the environment may significantly increase the person with dementia's ability to take an adequate diet and have a positive mealtime experience. Speech and language therapists can provide detailed assessment of the eating environment and make appropriate recommendations to ensure maximum independence.

Management of eating and drinking should always encompass the person's cultural needs.

- **Contribution to multidisciplinary problem solving and care planning**

Inability to communicate effectively may be the cause of much of the behaviour that challenges (James, 2011; Bryan and Maxim, 2003). The RCSLT dementia expert working group consider the work of SLTs to be most effective when the therapist is a permanent member of the multidisciplinary team. As well as specific benefits for people with dementia, the whole team benefits from heightened awareness of communication disorder and advice and support to manage it. Difficulty in eating and drinking may need a specialist view to differentiate behaviour that challenges from dysphagia. Speech and language therapists can offer training to the multidisciplinary team in the

assessment and management of clinical risk associated with dysphagia and in the provision of nutrition that maximises independence and reduces clinical sequelae.

- **Assessment of capacity to consent to treatment and care**

Speech and language therapists are uniquely qualified to assess an individual's ability to understand and then communicate that understanding for the purposes of establishing mental capacity for decision-making. They advise on the most effective means of presenting information and choices to the individual, maximising their opportunity to exert free choice. The code of practice for the implementation of the Mental Capacity Act (England and Wales) recommends seeking the professional opinion of a speech and language therapists. (Mental Capacity Act Code of Practice, 2007)

- **Act as advocate for people with communication disorder**

All people with dementia have the right to maintain optimal use of their residual communication. Supporting and enabling communication is an ethical obligation for healthcare professionals (Barnett, 2000; Allan, 2001). Speech and language therapists have the specialist skills to facilitate optimal communication, maximising the individual's choice and degree of control. If required, they can advise an appointed Independent Mental Capacity Advocate (IMCA) to enable them to communicate effectively with the person with dementia.

- **Train others to manage communication and dysphagia**

As the person with dementia deteriorates, carers spend less time communicating and more time supervising them (Marin, 2000). The SLT has skills to enhance the performance of others and to optimise communication throughout the duration of the illness (Maxim et al, 2001).

It is crucial that those responsible for providing food and drink to people with dysphagia have the necessary understanding to follow the recommendations from a swallow assessment. The Dysphagia Diet Food Texture Descriptors (2012) assist with standardising the terminology and are used when training catering staff and carers.

- **Specialist input to inform decision making around complex swallowing difficulties and non-oral feeding**

Eating and swallowing difficulties are often part of the complex picture presented to clinicians in those with advanced dementia. End of life decisions therefore frequently involve discussion of such issues within the multidisciplinary team.

“Speech and language therapists can advise on strategies to minimise aspiration risk, facilitate eating and drinking, and improve nutritional status. These are modifications of food and fluids including changes to

texture, consistency and quantity; swallowing strategies including manoeuvres and sensory techniques; positioning and postural techniques; external strategies such as carer support, environment and administering food and drink; and behavioural and cognitive techniques.” (Royal College of Physicians, 2010).

The information provided by SLTs is therefore vital to the decision making process. Appropriate management of eating and swallowing is integral to a comprehensive end of life approach (Smith et al, 2009).

- **Specialist input to clinical networks for policy development, risk management, ethical decision-making, research and audit**

The speech and language therapist has unique skills and expertise that complement and complete the knowledge base of the multi-professional team within specialist mental health services. The Royal College of Psychiatrists (2007) states, “in the increasing joint working between the professions, it is clear that we share more common ground than we have differences and that our greatest effectiveness is when we work in close and coordinated collaboration.”

- **Providing training to staff in non-specialist settings in effective communication to promote good care**

As indicated in the Francis report on the Mid Staffordshire NHS Foundation Trust Public Inquiry (2013), people with dementia should receive care from staff appropriately trained in dementia care. The report recommends that dementia care training should include, “the importance and use of communication skills for working with people with dementia”.

- **Reducing admissions to hospital from care homes**

A quality report by Sandwell Community Healthcare Services (2009) of their speech and language therapy rapid response dysphagia service highlights a 47% fall in the number of ward referrals for dysphagia related end of life dementia. Feedback from care home staff demonstrated an increased competence in managing end of life care for people with dementia.

## **9 The risks of not providing a speech and language therapy service**

### **Risks to individuals**

- **Decrease in quality of life, wellbeing, sense of personhood and quality of relationships for both the person with dementia and their carers**

The loss of meaningful interaction and conversation places increases pressure on the caring relationship (O'Connor et al, 1990; Nolan et al, 2002). Gilleard et al (1984) found that carers of people with dementia exhibiting communication and behavioural difficulties were twice as likely to report symptoms of their own psychiatric distress.

