Dementia – guidance

Introduction

The purpose of these pages is to outline the role of the speech and language therapist (SLT) when working with people living with dementia to highlight best practice, provide practical guidance and signpost to other resources. The information detailed in this guidance is not exhaustive and clinicians should continue to use their own evidence-based clinical judgement.

There are also some emerging areas of interest that are noted in this guidance, but the research is currently insufficient to inform practice at this time, for example specific outcome measures, progressive apraxia of speech, and the use of medication for people with primary progressive aphasia. These areas will be updated as and when sufficient evidence is available.

For information on the SLT role in supporting people living with dementia and value for commissioners, as well as information on prevalence and incidence of dementia and the benefits of speech and language therapy, refer to the **position paper.**

For general information about how SLTs can support people living with dementia, refer to the **public webpages.**

For general information about the different types of dementia, see the **Alzheimer's Society factsheets**.

For other RCSLT guidance relevant for SLTs working with people living with dementia, please visit our **resources page**.

The role of the SLT in dementia

The role of the SLT in supporting people living with dementia is varied and will continue to evolve over time. Some of the main roles of the SLT in dementia are:

Assessment and intervention

- Contribution to accurate and timely diagnosis of dementia and type of dementia.
- Specialist assessment and interventions relating to speech, language and communication.
- Specialist assessment and interventions relating to eating, drinking and swallowing difficulties (including mealtime difficulties).
- Maximisation of psychological wellbeing through promoting good communication principles, supporting eating, drinking and swallowing needs, and optimisation of the communication environment at all stages of dementia.
- Providing brain health advice as part of primary, secondary and tertiary prevention of dementia.
- Supporting people living with dementia who experience distress, as well as the care team around them, to reduce carer / placement breakdown.
- Development of resources that meet the accessible information standard and the **five good communication standards**.

Training and education

Providing training and education on speech, language and communication and eating, drinking and swallowing for:

- family / caregivers (paid and unpaid)
- healthcare professionals
- social care workforce
- voluntary / third sector organisations
- SLT students and colleagues
- awareness raising / public health information.

Advocacy and support

- Advocacy to enable people to remain independent in their community and promote social inclusion.

- Supporting Mental Capacity Act assessments.
- Supporting involvement in best interest meetings.
- Advance Care Planning / End of Life support.
- Community development and support with mental capacity evaluation.
- Direct e.g., working directly with the person with dementia, indirect e.g., working with their carers or family and consultancy, e.g., working with an organisation to improve access to services.
- Supporting decision making using inclusive communication.
- Supporting transitions from hospital to home / hospital to care home / home to care home.

Multidisciplinary working

- Collaborating with a multidisciplinary team to facilitate complex case discussion and planning and ensure a holistic approach to meeting the person’s needs and goals throughout the trajectory of their dementia diagnosis.
- Working with charities, primary and secondary care services to enable early access to SLT.
- Signposting to other agencies.

Research and development

- Identifying gaps in the evidence base.
- Conducting research activities.
- Implementing research findings into practice.
- Involvement in quality improvement initiatives.
- Development of appropriate care pathways.

SLTs may work with people living with dementia in a range of settings, including specialist memory services, community mental health teams, acute and community hospital inpatient wards, outpatient and community services, learning disability services, care homes, day care, forensic services, third sector, and training and education settings. Services may be provided in-person or via digital healthcare and telephone support services.

To read real-life examples of SLTs working in a variety of roles and settings, see our case study section later in this guidance.

A person-centred approach

The current policy agenda is clear that services must be designed around the needs and individual choices of people living with dementia and their families.

The philosophy of person-centred care was encompassed within the work of Kitwood (1997) and has been developed and expanded by a number of researchers and practitioners to include relationship-centred approaches. Person-centred care involves putting the person's needs, rights and personhood at the centre of their care (Paparella 2015) and treating people with respect and courtesy (Robinson et al. 2008). 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 and contribute.

Furthermore, dementia is increasingly being recognised as a condition which results in disability, and it is widely accepted that people with dementia should have the same rights to citizenship and social inclusion as anyone else (Bartlett 2014). This stance lends itself to considerations of relationship-centred care in dementia. Relationship-centred care is a framework that recognises the impact of relationship quality on healthcare outcomes and has been posited as an alternative to person-centred care (Soklaridis, S. *et al.* 2016a) However, as it places personhood as a central tenet (Beach and Inui 2006), for the purposes of this guidance, person-centred care is considered to encompass relationship-centred care and the term person-centred care will be used as an umbrella term.

