



Dementia Position Paper

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Executive summary

Dementia is a severe and devastating disease. There were around 944,000 people with dementia in the UK in 2022 and this number is predicted to rise to almost 1.6 million by 2040. There are real concerns about how service planners, commissioners and decision makers will meet this demand and how they will address the needs of the rapidly growing population with dementia.

People living with dementia are likely to experience speech, language and communication difficulties and / or eating, drinking and swallowing difficulties at some point in their disease journey. Speech and language therapists (SLTs) are uniquely trained to provide expert support to people living with dementia who experience these difficulties, as well as the caregivers (paid, unpaid and family caregivers) who support them.

There is currently an inequity in service provision for people living with dementia. There are consequently significant individual and organisational risks if access to specialist speech and language therapy services are not provided for people living with dementia and those who support them. Without SLT support, people living with dementia, with speech, language and communication or eating, drinking and swallowing difficulties, or both, are at an increased risk of:

- experiencing a delay in receiving an accurate and timely diagnosis
- experiencing a reduction in quality of life, well-being and quality of relationships
- experiencing increased difficulties in accessing other health and social care services and support
- becoming lonely and socially isolated, which increases the risk of cognitive decline and mortality
- being excluded from decision making and service planning
- avoidable death due to malnutrition and choking
- becoming dependent on others at an earlier stage
- experiencing unnecessary admissions and readmissions to hospital
- not having their physical, social and psychological needs met.

These, in turn, have an impact on the caregivers of the person with dementia. Social isolation, loneliness and negative mental and physical health outcomes have been identified as significant health risks in supporters of people living with dementia.

Involving SLTs throughout the course of dementia will reduce the above risks. The benefits of providing a SLT service for people living with dementia and their caregivers include:

- specific and specialised assessments to inform an accurate and timely diagnosis
- meeting their legal rights by supporting issues relating to decision making and mental capacity
- provision of specific interventions to maximise quality of life and live well for longer.

- supporting caregivers to care and maintain relationships and well-being throughout the timeline of the condition
- providing specialist input to inform complex decision making in relation to eating, drinking and swallowing
- supporting the person living with dementia to manage the everyday challenges they face with interactions in their community.

Following a review of research evidence, expert clinical experience, and feedback from Experts by Experience (people with lived experience of dementia) and key stakeholders, this position paper concludes that commissioners, decision makers and service providers should ensure there is easy access to adequately resourced speech and language therapy services for people living with dementia from the point of diagnosis to the end of life. Specialist SLTs should be integrated into all multidisciplinary teams on a permanent basis.

Background

Purpose of position paper

This position paper highlights the speech and language therapy provision that should be available to meet the needs of people living with dementia, their family members and caregivers. It also highlights the key role that SLTs have within the multidisciplinary team.

The position paper should be read by those seeking to develop a business plan for speech and language therapy for dementia, for clinicians working in the field, or students developing an understanding of the role of SLTs in dementia. This paper is also for managers and commissioners to understand the breadth and role of speech and language therapy in dementia.

This paper aims to offer guidance to SLTs and service managers to influence commissioning arrangements and it is hoped the paper will also be useful for other organisations committed to supporting the rights of people living with dementia.

This position paper is relevant to speech and language therapy services across the four nations, however, the context for delivering services in those clinical areas may vary between England, Scotland, Wales and Northern Ireland due to legislative, regulatory, national and local policy differences.

This position paper should be read in conjunction with other relevant guidance from RCSLT, including guidance on dysphagia, decision-making and mental capacity, delirium, learning difficulties, mouthcare, palliative care, eating and drinking with acknowledged risks and long-term care.

Terminology and dementia types

All types of dementia have a significant impact on speech, language and communication. Most people living with dementia develop eating, drinking and swallowing difficulties. Different dementias and cognitive profiles produce distinct communication deficits and needs, and dementia diseases also differ substantially in their impact on swallowing and in the timing of this. The SLT has an important role to play in targeting specific communication functions that are at risk in particular dementias, and tailoring interventions accordingly.

There is variability in terminology related to dementia. This paper uses the World Health Organisation's ICD-10 (WHO, 2010) definition of dementia. WHO describes dementia as: *"a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement"*. Dementia is progressive, which means the symptoms will gradually get worse. The speed of disease progression will depend on the individual person and the type of dementia they have.

