Position Paper

v1.11

Survey Monkey Draft

Speech and Language Therapy Provision for People with Dementia

DRAFT

FOREWARD TO BE ADDED

CONTENTS PAGE TO BE ADDED

INTRODUCTION TO BE ADDED

DRAFT

1. Executive Summary

Definition

The term 'dementia' describes a set of symptoms which include loss of memory, mood changes, and problems with communication and reasoning. Dementia has many causes.

Demographics

Dementia is very common (National Dementia Strategy, 2009). There are approximately 800,000 people with dementia in the United Kingdom & this figure is predicted to rise to over 1 million by 2021 (Alzheimer's Society, 2013a).

The need for Speech & Language Therapy provision

Dementia causes:

- communication difficulty for the individual and their carers
- eating, drinking & swallowing difficulties

Speech & Language Therapists have the knowledge & skills to assess and manage these problems.

Philosophy of care

A philosophy of care 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 well- being encourages the belief that all people with dementia, at all stages, have something to communicate. More recently, emphasis has shifted from Person-Centred care to Relationship-Centred care (Nolan et al 2004).

It is therefore essential that all people with dementia and their carers are able to access specialist services such as Speech and Language Therapy if this agenda and philosophy is to be met locally.

The role of the Speech and Language Therapist

SLTs work in a variety of settings to contribute to the care of people with dementia, including: specialist memory services, older peoples community mental health teams, hospital wards, community SLT services, learning disability services, care homes, day care, and forensic services.

The core role encompasses the following:

- Assessment to inform differential diagnosis
- Assessments to outline needs and inform interventions
- Interventions to improve and maintain communication for people with dementia and their carers
- Assessment and management of eating, drinking and swallowing difficulties
- Training of broad range of care staff and families
- Research and Development

The benefits of Speech and Language Therapy

There are significant benefits of providing a Speech & Language Therapy service, and to not provide this service potentially puts both individuals and organisations at risk.

DRAFT

There is a growing body of evidence to justify that intervention with people who have dementia and their carers improves communication. Please see Professor Pam Enderby's Literature Review available here:http://www.rcslt.org/about/docs/slcn_resource_manual

DRAFT

2. 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 damaged by certain diseases, including Alzheimer's Disease and damage caused by a series of small strokes. 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 (version 2010) definition of dementia includes: "disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement" as features of dementia.

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 & VaD) 10%
- Dementia with Lewy bodies 4%
- Fronto Temporal Dementia (FTD) 2%
- Other Dementias 3%

(Alzheimer's Society, 2013a)

DRAFT

3. Demographics

Dementia is one of the most severe and devastating disorders we face. It is also very common (National Dementia Strategy, 2009). There are approximately 800,000 people with dementia in the United Kingdom & this figure is predicted to rise to over 1 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 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. The current number of people with dementia in minority ethnic groups is around 15,000 but this is set to rise sharply.

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

The Royal College of Psychiatrists (2005) reported around two thirds of medical beds in acute hospitals are occupied by people over the age of 65 years, and the prevalence of dementia is around 30%.

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 under-estimate, 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 people without a learning disability, but there are some important differences.

- People with a learning disability are at greater risk of developing dementia at a younger age.
- Research indicates that the overall percentage of adults with Down's syndrome who develop dementia is similar to that of the general population (Down's Syndrome Association, 2013).
- People with Down's 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)

DRAFT

4. The need for Speech & Language Therapy provision

Dementia causes:

- communication difficulty for the person with dementia
- communication difficulty for carers; and
- eating, drinking & swallowing difficulties

Speech & Language Therapists have the knowledge & skills to assess and manage these problems.

"Communication is impaired to some degree in all forms of dementia and by the end stages is virtually non-existent, there are different patterns of impairment & preserved abilities across the degenerative illness trajectories" Bourgeois (2010). Language impairment may be an initial presenting feature of the disease, particularly in Fronto-Temporal Dementia (FTD) variants: Primary Progressive Aphasia (PPA) & Semantic Dementia (SD).

Communication difficulty is one of the earliest presenting features for most people with dementia (Bourgeois 2010). This has been described as one of the most frequent and hardest to cope with experiences for family carers (Egan et al 2010). Knowing how to respond to changes in communication is very difficult. Carers report feeling exhausted by having to think more about what to say & how to say it. Carers suffering from depressive symptoms have also been found to use less positive communication themselves (Braun et al 2010). It is also 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.