In line with this, assessment and treatment of speech, language and communication and eating, drinking and swallowing should be individualised, should draw from the broad range of approaches available, and should take account of the preferences of the individual living with dementia and those who support them.

For further reading, please visit our **resources page**

General approaches for assessment and intervention

In this section, you will find an overview of ideas for supporting a person living with dementia who accesses SLT services. You will also find some real-life case scenarios of how SLTs work with people living with dementia.

Working with people with dementia is an important and developing field for SLTs and requires clinicians to take a bespoke approach to working with individuals and their families: "This is a complex area requiring the SLT to use a person-centred, dynamic and evolving approach to craft a bespoke intervention that meets the needs of the individual" (Volkmer et al. 2022, pg. 12).

It is also essential that SLTs work as part of the specialist multidisciplinary team when supporting people living with dementia with speech, language and communication and eating, drinking and swallowing difficulties.

Case history taking

It is important to take a detailed, holistic case history from the person themselves as well as family members and / or supporters where possible. With permission from the person, separate appointments should be offered to family members for them to be able to share relevant information without speaking about the person in their presence, which may be uncomfortable for both parties.

In particular, ask the person and family about onset of cognitive impairment. When did they notice, what did they notice first, what impact has it had on function? A detailed timeline is crucial for diagnosis – did they notice changes to speech and / or language first? Can they give any examples? It is also important to ask about communication strengths / ways in which the individual is already adapting their communication as these existing strategies can be built on in therapy sessions.

Gaining a sense of an individual's lifestyle and values is crucial to ensure that any intervention, for both communication and eating, drinking and swallowing, is person-centred and relevant to the individual. Consideration also 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**). SLTs need to be aware of dementia-related language issues where English is not a first language and should aim to reduce stigma in relation to dementia for the individual, as well as the wider community. The Enriched Model of dementia care is a framework that can be used to support the gathering of relevant information on which to base further assessment (if appropriate) and intervention (May et al. 2009.)

Assessment of speech, language and communication

Assessment of speech, language and communication may take place over multiple appointments and in one or more environments. Formal assessments should only be conducted where the outcome will influence diagnosis or provide information to be used for specific interventions. Clinicians should be cautious of 'over-testing' and should only carry out as much assessment as is required to inform their next steps.

It is important to carefully explain the purpose of the assessment and the possible outcomes to support the person to feel comfortable about the process and understand the purpose of it. The assessment experience should be person-centred, strengths-focused and aim to build a therapeutic relationship that values both the person and those who provide care.

Standardised assessments that may be useful for assessing people living with dementia include:

- Arizona Battery for Cognitive-Communication Disorders (ABCD-2)
- Assessment of Comprehension and Expression (ACE)
- Barnes Language Assessment
- Cognitive Linguistic Quick Test (CLQT+)
- Comprehensive Aphasia Test (CAT) **Complete the RCSLT how to formal assessment eLearning for CAT course**
- Psycholinguistic Assessments of Language Processing Abilities (PALPA)
- Functional Linguistic Communication Inventory (FLCI-2).

It is important to note that some of these assessments have not been standardised for people living with dementia.

Informal assessment may be used for those who cannot participate in formal assessment, or for whom formal assessment would be unhelpful, to identify their current level of functioning to inform care, contribute to goal formulation discussions and identify unmet needs. Informal assessments may include observations, use of therapist-designed resources and conversation. It may be helpful to observe the person communicating with family or carers and in environments in which they usually communicate, to gain a better understanding of how they communicate with people they know well.

For diagnostic assessments for language-led dementias (e.g., Primary Progressive Aphasia (PPA)), in-depth, standardised cognitive and / or language assessments may be helpful, with reference to diagnostic criteria for subtypes of PPA (Gorno-Tempini et al. 2011; Marshall et al. 2018). More details of subtypes can be found below.

As with all SLT assessments, regardless of diagnosis, it is important to consider cultural learning and language diversity during the assessment process and how these are impacted throughout the trajectory of the condition. See RCSLT **Bilingualism guidance**.