There are over 100 different forms of dementia including Alzheimer's disease, Vascular dementia, Dementia with Lewy Bodies and Frontotemporal dementia. Some dementia types may present as language-led dementias, known as Primary Progressive Aphasia, and are associated with Alzheimer's disease and Frontotemporal dementia (Marshall et al., 2018.) There is a developing literature that highlights the significant language difficulties observed across dementia types (Suarez-Gonzalez et al., 2021). Irrefutably, all cognitive difficulties will impact communication and interaction.

Prevalence and incidence

Dementia is a severe disease that can be devastating. There were 944,000 people living with dementia in the UK in 2022 (Alzheimer's Research UK, 2022) and this number is predicted to rise to almost 1.6 million by 2040 (Care Policy and Evaluation Centre 2019). It is estimated that around 70,800 people are living in the UK with young onset dementia (diagnosed under the age of 65) (Alzheimer's Research UK, 2022). Alzheimer's disease is the most common form of dementia (Alzheimer's Society, 2021).

The estimated national cost of dementia in 2022, considering healthcare, social care and unpaid care, was £25 billion and this is estimated to rise to over £47 billion in 2050 (Alzheimer's Research UK, 2022).

More than 85% of people living with dementia experience eating, drinking and swallowing difficulties (Espinosa et al., 2020). Whilst there is little information available on the exact prevalence of speech, language and communication difficulties, the majority of people living with dementia will develop speech, language and communication difficulties as a result of the condition. Mesulam (2001) has previously estimated that up to 20% of people living with dementia have a language led dementia. UK data is much more conservative and indicates around 3,000 people living with Primary Progressive Aphasia related to frontotemporal dementia (Coyle-Gilchrist et al., 2016). There is also an important subgroup of people with Alzheimer's disease who may not strictly fulfil criteria for PPA but nevertheless have early and prominent word finding difficulty.

Speech, language and communication difficulties in dementia

Dementia causes speech, language and cognitive communication difficulties. This can impact on a person's ability to express themselves and understand what others say. Speech, language and communication difficulties are under-reported for people living with dementia, as it is often, incorrectly, thought that nothing can be done to improve communication for people living with dementia. Unmet speech, language and communication needs can result in stress and distress for the person, which may be conveyed through the person's interaction / behaviour, and those who care for them and can result in a care crisis (Alzheimers Scotland, 2018). Speech, language and communication difficulties are thus one of the biggest unmet needs for people living with dementia.

Speech, language and communication difficulties can impact on the person's ability to participate in activities such as conversation with family, understanding information in relation to a decision and expressing thoughts, feelings and needs (NICE, 2018). This can result in a loss of identity and role, low mood, increased vulnerability and social isolation.

Speech, language and communication difficulties have been described as amongst the most frequent and hardest to cope with experiences for family caregivers (Braun et al., 2010; NICE, 2018; Volkmer et al., 2023). These difficulties can become increasingly challenging as the disease progresses (Bourgeois, 2010), ultimately increasing the risk of premature institutionalisation, increased dependence and reducing quality of life.

Different types of dementia can result in different profiles of speech, language and communication difficulties. For example, the language-led dementias, Primary Progressive Aphasia, present with language as the leading symptom of the disease (Ruksenaite et al., 2021; Gorno-Tempini et al., 2011). Speech, language and communication difficulties may also be a prominent symptom in Lewy Body dementia and Parkinson's disease dementia (Ash et al., 2010; Lindeberg et al., 2022).

Consideration needs to be given to how dementia can be perceived by different cultures and what that might mean for the approach in terms of the person living with dementia and their caregivers (Alzheimer Europe and NHSE, 2023). Speech and language therapists should be aware of dementia-related language issues where English isn't a first language. Speech and language therapists should aim to reduce stigma in relation to dementia for the individual, as well as the wider community.

Eating, drinking and swallowing difficulties in dementia

Dementia can result in difficulties with eating, drinking and swallowing. Dementia can impact on the swallow mechanism and the person's cognitive ability to participate in eating and drinking. Different types of dementia can result in different profiles of eating, drinking and swallowing difficulty. For example, people with Progressive Supranuclear Palsy (Clark, 2020) and Lewy Body dementia (Payne et al., 2018) may experience early eating, drinking and swallowing symptoms. For people living with other dementias, this may be more significant in the later stages (Mira et al., 2022). Studies have found that 84-93% of people with moderate-severe Alzheimer's disease have eating, drinking and swallowing difficulties, as a result of cognitive and non-cognitive symptoms (Espinosa-Val et al., 2020; Mira et al., 2022).