Studies that look at the incidence of eating, drinking & swallowing difficulty in dementia show a high rate of dysphagia: 68% of those in a Home for the Aged (Steele et al 1997). Horner (1984) found that bronchopneumonia was the leading cause of death in Alzheimer's Disease; 28.6% in this study were found to be aspirating. Swallowing problems are also a concern in other types of dementia eg, vascular dementia (Stach 2000) and those conditions where neurological signs are present alongside cognitive impairment eg, Huntington's disease, progressive supranuclear palsy, Parkinson's disease and dementia with Lewy bodies (Logemann 1998).

DRAFT

5. 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 well- being encourages the belief that all people with dementia, at all stages, have something to communicate. More recently, emphasis has shifted from Person-Centred care to Relationship-Centred care (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 & language therapy, as an essential element of high quality care to support identity & social engagement.

James (2011) has argued 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 specialist services such as speech and language therapy if this agenda and philosophy is to be met locally.

DRAFT

6. The role of the Speech and Language Therapist

SLTs work in a variety of settings to contribute to the care of people with dementia, including: specialist memory services, older peoples community mental health teams, hospital wards, community SLT services, learning disability services, care homes, day care, and forensic services.

The core role encompasses the following:

Assessment to inform differential diagnosis

- In those who present with a prominent language disorder e.g, frontotemporal dementia, primary progressive aphasia and language presentation of Alzheimer's Disease.

- In those who present with prominent speech difficulties (dysarthria) e.g. cognitive difficulties associated with Parkinsons Disease, Dementia with Lewy Bodies, Vascular Dementia, Huntington's Disease, Motor Neurone Disease etc.

- Work with other professionals to ensure that the extent of the speech & 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 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

- 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 manner

Interventions for people with dementia and their carers

- Direct intervention with the person with dementia to provide specific programmes to maximise communication function e.g. personalised communication and memory strategies (including communication passports and life story work) etc.

- Work with formal and informal carers to implement personalised communication strategies

- Facilitate use of communication strategies in all environments, within the home & in the wider community

DRAFT

- Help family carers manage stress resulting from communication difficulties

- Group intervention to maximise retained communication skills & provide a supportive environment for socialisation e.g. Sonas groups, cognitive stimulation therapy, reminiscence etc.

- Contribute to post diagnostic services for people with dementia and their carers e.g. sessions on communication within information and support groups

- Incorporate the individual's specific communication requirements into the multi-disciplinary team care plan

- Ensure people with dementia have equal access to services promoting rehabilitation and enablement.

- Advocate for an individual with complex communication needs arising from their dementia

Assessment and management of eating, drinking and swallowing difficulties

- Identify the nature and severity of any eating, drinking and swallowing disorder and the impact this has on enjoyment of food and mealtimes.

- Assess the risk of aspiration and choking

- Contribute to an holistic assessment of mealtime difficulties e.g. mood, behaviour, the care environment, physical and sensory issues.

- Make 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.

- Contribute to future planning of eating and drinking needs including where tube feeding and end of life issues are under discussion
- Plan, review and monitor to prevent unnecessary admission to hospital.

- Ensure family carers 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

- Recognition and management of atypical dementias where the primary symptoms are with language and communication rather than memory e.g. nonfluent primary progressive aphasia and semantic dementia.

- Management of eating, drinking and swallowing difficulties in dementia.

- The role of SLT in dementia

DRAFT

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

Research and Development

SLTs are engaged in a variety of project to:

- Identify gaps in the evidence base
- Carry out research activities
- Promote best practice in service provision

DRAFT

7. The benefits of providing a speech and language therapy service

The SLT 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 & 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 decipher these different patterns of impairment. Detailed language assessment is particularly important in examining frontotemporal dementia and the progressive aphasias (Gorno-Tempini et al 2011, Snowden, 2003). SLTs are qualified to carry out such assessments and therefore have a crucial role to play when language symptoms are prominent eg, frontotemporal dementia, progressive aphasia, language presentations of Alzheimer's Disease and corticobasal degeneration.

  Examination of speech disturbance and dysarthria by the SLT may be important in conditions affecting motor and subcortical areas eg cognitive difficulties associated with Parkinsons disease, dementia with Lewy bodies, vascular dementia, Huntington's disease.