Primary Progressive Aphasia

People with Primary Progressive Aphasia (PPA), or language-led dementia, are increasingly being referred to speech and language therapy services. These dementias are associated with two primary underlying pathologies – Alzheimer's disease pathology and Frontotemporal dementia (FTD) pathologies. FTD is an umbrella term for a diverse range of syndromes associated with a TDP-43 or Tau protein pathology (Marshall et al,, 2018; Ruksenaite et al,, 2021). The exact prevalence of FTD and related syndromes is not well understood but based on a study undertaken by Coyle-Gilchrist et al (2016) it is estimated that around 11/100,000 people in the UK have a diagnosis of FTD of a related syndrome.

FTD subtypes include:

- Behavioural variant FTD (bvFTD)
- Primary Progressive Aphasia (PPA)
- Progressive Supranuclear Palsy (PSP)
- Corticobasal Degeneration (CBD), also referred to as Corticobasal Syndrome (CBS).

PPA is considered a rare phenotype within dementia, with conservative estimates suggesting around 3,000 people in the UK are living with the disease (NB: these estimates exclude PPA's associated with Alzheimer's disease; Coyle-Gilchrist et al, 2016).

There are three internationally recognised PPA variants, listed below with some of their typical symptoms:

- Semantic (svPPA)
    - associated with Frontotemporal dementia
    - difficulties using and understanding words, particularly nouns, as well as objects.
- Logopenic (lvPPA)
    - associated with an underlying Alzheimer's disease pathology
    - difficulties in word retrieval and verbal memory, leading to hesitation, speech sound errors and difficulties processing longer sentences
- Non-fluent (nfvPPA)
    - associated with Frontotemporal dementia

  - experience effortful, halting speech (apraxia) and / or difficulties understanding and using grammar

Though all types of dementia can have a significant impact on speech, language and communication, SLTs' involvement is particularly relevant in PPA due to its targeted and early impact on these systems. However, there is a developing literature that highlights the significant language difficulties observed across other dementia types (Suarez-Gonzalez et al. 2021). This review indicates that despite being an extreme phenotype, people with other dementia types will often present with language profiles similar to those seen within PPA, for example people with bv FTD often present with a profile not dissimilar to that observed in nfvPPA and svPPA, whilst people with Alzheimer's disease or Posterior Cortical Atrophy (PCA) can often present with difficulties similar to those observed in lvPPA (Suarez-Gonzalez et al. 2021). There is also some evidence that highlights a link between PPA and Motor Neurone Disease, with further research in this area needed (Aiello et al., 2022).

The role of the SLT in FTD / PPA is as with any other diagnosis of dementia described in the role of the SLT in dementia section of this guidance.

For further reading, please visit our resources page and also the RCSLT clinical guidance on **progressive neurological disorders**.

Assessment of eating, drinking and swallowing

Where possible, eating, drinking and swallowing assessments should take place in a familiar environment to the person living with dementia and should include observation of a mealtime. The unfamiliar environment of a hospital or outpatient clinical setting can be particularly distressing for individuals with dementia and can have a detrimental impact on bedside swallow assessments. Involving family members / carers in assessments can help to alleviate some of this distress and is therefore always worth considering when assessing an individual with dementia in a hospital setting. The SLT should be aware of the impact their presence can have during an eating, drinking and swallowing assessment and take steps to reduce this, based on the needs of the individual.

The dementia process can result in a person experiencing both cognitive and non-cognitive changes in relation to eating, drinking and swallowing, which should be considered when assessing eating, drinking and swallowing.

Cognitive changes include the impact of:

- memory difficulties, e.g., not remembering when they last had something to eat or drink
- attention difficulties, e.g., struggling to stay focused on eating for a whole meal
- communication, e.g., finding it difficult to communicate preferences regarding eating and drinking
- perception, e.g., recognising food or drink, or associated equipment such as cutlery
- oral praxis, which impacts the ability to chew food
- executive functioning, e.g., being able to balance risks associated with eating and drinking difficulties and the impact of being impulsive, which may result in eating very quickly or putting too much food in the mouth.

Non-cognitive considerations would include:

- psychosis, which may result in abnormal eating patterns. The use of anti-psychotics may also result in compulsive eating behaviours (Stogios et al., 2020)
- mood disturbances, e.g., depression, which may supress a person’s appetite
- altered sleep patterns and associated fatigue, which may make it difficult for a person to attend to eating and drinking
- presence of any distress, which may result in a decrease in intake of food and drink or reluctance to accept support from others, if they are the cause of the distress.