Dysphagia has well documented effects on physical health but also has adverse effects on self-esteem, socialisation and enjoyment of life including anxiety and panic during mealtimes (Ekberg, 2002).

- **Delay in diagnosis and/or incorrect diagnosis**

As outlined under the benefits above, SLTs have a crucial role in differential diagnosis particularly where language disorder is prominent. Without contribution of this specialist knowledge and skills as part of the team, people may be misdiagnosed and appropriate treatment delayed.

Atypical dementias may present a particular challenge to memory services as the presence of complex language disorder impacts on the delivery and reliability of formal testing.

- **Barriers to accessing and communicating with other professionals**

People with dementia have complex needs and it is therefore vital that services are coordinated and seamless. The problems they face include delays in diagnosis, poor integration of the different agencies providing care and lack of understanding about dementia and dementia services among key professional groups (Audit Commission, *Forget Me Not*, 2000 and 2002; Briggs and Askham, 1999). As communication is so fundamental, SLTs should be core multidisciplinary team members, readily accessing and being accessed by other professionals, sharing goals of intervention and preparing joint goals. Evidence suggests SLTs have a role in assisting other professionals to achieve effective communication with patients who have dementia (Orange and Ryan 2000).

- **Social exclusion**

Within the population with dementia, there is a group of people with *specific* communication difficulties (ie where language is the domain most affected) who are particularly vulnerable to social exclusion and warrant

specific service provision. Hagberg (1997) suggests intervention should aim to enhance coping skills and self-efficacy, combat threats to self-esteem and help the person with dementia to make the best possible use of their individual resources. The Alzheimer's Society (2013d) report on Building Dementia Friendly Communities acknowledges the barriers to effective communication and the need for clear communication, tailoring communication to the needs of the individual and promoting strategies to aid effective communication.

- **Increased level of dependence at an earlier stage**

Communication skills are vital for independence. Communication and memory therapy for people with early dementia can maximise and maintain communication skills and independence for longer (Clare and Woods, 2001; Powell, 2000; Bourgeois, 1991). In the early stages some areas of cognition may be relatively spared and some individuals may be able to learn and retain strategies taught to them to increase communicative effectiveness and therefore reduce dependence (Azuma and Bayles, 1997; Acton et al, 1999).

Training for carers within the residential setting is effective (Jordan et al, 2000) and the role of SLTs as trainers has been outlined in this (Maxim et al, 2001).

The onset of feeding dependence correlates with the onset of dysphagia in dementia. It is therefore essential that staff and relatives caring for the person with dysphagia are aware of ways in which they can assist and prompt without reducing the person's ability to self-feed (Siebens 1986).

- **Avoidable death due to malnutrition, choking and aspiration pneumonia**

Dysphagia, if not managed, results in malnutrition and dehydration (Hudson, 2000), and is a causal factor in repeated chest infections and choking risk. However, weight loss in dementia is not inevitable (Wang, 1998). Aspiration is an important etiological factor leading to pneumonia in older people. Pneumonia is a major cause of morbidity and mortality in older people and is the leading cause of death among residents of nursing homes (Marik and Kaplan, 2003). El Sohl et al (2004) examined the indicators of recurrent hospitalisation for pneumonia in older people and found swallowing dysfunction to be top of their list of hazardous variables. These studies highlight the importance of swallowing assessment to manage aspiration and the consequences on morbidity, mortality and hospitalisation.

- **People excluded from decision making and service planning**

The SLT is often the person best qualified to advise on the most effective means of presenting information and choices to the person with dementia who has significant communication disorder, in a way that maximises their opportunity to exert free choice. This is a particularly

important role for SLTs in relation to legislation which applies to people with dementia.

### **Risks to organisations:**

Organisations are at risk of receiving formal complaints, high profile adverse publicity and becoming involved in costly litigation if they fail to meet the policy agenda, or as a consequence of incidents involving individuals or groups of patients as highlighted below.

- **Unnecessary admission and readmission to hospital and residential/nursing care**

Brody and Peters (1991) showed that training carers reduced unnecessary admission and was cost effective in avoiding respite and residential care costs. Direct speech and language therapy intervention with carers providing training, advice and support on communication disorder and memory difficulties enables them to continue in the caring role for longer (Barnes 2003).

People with dysphagia are often admitted to hospital when they reach the stage of severe malnutrition or aspiration – timely intervention can prevent this (Sandwell Community Healthcare Services, 2009). Speech and language therapists can give advice, re: reduction of clinical risks, maximising independence and improving wellbeing in people with dementia related to their mealtimes. Optimal management of dysphagia should reduce clinical risks and decrease the need for crisis management and hospital admissions.