  SLTs have a key role in the recognition of different types of dementia (Snowden and Griffiths 2000) and make a vital contribution in a multi-disciplinary assessment to early diagnosis (Garrard and Hodges 1999). SLTs 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 & swallowing**

  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 undernutriton. Multidisciplinary team working is essential in managing people with oral feeding difficulties and a SLT is a key member of the team (Royal College of Physicians, 2010).

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

  There is a growing body of evidence to justify that intervention with people who have dementia and their carers improves communication. Please see Professor Pam Enderby's Literature Review available here:

  http://www.rcslt.org/about/docs/slcn_resource_manual

  Communication in Primary Progressive Aphasia can be maintained and enhanced by specific interventions (Carthery-Goulart et al 2013).

  Interventions may include the use of communication passports, alternative & augmentative communication, life story work, Talking Mats etc. (Bourgeois 2009; Murphy & Oliver 2013; Savitch & Stokes, 2011)

DRAFT

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

  How much and for how long a family member provides care is strongly correlated to the extent of the person's dementia, the carers experience of burden and depression and in particular their experience of challenging behaviours 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 therapy such as cognitive behaviour or reframing therapy (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). Research in this area has also identified significant effects on carer self–efficacy and carer quality of life.

  SLT's 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 the communication that occur between the carer and the person with dementia.

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

  Mealtime difficulties such as food refusals, difficulty eating certain foods 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 and improve nutritional intake (Biernacki and Barratt 2001).

- **Maintenance of an ongoing interpersonal relationship between the individual 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 SLT's are able to work with carers and people with dementia to help maintain their interpersonal relationships. When enabled with resources e.g. life story book and opportunities e.g. 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. Whilst dementia can reduce the potential for empathy, carers also report significant benefit from meeting with other carers and health professionals who understand their situation.

- **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. SLTs 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).

DRAFT

- **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 well being. SLTs 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. SLTs 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 multiprofessional problem solving and care planning**

  Inability to communicate effectively may be the cause of many challenging behaviours (James, 2011: Bryan and Maxim 2003). The RCSLT Dementia expert working group consider the work of the SLT to be most effective when the SLT is a permanent and specialist member of the multiprofessional team. As well as specific benefits for people with dementia, the whole team benefit 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 challenging behaviour from dysphagia. SLTs 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**

  SLTs are uniquely qualified to assess an individual's ability to understand & then communicate that understanding for the purposes of establishing mental capacity for decision making. SLTs 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 recommends seeking the professional opinion of an SLT.

- **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). SLTs have the specialist skills to facilitate optimal communication, maximising the individual's choice and degree of control. If required, a SLT 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 diet & fluids to people with dysphagia have the necessary understanding to follow the recommendations from a swallow assessment.

DRAFT

The Dysphagia Diet Food Texture Descriptors (2012) assist with standardising the terminology and are used when training catering staff & carers.

- **Specialist input to inform decision making around complex swallowing difficulties & 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 MDT. "SLTs 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 an SLT 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 SLT 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) state "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 dementia in effective communication to promote good care**

  As indicated in the Francis report of 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 & 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 SLT 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.

DRAFT

8. The risks of not providing a speech and language therapy service

Risks to individuals

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

  The loss of meaningful interaction and conversation places increased 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 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 present a particular challenge to memory services as the presence of complex language disorder impacts on the delivery & reliability of formal testing.

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

  People with dementia have complex needs and it is therefore vital that services are co-ordinated 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 that 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 that 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 & 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

DRAFT

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 has been shown to be effective (Jordan et al 2000) and the role of SLTs as trainers has been outlined (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 (Hudson 2000) and dehydration, and is a causal factor in repeated chest infections and choking risk. However, weight loss in dementia is not inevitable (Wang 1998). Oropharyngeal aspiration is an important etiological factor leading to pneumonia in the elderly. Pneumonia is a major cause of morbidity and mortality in the elderly 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 the elderly 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 current legislation such as the Adults with Incapacity Act (2000) (Scotland) and the Mental Capacity Act (2005) (England).

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**

  A study by Brodaty and Peters (1991) showed that training carers reduced unnecessary admission and was cost effective in avoiding respite and residential care costs. Direct SLT 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). SLTs can give advice re: reduction of clinical risks, maximising independence and improving well being 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.