The presence of cognitive, non-cognitive and sensory changes (see dementia and sensory changes section) can result in responses such as spitting out food or drink or the person holding food or drink in their mouth. These responses may also be impacted by psychotropic medication, therefore it is important to review medication as part of the assessment to identify any that may impact eating, drinking and swallowing. The SLT should be aware how medications may impact the eating, drinking and swallowing process and discuss this impact with the person with dementia and other relevant professions, i.e., pharmacist, consultant and GP. The SLT should also ensure that the person with dementia is able to effectively swallow their medication to achieve maximum therapeutic effect. If the person is unable to swallow medication, then the SLT should discuss this with the individual, carers, pharmacist, GP and consultant to establish a medication administration plan.

As with all cases of eating, drinking and swallowing difficulties, further assessment using instrumental measures (e.g., video-fluoroscopy / Fibreoptic Endoscopic Evaluation of Swallow) should be considered if these would make a difference to the recommendations made. Where these methods would be useful, a person should not be excluded from access because they have a diagnosis of dementia. The referring SLT should work with the person with dementia to provide as much orientation to the assessment and clinical setting as possible prior to the instrumental assessment. It is also good practice for the referring SLT to be present during the instrumental assessment to help inform those carrying out the assessment on possible interventions, to give advice on the persons abilities during the assessment as compared to within a familiar environment, to reassure the person and to provide feedback following the results in a way that is accessible to the individual.

SLTs may be involved in supporting multi-disciplinary decision making around non-oral nutrition and hydration. The option of non-oral nutrition and hydration should not be discounted purely on the basis of a person having a diagnosis of dementia. However, the physical and psychosocial impact of non-oral feeding, as well as the person's prognosis, should be taken into account when making decisions about oral versus non-oral feeding. There is insufficient evidence to support the use of enteral feeding for people with advanced dementia (Sampson et al. 2009) and with mild/moderate dementia (Ticinesi et al. 2016). However, there is some clinical support for the use of non-oral feeding in some individuals with less advanced dementia (Regnard et al. 2010) therefore a person-centred approach should be taken when facilitating decisions about non-oral feeding.

In the event of a decision being made that non-oral feeding is not appropriate for an individual, either due to their own personal preference or following multidisciplinary and family / caregiver discussions, SLTs can provide assessment, advice and ongoing support to facilitate continued oral intake of food and fluids. Please refer to the **RCSLT eating and drinking with acknowledged risk guidance** for further information. Close liaison with dietetic colleagues is important in these cases.

Dementia and sensory changes

The senses are often affected as people get older, and this can reduce the ability to compensate for cognitive changes, or even contribute to cognitive decline. It is well known that optimising hearing and eyesight with appropriate aids and spectacles improves cognitive functioning.

It is important to remember that it is not only the ability to hear, see, smell, taste and feel that may change in dementia. The physical senses may still be functioning, but proprioceptive receptors and the ability to process and interpret the sensory messages coming from your ears, eyes, nose, mouth and touch may be impaired.

Sensory overload and processing time

People with dementia report being overwhelmed by noise, movement, temperature or touch sensations and visual impressions. The threshold of sound and light and other sensory input needed may be much narrower than for a person without dementia. In other words, when the sound is loud enough and the light bright enough, it doesn't take much of an increase for it to be too loud or too bright.

A person with dementia may need additional time to process a sensory signal. By the time the person has realised that someone is speaking to them, the message may be redundant. Allowing significant pauses for processing may make all the difference.

Dealing with multiple sensory impressions at the same time may also be very challenging. For example, background music in an instruction video may make the instructions impossible to understand.

Walking up to someone with a verbal greeting and handshake may also be onerous for a person living with dementia as this challenges three senses at once. Taking vision, hearing and touch in turn may allow the person to work out what is happening without getting alarmed. This would involve making eye contact, then waiting before speaking and waiting again before approaching.

Hearing

Changes in auditory brain function are common in dementia and produce hearing and communication limitations beyond those imposed by peripheral deafness. These limitations do not respond to standard hearing aids, which rely on sound amplification, and need more bespoke hearing and communication interventions. However, all people with dementia and communication problems should have their peripheral hearing assessed and should wear hearing aids as prescribed, to ensure the signal received from the ears is optimal, as this will reduce processing load on the brain.