Eating, drinking and swallowing difficulties can have a significant impact on the person's mental and physical health, increasing the risk of malnutrition and dehydration, aspiration and choking (Payne et al., 2018). All of these are associated with an increase in mortality risk (Manabe et al., 2017). Eating, drinking and swallowing difficulties also impact the person's ability to participate in social activities such as mealtimes (Faraday et al., 2019; Faraday et al., 2021; Collins, 2020). This can in turn have a negative impact on mood and well-being (Collins, 2020). Mental health, social identity, dignity, autonomy and cultural differences should all be considered when working with a person living with dementia who experiences eating, drinking and swallowing difficulties.

Speech and language therapy services

People living with dementia should have equal access to specialist speech and language therapy services to provide assessment of, and intervention to support, both speech, language and communication and eating, drinking and swallowing needs at every stage of their disease. At present some services are only commissioned to support eating, drinking and swallowing. Services should be equitable and not exclude support for speech, language and communication.

The role of the speech and language therapist in speech, language and communication

SLTs are involved in assessing people living with dementia to inform accurate and timely diagnosis. Additionally, SLTs provide long term support of speech, language and communication in dementia through delivery of interventions.

Working collaboratively with memory disorder clinics, or other diagnostic services, SLTs should be employed to deliver specialist assessment of speech, language and communication and contribute to accurate and timely differential diagnosis as part of the multidisciplinary team (NICE, 2018; Henry and Grasso, 2018). Person centred assessment (including case history, carer interview, informal and formal assessment) should be undertaken throughout the person's disease journey to identify areas of need and ensure the delivery of appropriate and relevant interventions (Gallee et al., 2023.) Where there is agreement from the person, diagnostic appointments should be undertaken collaboratively in joint sessions with other members of the multidisciplinary team.

People living with dementia, their families and caregivers will benefit from SLT interventions throughout the course of their dementia (Hardy et al., 2023). Interventions may aim to enable and maintain speech, language and communication skills (Cartherey-Goulart et al., 2013; Jokel et al., 2014; Cadario et al., 2017; Volkmer, Rogalski et al., 2020). Alternatively, interventions may aim to provide strategies to compensate for these symptoms (Volkmer and Rogalski et al. 2020) or work with people around the person to address speech, language and communication needs (NICE, 2018; Volkmer et al., 2022.) It is important to note that people living with dementia may have speech, language and communication difficulties early on and would benefit from support at this early stage.

SLT interventions reduce negative mental health consequences and promote independence and well-being (NICE, 2018.) Following joint goal setting, the SLT will collaborate with the person living with dementia, their families, caregivers and the wider MDT, to select evidence based, personally relevant interventions (NICE, 2018), and provide the necessary education and support for these interventions. Interventions may be delivered individually and / or in a group format.

The role of the speech and language therapist in eating, drinking and swallowing difficulties

Speech and language therapists use specialist skills to assess and support eating, drinking and swallowing difficulties and identify potential risks to inform a person-centred intervention plan (NICE, 2018).

Intervention plans will consider both the safety and dignity of people living with dementia and provide support to families and caregivers. Interventions may aim to reduce the physical health risks including malnutrition and dehydration, aspiration and choking, as well as maximising participation in social related activities around mealtimes, supporting quality of life and personal preferences. This may include recommendations for optimising eating, drinking and swallowing on a day-to-day basis, and provision of advice, training and education for formal and informal caregivers, including family members. Discussions around future planning, including discussions with and / or about the person around eating and drinking with acknowledged risk (RCSLT, 2021) may also be part of SLT intervention.

Decision making and Mental Capacity

A diagnosis of dementia does not equate with a person lacking decision making capacity. However, people living with dementia may have increasing difficulties participating in decision making as the disease progresses (Moye et al., 2007). On the functional test of decision making capacity (United Kingdom. Mental Capacity Act, 2005), people living with dementia are most likely to have difficulties in the domains of understanding and retaining information without specialist adaptation, and expressing a choice without support (Volkmer, 2016).

In line with RCSLT guidance, Mental Capacity Act legislation, Mental Capacity Act Code of Practice and NICE Guidance (2018), a SLT should be involved in supporting a person with dementia in: decision making; advanced care planning in relation to advance decisions to refuse treatment; advance statements; capacity assessments; and best interests decision making, if they need support with speech, language and communication. This may include advocating for people living with dementia, and working with Independent Mental Capacity Advocates or surrogate decision makers.