- **Behaviour that challenges not managed effectively**

Goudie and Stokes (1989) first proposed that much behaviour that challenges can be understood within the framework of poorly communicated need. Failure to evaluate and maximise potential for communication may contribute to unmet needs, frustration and behavioural change.

Staff and family carers who are trained to recognise how people in their care communicate distress, anxiety or pain through their behaviour (verbal and non-verbal) are better equipped to identify the triggers of behaviour that challenges in an individual, and address the potential for a person with dementia to harm themselves or others.

- **Needs of vulnerable adults not met**

Those with communication disabilities are particularly vulnerable to abuse or neglect and are least able to report it. Organisations have a duty of care to ensure staff are alert to signs of abuse/neglect and are aware of safeguarding procedures. Effective and sensitive communication skills are required for this purpose. Kitwood (1990) describes the malignant social psychology in which people with dementia are disempowered and denied a voice. Optimal management of

communication including training carers and care staff may help to protect and meet the needs of this vulnerable group.

The Royal College of Psychiatrists (2011) recommends that, "the chief executive officer should ensure that non-reporting of nutritional status, missed meals or other risk to nutrition is considered a safeguarding issue for people with dementia and reported in accordance with guidance." Their national audit of dementia care in acute hospitals found that 3% of wards had no access to speech and language therapy services.

- **Perpetuation of inappropriate/harmful practice**

Without comprehensive assessment and advice people may inadvertently be inappropriately managed. For example, those with communication problems may be at risk of isolation and social exclusion and if this is not managed, depression. The Royal College of Psychiatrists (2013) found that, "approximately three-quarters of hospitals had a formal system in place for gathering information pertinent to caring for a person with dementia. Where this information is recorded in the notes, less than half contained information about details which aid communication with the person".

Individuals with dysphagia are at risk of malnutrition and aspiration (Orange and Ryan, 2000).

## **10 Key recommendations**

- There should be access to speech and language therapy services for people with dementia. Commissioners, decision makers and service providers, who are aware of the needs of their local population, should ensure there is access to speech and language therapy services to meet those needs.
- Speech and language therapy services should provide equal access to intervention for communication and for swallowing disorders.
- Speech and language therapy services should be adequately resourced to provide quality care for people with dementia.
- Speech and language therapy services for people with dementia should be provided within an integrated multidisciplinary context to ensure the philosophy and goals of intervention are shared and consistent.
- “Cost per case” arrangements or service level agreements with minimal levels of provision for SLT are unlikely to provide a service of the quality and expertise that people with dementia require.
- Communication and swallowing are the responsibility of the whole team – the role of the speech and language therapist is to empower and educate others as well as providing direct specialist input as appropriate.
- Early speech and language therapy intervention is crucial so that people with dementia and their carers have their needs met in a timely way.

## 11 Further information

This document complements other RCSLT publications:

**RCSLT Resource Manual for Commissioning and Planning Services for SLCN; Dementia (2013)**

[http://www.rcslt.org/about/docs/slcn\\_resource\\_manual](http://www.rcslt.org/about/docs/slcn_resource_manual)

**RCSLT Resource Manual for Commissioning and Planning Services for SLCN; Dysphagia (2009)**

### **RCSLT Clinical Guidelines (2005)**

The guidelines contain recommendations that are explicit statements providing specific clinical guidance on the assessment and management of each clinical area. Each recommendation is supported by evidence from the literature or is based upon the consensus of clinical experts.

### **RCSLT Communicating Quality 3 (2006)**

Standards and guidelines that represent the benchmarks of SLT practice and provide criteria against which compliance can be judged.

**RCSLT Position Paper Speech and Language Therapy Provision for Adults with Learning Disabilities 2010**

[http://www.rcslt.org/members/publications/ald\\_position\\_paper](http://www.rcslt.org/members/publications/ald_position_paper)

This document provides a detailed account of the principles and processes surrounding good practice. It also discusses the wider policy and service delivery issues that SLTs need to engage with if they are to work effectively in this field

### **Other useful documents include:**

**British Geriatrics Society, Best Practice Guide**

**Dysphagia management for older people towards the end of life**

[http://www.bgs.org.uk/index.php?option=com\\_content&view=article&id=2328:bpgdysphagia&catid=12:goodpractice&Itemid=106](http://www.bgs.org.uk/index.php?option=com_content&view=article&id=2328:bpgdysphagia&catid=12:goodpractice&Itemid=106)

**Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists (2007) Challenging behaviour: a unified approach**

<http://www.rcpsych.ac.uk/files/pdfversion/cr144.pdf>

**Alzheimer's Society** <http://www.alzheimers.org.uk/>

**The Frontotemporal Disease Support Group** <http://www.ftdsg.org/>

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