The kinds of ‘brain hearing’ problems experienced by people with dementia vary with the particular dementia diagnosis and are particularly common in people with Alzheimer’s disease and PPA. Problems may include:

- increased sensitivity to sound, and subsequent avoidance of noisy environments
- difficulty following conversations when more than one person is speaking or in noisy environments
- difficulty following speech over the phone
- difficulty recognising voices and everyday environmental noises, such as the sound of a doorbell.

There is growing evidence linking hearing loss to dementia, with some researchers suggesting that hearing loss is a top risk factor for dementia (Livingston et al. 2020; Heywood et al. 2017). The reasons for this continue to be explored, with some studies currently underway, e.g., the **ACHIEVE study**, which is looking at the effect of hearing intervention on brain health in older adults.

When a person can hear but not understand speech, it is important to check whether they can understand language presented in another medium.

Vision

With or without changes such as macular degeneration, cataract or glaucoma, spatial awareness, recognising faces or objects, seeing steps and understanding shadows can all be difficult; patterns on tablecloths or carpets can look like objects, reflections can be alarming and dark patches on the floor can look like holes. Food may also look unrecognisable and unappetising, resulting in reduced oral intake.

Reading can be affected by language difficulties but also by visual processing. Shiny paper can have reflections which disrupt the image, and text on a varied background such as a picture makes both the picture and the script difficult to interpret. It helps if writing is in a dark colour on a pale background. Type should be in a non-serif font and at least 12-point.

Bold colour contrasts help object recognition, so does even lighting which does not cast deep shadows.

Posterior cortical atrophy is a rare type of dementia which affects the visual cortex, leading to impairments in visual processing. Visual perceptual changes may also be present in Alzheimer's Disease, Parkinson's Disease, Lewy Body dementia and Vascular dementia from an early stage, but are more common later on in the disease progression (Collerton et al., 2012).

People with sight loss or other visual difficulties may also experience hallucinations, and sometimes the brain will substitute images for the parts of the picture that are missing (eg Charles Bonnet syndrome, which can occur with or without dementia).

Smell and taste

Studies show that sweet taste receptors tend to deteriorate faster than bitter receptors, which affects the perception of sweetness, and this may happen faster in dementia. Food may need to be adjusted to compensate for this, for example by adding honey to vegetables to make them taste sweeter. Perception of salty flavours is also reduced (Suteepichetpun et al., 2022).

Preferences may change, along with the ability to recognise smells or flavours. This can lead to confusion where a person may believe that a drink has been modified or even poisoned. A strong taste may seem milder, or a mild taste overpowering.

Touch, temperature and proprioception

People report losing the ability to distinguish between hot and cold, which affects eating and drinking as well as many other activities. They may also lose the ability to recognise physical sensations such as hunger or thirst, which might be experienced as discomfort without the cause being understood. This can have a big impact on appetite and well-being, especially if combined with other sensory changes.

In addition to visual appreciation of space, balance and awareness of where the body is in space can be affected. This may result in all sorts of difficulties, for example conveying food or drink to the mouth. Knowing what the lips and tongue are doing, and what is happening to the food in the mouth, whether it is full and when it is time to swallow may also be difficult.

Implications for speech and language therapy

Most of these changes have the potential to cause distress and to affect communication and eating and drinking. Sensory processing difficulties can be hard to identify, and the possibility of unrecognised changes should always be kept in mind. Tailored ways of providing information and advice need to be explored to ensure accessibility for people with sensory changes.

Sensory changes can also affect cognitive testing, so it is important to take this into account.

Interventions for speech, language and communication

See the **public guidance webpages** on this site for general strategies that might be useful for supporting communication.

Interventions for speech, language and communication will be based on establishing realistic goals. This should be a collaborative process and may involve looking at various environments and partnerships or groups in which the person communicates. This includes working with other members of the multidisciplinary team, including contributing to formulation meetings and supporting psychosocial approaches to help reduce medication use and improve well-being (Ballard et al, 2020).

Managing expectations is part of therapy and needs to be sensitive to the emotional impact of the illness and the difficulty of changing long established habits. Adjusting to new ways of interacting can be challenging and often the burden of this falls to communication partners.

The type of intervention depends on the objectives identified and may involve one or more of the following approaches. Bear in mind that impairment-based therapy can be of value for specific functional aims, such as making a bus journey or ordering in a cafe, but other strategies are likely to have more general and long-term impact.