- **Challenging behaviour not managed effectively**

  Goudie and Stokes (1989) first proposed that much challenging behaviour 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 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 challenging behaviour 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 that staff are alert to signs of abuse/neglect & 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) recommend 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 SLT services.

- **Perpetuation of the current postcode lottery re access to SLT services**

  A survey of old age psychiatry services (Challis et al 2002) indicated that many services are not fully multidisciplinary and that service variability continues to exist with many services not yet fully compliant with the standards in the *NSF for Older People (England*) (2001). There has not been a more recent assessment since Challis et al 2002.

  An Alzheimer's Society report on eating and drinking in dementia (2000) found that while a third of respondents were concerned about swallowing difficulties, few (8% carers and 40% care professionals) had obtained SLT advice. In addition, the survey by Ponte (2001) showed that 40% of NHS providers did not offer specialist SLT assessment and advice for communication problems in dementia.

  Therefore, there is current evidence of inequity of both access to, and provision of, speech and language therapy, communication and swallowing services (Ponte 2001).

- **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. When this information is recorded in the notes, less than half contained information about details which aid communication with the person".

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

9. Key Recommendations

- There should be equity of access to Speech & Language Therapy services. Commissioners and service providers, who are aware of the needs of their local population, should ensure there is access to Speech & Language Therapy services to meet those needs.

- Speech and language therapy services should provide equal access to intervention for communication and 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 SLT 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.

DRAFT

10. Further information

This document complements several other RCSLT publications, which are outlined below:

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

http://www.rcslt.org/about/docs/slcn_resource_manual

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 (2003)

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.

http://www.rcslt.org/docs/free-pub/position_paper_ald.pdf

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

DRAFT

11. References

Acton GJ, Mayhew PA, Hopkins BA and Yauk S. (1999) Communicating with individuals with dementia: the impaired person's perspective. Journal of Geriatric Nursing; 25: 6-13.

Adults with Incapacity Act (Scotland) (2000)
http://www.legislation.gov.uk/asp/2000/4/pdfs/asp_20000004_en.pdf

Allan K. (2001) Communication and consultation: exploring ways for staff to involve people with dementia in developing services. Bristol: Policy Press.

Alzheimer's Society UK (2000) Food for Thought. Alzheimer's Society UK.

Alzheimer's Society (2013a)
http://www.alzheimers.org.uk/infographic

Alzheimer's Society (2013b)
http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=164

Alzheimer's Society (2013c)
http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103

Alzheimer's Society (2013d) Building Dementia Friendly Communities: a priority for everyone
http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1916

Audit Commission. (2000) Forget me not - Mental Health Services for Older People. London: Audit Commission.

Azuma T and Bayles KA. (1997) Memory impairments underlying language difficulties in dementia. Topics in Language Disorders; 18, 58-64.

Barnes CJ. (2003) Chatter Matters. A presentation for Carers of People with Communication and Memory Difficulties. Published by the Author.

Barnett E. (2000) Involving the person with dementia in designing and delivering care: "I need to be me!" London: Jessica Kingsley.

Biernacki C and Barratt J (2001) Improving the nutritional status of people with dementia. British Journal of Nursing; 10, 1104-1114.

Bourgeois, MS. (1991) Communication treatment for adults with dementia. Journal of Speech and Hearing Research; 34, 831-844.

Bourgeois MS & Hickey EM (2009) Dementia: from diagnosis to management. A functional approach. New York: Taylor & Francis

Braun, M. et al, (2010). Toward a better understanding of psychological well-being in dementia caregivers: The link between marital communication and depression. Family Process, 49 (2), 185-203

Briggs K and Askham J. (1999) Needs of people with dementia and those who care for them – a review of the literature. London Alzheimer's Society.
Brodaty H and Peters KE. (1991) Cost effectiveness of a training programme for dementia carers. International Psychogeriatrics; 3, 11-23.

Bryan K and Maxim J. (2003) Managing language and communication difficulties in Alzheimer's dementia: the link to behaviour. In Adams and Manthorpe (eds) Dementia Care. London: Arnold.