Settings and services

SLTs work in a variety of settings to contribute to the care of people living with dementia, including specialist memory services, specialist mental health inpatient settings, community mental health teams, hospital wards, outpatient and community services, learning disability services, care homes, day care, and forensic services. These services may be delivered in person or via telehealth. SLTs play a vital role in these interdisciplinary teams within inpatient, outpatient and community settings. These services may be delivered within public, independent or third sectors. Additionally, people may access SLT support through participation in research studies.

People living with dementia, their families and caregivers should be involved as service user representatives in the design and evaluation of services for people living with dementia and delivery of teaching about dementia. This should include representatives from marginalised communities.

Benefits of providing a speech and language therapy service

There are many benefits of providing a speech and language therapy service. SLTs support people living with dementia, their caregivers and the wider health and social care team in a variety of ways:

- Increased accuracy of differential diagnosis (Snowden and Griffiths, 2000; Henry and Grasso, 2018).
- Specialist assessment of speech, language and communication, and eating, drinking and swallowing in dementia (Volkmer et al., 2022; Gallee et al., 2023).
- Delivery of evidence-based management plans to maintain function within their environment, including supporting people living with dementia to remain in paid employment through specific speech, language and communication support that enables them to continue to function in their employment and / or receive appropriate benefits, e.g., Access to Work Grants, Personal Health Budgets and Personal Independence Payment.
- Reducing the risk of negative mental health consequences for the person living with dementia and their caregivers, such as depression and anxiety (Searson et al., 2008; Selwood et al., 2007; Gallagher-Thompson and Coon, 2007; Vernooij-Dassen, 2011; Thompson et al., 2007; Biernacki and Barratt, 2001).
- Maintenance of interpersonal relationship between the person living with dementia and caregivers (Bourgeois, 2010).
- Support to access right to decision making in line with MCA legislation (2005) and Code of Practice (2007) (Murphy and Oliver, 2013).
- Reducing risk of emergency medicine or mortality by addressing physical health risks associated with eating, drinking and swallowing difficulties including malnutrition, dehydration, aspiration and choking (Royal College of Physicians, 2010; Smith et al., 2009; Sandwell Community Healthcare Services, 2009).
- Ensuring people living with dementia have access to staff trained in how to support their speech, language and communication. (Francis report on the Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013).
- Reducing the use of antipsychotic medications (Dyer et al., 2018).

Risks of not providing a speech and language therapy service

There are risks of not providing a speech and language therapy service for people living with dementia.

Risks to individuals

- Delay in diagnosis and/or incorrect diagnosis which can delay access to support services and appropriate treatments (Volkmer et al., 2018, 2020, 2023).
- Preventable increased rate in progressive loss of functional communication skills resulting in increased level of dependence at an earlier stage and negative impact on relationships (Clare and Woods, 2001; Powell, 2000; Bourgeois, 1991; Azuma and Bayles, 1997; Acton et al., 1999; Maxim et al., 2001).
- Increased risk of depression, anxiety and negative mental health consequences for people living with dementia and their caregivers (Searson et al., 2008; Selwood et al., 2007; Gallagher-Thompson and Coon, 2007; Vernooij-Dassen, 2011; Thompson et al., 2007; Biernacki and Barratt, 2001).
- Deterioration in the quality of relationships for both the person living with dementia and their caregivers, ultimately leading to breakdown and increased risk of institutionalisation (Liu et al., 2021).
- Barriers to accessing and communicating with other professionals (Benbow and Lennon, 2000; Audit Commission, Forget Me Not, 2002; Briggs and Askham, 1999; Orange and Ryan, 2000).
- Social exclusion (The Alzheimer's Society, 2013; Suarez-Gonzalez et al., 2021).
- Avoidable death due to malnutrition, choking and aspiration (Mira et al 2022).
- Exclusion from decision making and service planning (Jayes et al. 2021).
- Risk of unmet needs due to difficulties in accessing health services resulting from speech, language and communication difficulties.

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 needs of people living with dementia, or because of incidents involving individuals or groups of patients as highlighted below.