Brain health and dementia prevention

The NHS Five Year Forward review in October 2014 recognised the need for dementia prevention. Livingston et al (2020) found 9 risk factors for dementia; one which is ‘infrequent social contact.’ SLTs are in a strong position to provide intervention on this. It is already well within our regular business to link people at risk of decreased social opportunity in with their communities, particularly using the expertise of local third sector organisations.

The systematic review by Valenzuela et al (2006) found a 46% lower risk of dementia in those with high levels of mental activity than those with low mental activity. Cognitive Stimulation, including reading and language-based activities is one way to achieve this. Again, SLTs are often best place to advise on this: we can advise on appropriate activities to suit the individuals’ strengths.

Compensatory approaches

SLTs work with people living with dementia to identify appropriate Augmentative and Alternative Communication (AAC), considering the person’s cognitive needs and personal communication goals.

AAC may include: talking Mats; life story books; communication books; communication charts; communication passports; and text or symbol to speech apps.

Impairment-based approaches

Examples of impairment-based approaches include: word or lexical retrieval therapy, semantic feature analysis, script training or spaced retrieval training, and Cognitive Stimulation Therapy. An errorless learning approach should be considered.

Education, training and empowering others

Education and training can take place in a range of settings and with a range of people to meet the communication needs of the individual and to promote social inclusion. Types of education and training can include:

- communication partner training
- one to one and / or group intervention, tailored to meet the needs of the individual(s). Interventions may provide opportunities for problem solving and practicing strategies, as well as providing moral support
- the demonstration of adaptive interaction techniques to promote social interaction and wellbeing for people who do not have the ability to use speech.

Provision of individualised communication advice may also be shared via documentation, such as clinical notes, leaflets, care plans or reports, with relevant professionals and family members to promote the person’s independence and quality of life.

Interventions for eating, drinking and swallowing

See our **public guidance webpages** on this topic for general strategies that might be useful for eating and drinking.

People living with dementia should be involved in decisions relating to eating, drinking and swallowing, including what they would like to eat and drink and in what environment. Individual preferences should be the starting point for developing an intervention plan, in line with a person-centred approach to care. This should also include using equipment and utensils that are familiar to the person and knowing about an individual's previous eating habits and history.

People living with dementia may benefit from environmental adaptations to facilitate their eating and drinking. Such adaptations include reducing unhelpful distractions, ensuring the person has sensory aids and appropriate cutlery, allowing sufficient time for meals and providing a socially inclusive environment. Underlying factors that may be impacting on a person's ability to eat and drink should also be addressed e.g., a sore mouth, dentition, acute illness or low mood.

Compensatory strategies

A variety of strategies can be used to reduce the impact of eating, drinking and swallowing difficulties, some examples include:

- providing modified assistance to support with access to eating and drinking e.g., hand over/under hand assistance, being supported one to one by family, carers or a familiar person
- strategies which assist with pacing or bolus size during eating and drinking
- considering how food or drink is presented, what support or prompting is required from mealtime partner/carer, and utensils used during eating or drinking
- signposting the person or family members to dental / oral care specialists to support good mouth care.

Food and drink texture modification may be considered for some individuals (e.g., to increase comfort and quality of life, and reduce distress) however, physical and mental health, and quality of life should always be carefully considered and discussed with the person living with dementia and families / carers when considering texture modification. Texture modification of diet can impact on visual recognition of the food item, oral sensory recognition of the item and the ability of the person to feed themselves. It is also noted that within this population, there is limited evidence to support the use of thickened fluids to reduce the risk of aspiration pneumonia. The use of thickened fluids for people with dementia should be person centred and there should be a discussion with the person and their carers as to the potential benefits and potential risks (see **RCSLT position statement on thickened liquids**).

Choosing strong flavours of food and drink can help to stimulate taste and encourage chewing and swallowing, as well as increase enjoyment of eating and drinking. Access to food smells before mealtimes can increase appetite and engagement during mealtimes.

Education, training and empowering others

SLTs should provide general education and training to family, caregivers and members of the multidisciplinary team in relation to eating, drinking and swallowing difficulties and the ways this can impact on a person living with dementia. Training may take place in a range of settings and with a range of people to meet the needs of the individual.

It is important to communicate any individualised eating, drinking and swallowing advice through documentation (this could be through clinical notes, care plans or reports) to relevant professionals and family members to ensure that the individuals' needs and preferences are supported.

A clear eating, drinking and swallowing care plan should be shared for any individual admitted to a hospital, care or to a secure setting.