Carthery-Goulart, M.T, da Costa da Silveira, A., Machado, T.H., Mansur, L.L., de Mattos Pimenta Parente, M.A., Hosogi Senaha, M.L., Dozzi Brucki, S.M. & Ricardo Nitrini (2013) Nonpharmacological interventions for cognitive impairments following primary progressive aphasia: A systematic review of the literature. Dementia & Neuropsychologia Vol 7:1 122-131

Challis D, Reilly S, Hughes J, Burns A, Gilchrist H and Wilson K. (2002) Policy, organisation and practice of specialist old age psychiatry in England. International Journal of Geriatric Psychiatry; 17, 1018-1026.

Clare L and Woods R (2001) Cognitive Rehabilitation in Dementia. A special issue of Neuropsychological Rehabilitation; 11 (vols 3 and 4) 193- 517.

Comas-Herrera A, Wittenberg R, Pickard L and Knapp M (2007). 'Cognitive impairment in older people: future demand for long-term care services and the associated costs'. International Journal of Geriatric Psychiatry, 22:10, 1037–45.

Department of Health England. (2001) National Service Framework for Older People. London: Stationery Office.

Department of Health (2009) Living Well with Dementia: A National Dementia Strategy. London, Department of Health.

Department of Health (2012) Prime Ministers Challenge on Dementia: Delivering major improvements in dementia care and research by 2015
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf

Department of Health (2013) Improving care for people with Dementia
https://www.gov.uk/government/policies/improving-care-for-people-with-dementia

Department for Health, Social Services & Public Safety. Improving Dementia Services in Northern Ireland: A Regional Strategy (2011)
http://www.dhsspsni.gov.uk/improving-dementia-services-in-northern-ireland-a-regional-strategy-november-2011.pdf

Downs Syndrome Association (2013)
http://www.downs-syndrome.org.uk/information/for-familiescarers/adults-18/ageing.html

Dysphagia Diet Food Texture Descriptors (2012)
http://www.bda.uk.com/publications/statements/NationalDescriptorsTextureModificationAdults.pdf

Egan, M., Berube, D., Racine, G., Leonard, C and Rochon, E. (2010).Methods to enhance verbal communication between individuals with Alzheimer's Disease and their formal and informal caregivers: A systematic review. International Journal of Alzheimer's Disease

Ekberg O, Hamdy S, Woisard V, Wuttge-Hannig A and Ortega P, (2002) Social and Psychological Burden of Dysphagia: Its Impact on Diagnosis and Treatment. Dysphagia; 7:2, 139-46.

El Sohl A, Brewer T, Okada M, Bashir O and Gough M. (2004) Indicators of Recurrent Hospitalisation for Pneumonia in the Elderly, Journal of the American Geriatrics Society; 52, 2010-2015.

DRAFT

GALLAGHER-THOMPSON, D. and COON, D.W., 2007, Evidence based psychological treatments for distress in family caregivers of older adults. Psychology and aging, 22, 37-51

Garrard P and Hodges JR. (1999) Semantic dementia: Implications for the neural basis of language and meaning. Aphasiology; 13, 609-623.

Gilleard CJ, Belford H, Gilleard E et al. (1984) Emotional distress among the supporters of the elderly mentally infirm. From Butler and Pitt (Eds) (1998) – Seminars in Old Age Psychiatry. British Journal of Psychiatry, 145, 172-177.

Gorno-Tempini ML, Hillis AE, Weintraub S, Kertesz A, Mendez M, Cappa SF, Ogar JM, Rohrer JD, Black S, Boeve BF, Manes F, Dronkers NF, Vandenberghe R, Rascovsky K, Patterson K, Miller BL, Knopman DS, Hodges JR, Mesulam MM, Grossman M. (2011) Classification of primary progressive aphasia and its variants. Neurology. Mar 15;76(11):1006-14

Gorska, S., Forsyth, K., Irvine, L., Maciver, D., Prior, S., Whitehead, J., Flockhart, J., Fairnie, J. and Reid, J. (2013) Service-related needs of older people with dementia: perspectives of service users & their unpaid carers. International Psychogeriatrics

Goudie F and Stokes G. (1989) 'Understanding Confusion' Nursing Times; 85:397 pp 35-37.

Hagberg B. (1997) The dementias in a psychodynamic perspective. In Miesen, and Jones (Eds) Care-giving in Dementia: Research and Applications. Vol 2. London: Routledge.

Horner J, Alberts MJ, Davison D, Cook GM. (1994) Swallowing in Alzheimer's disease. Alzheimer's Disease and Associated Disorders; 8:3, 177-189.