- Unnecessary admission and readmission to hospital and residential / nursing care (Brodaty and Peters, 1991; Barnes, 2003; Sandwell Community Healthcare Services, 2009).
- Stress and distress not managed effectively (Goudie and Stokes, 1989).
- Needs of vulnerable adults not met (The Royal College of Psychiatrists, 2011).
- Perpetuation of inappropriate / harmful practice (The Royal College of Psychiatrists, 2013; Orange and Ryan, 2000).
- Reputational risk to individual organisations because of the above.

Areas for further research

There is, more broadly, a lack of evidence about both the needs of people living with dementia and their caregivers, and how SLTs can support them. The following research recommendations are not exhaustive and only provide initial areas for further work at the time of publication of this position paper:

1. A more in depth understanding of the perspective of people living with dementia and their caregivers about their speech, language and communication and eating, drinking and swallowing needs, at every stage of the disease journey is critical to the development of research in this field.
2. Coproduced interventions that address the maintenance of speech, language and communication should have a particular focus on participation and relationships.
3. A more in depth understanding of how we can best measure the benefits of intervention outcomes should focus on what is meaningful and significant to people living with dementia and their families to facilitate proactive rather than reactive interventions.
4. Exploration of how we best measure the economic benefit of speech and language therapy for people living with dementia and their caregivers.
5. Interventions that aim to maintain relationships, reduce loneliness and reduce the negative health consequences of speech, language and communication and eating, drinking and swallowing difficulties in dementia are a priority.
6. Understanding when and how much speech and language therapy interventions should be delivered to people living with dementia would be vital to informing future commissioning and development of care pathways.
7. There is a need for much more diversity in research representation, as well as clinical practice, as people living with dementia from non-British cultures / non-English-speaking backgrounds have unique speech, language and communication and eating, drinking and swallowing needs and are particularly vulnerable, ill served by current dementia services (including speech and language therapy) and under-represented in dementia research. SLTs have an important role to play in highlighting their specific needs and inequities and in helping bridge communication barriers to unlock other services. However, much more research is needed to understand barriers to access and assessment and to design appropriate interventions.
8. Auditory perceptual difficulties in dementia lead to difficulties in participating in conversations with multiple speakers and in noisy environment. It is important that

SLTs collaborate with audiology and ear, nose and throat professionals in dementia research.

9. There is a need for further research on the role of the SLT at the end of life and in palliative care of people living with dementia.
10. Research exploring the impact and implementation of RCSLT dementia guidance on speech and language therapy (commissioning, services and impact on people living with dementia and their family members) is vital to inform future refinements of the RCSLT guidance for SLTs.

Key recommendations

- All people living with dementia have the right to access speech and language therapy from the point of diagnosis to end of life.
- People living with dementia must have access to speech and language therapy services. Commissioners, decision makers and service providers, should analyse the needs of their local population, and ensure that 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 speech, language and communication and for eating, drinking and swallowing disorders.
- Given the developments in the field of dementia, training of SLTs on different dementia subtypes and the current research evidence on interventions in this field is essential at pre-registration as well for qualified speech and language therapists.
- Speech and language therapy services should be adequately resourced to provide quality care for people living with dementia by specialist speech and language therapists.
- Speech and language therapy services for people living with dementia should be provided within a multidisciplinary context to ensure care and goals of intervention are shared and consistent.
- Primary Progressive Aphasia (PPA) should be a core constituent of SLTs - with more involvement of SLTs in PPA research and education about PPA in speech and language therapy training programmes. SLTs should take a leading role in PPA research - particularly in the design of interventions - and to educate other professionals and lay stakeholders.
- Each service for people living with dementia should have an adequate level of dedicated speech and language therapy provision. Service level agreements with “cost per case” arrangements are not sufficient to provide a service of the quality and expertise that people living with dementia require.
- As well as providing direct, specialist input, SLTs should empower and educate members of the MDT to support speech, language and communication, and eating, drinking and swallowing in people living with dementia.

- SLTs working with people living with dementia should be employed to leadership roles where they can also participate in, or contribute to, lobbying or advocating for resourcing of services described in this document.
- Research must continue to be funded to further investigate the benefits of speech and language therapy for people living with dementia and their caregivers.

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The Royal College of Speech and Language Therapists (RCSLT) is the professional body for speech and language therapists in the UK. As well as providing leadership and setting professional standards, the RCSLT facilitates and promotes research into the field of speech and language therapy, promotes better education and training of speech and language therapists, and provides its members and the public with information about speech and language therapy.

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