Hudson HM, Daubert CR & Mills RH (2000) The Interdependency of Protein-Energy Malnutrition, Aging and Dysphagia. Dysphagia 15; 31-38

James, I.A. (2011) Understanding Behaviour in Dementia That Challenges: A Guide to Assessment and Treatment
Bradford Dementia Group Good Practice Guides

Jordan L, Bell L, Bryan K, Maxim J and Axelrod L. (2000) Communicate: Evaluation of a training package for carers of older people with communication impairments. London: Middlesex University/UCL Publication.

Kitwood T. (1990) 'The Dialectics of Dementia: with particular reference to Alzheimer's Disease' Ageing & Society; 10, 177-96.

Kitwood T. (1997) Dementia Reconsidered. Buckingham: OUP.

Knapp M, Prince M, Albanese E et al (2007). Dementia UK: The full report. London: Alzheimer's Society.

Le Dorze G, Genereux MJS, Larfeuil C, Navennec C, Laporte D and Champagne C. (2000) The development of a procedure for the evaluation of communication occurring between residents in long-term care and their caregivers. Aphasiology; 14, 17-51.

Logemann J. (1998) Evaluation and Treatment of Swallowing Disorders, 2nd Edition, College Hill Press.

Lubinski R. (1995) Dementia and Communication. San Diego: Singular Publishing.

DRAFT

Marik PE and Kaplan D. (2003) Aspiration Pneumonia and Dysphagia in the Elderly, Chest; 124:1, 328-336.

Marin DB et al. (2000) The Caregiver Activity Survey (CAS) Longitudinal validation of an instrument that measures time spent caregiving for individual with Alzheimer's Disease. International Journal of Geriatric Psychiatry; 15, 680-686.

Matthews FE, Arthur A, Barnes LE, Bond J, Jagger C, Robinson L & Brayne C (2013) A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. Lancet

Maxim J, Bryan K, Axelrod L, Jordan L and Bell L. (2001) Speech and language therapists as trainers: Enabling care staff working with older people. International Journal of Language and Communication Disorders; 36, supplement, 194-199

Mental Capacity Act (2005)
http://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf

Mental Capacity Act 2005 Code of Practice (2007)
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/224660/Mental_Capacity_Act_code_of_practice.pdf

Murphy J & Oliver T (2013) The use of Talking Mats to support people with dementia and their carers to make decisions together. Health & Social Care in the Community 21(2) 171-180

National Assembly for Wales: National Dementia Vision for Wales (2011)
http://www.scotland.gov.uk/Resource/0042/00423472.pdf

National Institute for Health & Clinical Excellence (2006) Dementia: Supporting people with dementia and their carers in health & social care (Clinical Guideline 42)
London, NICE

National Institute for Health & Care Excellence (NICE) Dementia QS1
http://guidance.nice.org.uk/QS1

National Institute for Health & Care Excellence (NICE) Dementia QS30
http://guidance.nice.org.uk/QS30

Neary D, Snowden JS. (2003). Classification of the dementias. Textbook of Geriatric Medicine and Gerontology: 6th edition. Churchill Livingstone

Nolan, M., Davies, S., Brown, J., Keady, J. & Nolan, J. (2004)
Beyond person-centred care: a new vision for gerontological nursing. Journal of Clinical Nursing 13 (3a):45-53

Nolan M, Ingram P, Watson R. (2002) Working with family carers of people with dementia. Dementia; 1:1, 75-93.

O'Connor DW, Pollitt PA, Roth M et al. (1990) Problems reported by relatives in a community study of dementia. British Journal of Psychiatry; 156, 835-841.

Orange JB. and Ryan EB. (2000) Alzheimer's Disease and other dementias: implications for physician communication. Clinics in Geriatric Medicine; 16, 153-173.

Ponte, N. (2001) Under survey: the elderly RCSLT Bulletin; 588.

Powell J. (2000). Care to Communicate - Helping the Older Person with Dementia. London: Hawker Publications Ltd.

Powell JA. (2000) Communication interventions in dementia. Reviews in Clinical Gerontology; 10, 161-168.

Royal College of Physicians and British Society of Gastroenterology (2010) Oral feeding difficulties and dilemmas: A guide to practical care, particularly towards the end of life. London: Royal College of Physicians

Royal College of Psychiatrists (2005) Who Cares Wins
London: Royal College of Psychiatrists
http://www.rcpsych.ac.uk/pdf/whocareswins.pdf

Royal College of Psychiatrists & the British Psychological Society (2009) Dementia & People with Learning Disabilities: Guidance on the assessment, treatment & support of people with learning disabilities who develop dementia
http://www.rcpsych.ac.uk/files/pdfversion/cr155.pdf

Royal College of Psychiatrists (2011). Report of the National Audit of Dementia Care in General Hospitals. Editors: Young J, Hood C, Woolley R, Gandesha A and Souza R. London: Healthcare Quality Improvement Partnership. http://www.rcpsych.ac.uk/pdf/NATIONAL%20REPORT%20-%20Full%20Report%201201122.pdf

Royal College of Psychiatrists (2013). National Audit of Dementia care in general hospitals 2012-13: Second round audit report and update. Editors: Young J, Hood C, Gandesha A and Souza R. London: HQIP. http://www.rcpsych.ac.uk/pdf/NAD%20NATIONAL%20REPORT%202013.pdf

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

RCSLT (2013) Resource Manual for Commissioning and Planning Services for Speech, Language and Communication Needs
http://www.rcslt.org/about/docs/slcn_resource_manual

Sandwell Community Healthcare Services (2009) Primary care rapid response assessment of dysphagia in end of life care
www.evidence.nhs.uk/qualityandproductivity

Savitch N, Stokes V (2011) We can do IT too: Using computers as part of activity programs for people with dementia. Speechmark publishing.

SEARSON, R., HENDRY A.M., RAMACHANDRAN, R., BURNS, A. and PURANDARE, N., 2008, Activities enjoyed by patients with dementia together with their spouses and psychological morbidity in carers. Aging & Mental Health, 12, 276-82.

SELWOOD, A., JOHNSTON, K., LYKETSOS, C. and LIVINGSTON, G., 2007, Systematic Review of the Effect of Psychological Interventions on Family Caregivers of People with Dementia. J Affect Disord, 101,75-89

DRAFT

Siebens H. (1986) Correlates and consequences of eating dependency in institutionalised elderly. Journal of the American Geriatric Society; 34, 192-8.

Smith, H.A., Kindell J., Baldwin, R.C., Waterman, D. and Makin, A.J. (2009) Swallowing problems and dementia in acute hospital settings: practical guidance for the management of dysphagia. Clinical Medicine 2009, Vol 9, No 6: 544–8

Snowden JS. (2003). Disorders of language. Encyclopaedia of the Neurological Sciences

Snowden JS and Griffiths H. (2000) Semantic dementia: assessment and management. In Best, Bryan and Maxim. Semantic Processing: Theory and Practice. London: Whurr.

Stach CB. (2000) Vascular Dementia and Dysphagia, Topics in Stroke Rehabilitation; 7:3, 1-10.

Steele CM, Greenwood C, Ens I, Robertson C and Seidman-Carlson R. (1997) Mealtime Difficulties in a Home for Aged. Dysphagia; 12: 1, 43-50.

The Mid Staffordshire NHS Foundation Trust Public Inquiry (2013). Report of the Mid Staffordshire. NHS Foundation Trust public inquiry. Executive summary. Chaired by Robert Francis QC. London: The Stationery Office.

The Scottish Government: Scotland's National Dementia Strategy (2013) http://www.scotland.gov.uk/Resource/0042/00423472.pdf

THOMPSON, C.A., SPILSBURY, K., HALL, J., BIRKS, Y., BARNES, C. and ADAMSON, J., 2007, Systematic review of information and support interventions for caregivers of people with dementia. BMC Geriatrics, 7

VERNOOIJ-DASSEN, M., DRASKOVIC, I., MCCLEERY, J. and DOWNS, M., 2011, Cognitive reframing for carers of people with dementia (Review). Cochrane database of systematic reviews, 11, CD005318

Wang S, Fukagawa N, Hossain M and Ooi W. (1998) Longitudinal weight changes, length of survival and energy requirements of long term care residents with dementia. Journal of the American Geriatric Society; 45:10, 189-95.

World Health Organisation (2010) International Classification of Diseases and Health Related Problems, Geneva: WHO.

DRAFT