See **RCSLT EDS competency framework** which describes levels of competency for non-SLTs and is supported by the **eLearning for health dysphagia** course.

End of life and palliative care considerations

SLTs can support people with dementia whose eating, drinking and swallowing is impacted at the end of their lives or during palliative care by considering:

- taste for pleasure
- mouth care with the person's favourite flavour
- cultural factors, linking with patients' cultural and religious preferences for end of life oral comfort
- advance care planning – supporting people to complete this and / or ensuring you know the plans when supporting end of life care.

SLTs supporting people living with dementia who experience eating, drinking and swallowing difficulties should work with the multidisciplinary team to develop appropriate intervention plans.

SLTs should work particularly closely with dietitians.

See RCSLT **end of life care guidance** and visit our **resources page** for further reading.

Dementia and learning disability

People with a learning disability are living longer and therefore are more likely to develop illness related to older age. There have also been studies which have found increased prevalence of dementia in people with a learning disability. 22% of people with a learning disability over the age of 65 will develop a dementia (Kerr, 2007), compared to around 9% of the general population (Luengo-Fernandez and Landeiro, in preparation). For people with Down Syndrome this prevalence increases further, to around 66% of people with Down Syndrome over the age of 60 developing dementia (Alzheimer's Society, 2022).

Families and carers, as well as healthcare professionals (including speech and language therapists) involved in supporting people with learning disabilities, may be able to identify early signs of dementia by observing changes in the person's independence during activities of daily living, their communication, behaviour and personality, and cognition (Alzheimer's Society, 2022).

We must not assume that every change a person experiences as they get older is because of a dementia, however, assessment should focus on baseline functions and what the person used to be able to do that has changed now. People who have known the person a long time can usually help with this assessment as well as the person themselves. We should pay attention to non-verbal communication signs if someone is unable to verbally communicate the changes to us. As with patients without a diagnosis of a learning disability, physical and mental health factors should be ruled out before dementia assessments, including urinary tract infections and depression.

Diagnosing dementia in people with a learning disability can be complicated, particularly if the person has always had short term memory problems, poor concentration or difficulties with activities of daily living. This is why specialist assessment should focus on baseline information and what the changes are now e.g., someone could not recall names very well of friends and external family, now they cannot recall names of immediate family. The **Dementia Questionnaire for people with Learning Disabilities** (DLD) can be a useful tool in assessment.

Supporting the person with the learning disability and dementia should follow similar guidelines to supporting a person with a dementia without a learning disability. Speech and language therapists play a key role in supporting individuals' communication and ensuring those involved in the person's care are aware of their speech, language and communication needs and are trained in using strategies that are helpful. Interventions such as life story work may be beneficial, along with education for the person and their caregivers and support to promote independence and maintain routines. Speech & Language Therapists also have an integral role in supporting individuals making decisions (including during mental capacity assessments), ensuring their speech, language and communication needs are met (NICE Guideline [NG54] 2016).

SLTs should work with any colleagues in learning disability services that know the patient. In particular, joint working between mental health, community and specialist learning disability SLTs is beneficial for the patient.

Decision making and mental capacity

For more in-depth information and guidance about the role of the speech and language therapist in relation to decision-making and mental capacity, see RCSLT **supported decision making and mental capacity** guidance.

Should there be evidence that a person with dementia may lack capacity to make a decision, then the relevant legislation must be consulted to ensure an appropriate assessment is undertaken. The **Mental Capacity Act (2005)** and accompanying **Code of Practice** (2007; updated 2023) is the legislation that outlines how professionals should support people who may lack decision making capacity across England and Wales. The **Adults with Incapacity (Scotland) Act 2000** and the **Mental Capacity Act (Northern Ireland) 2016** apply to the Scottish and Northern Irish legislative regions.

More importantly perhaps for people with dementia is the provision that is made within this legislation around planning for future decision-making. Whilst people with dementia are often able to participate in decision-making in the early stages of the disease, this declines as the condition progresses (Dening et al, 2017). People with dementia should be supported to make plans such as donating power of attorney for health and welfare, finances and exploring advance decision making.

The NICE guidelines on Decision-making and Mental Capacity recommend that people should be provided with an accessible document that records their wishes, beliefs and preference in relation to advance care planning and which they may take with them to show different services (such as a personal communication book). Speech and language therapists are ideally placed to support people with dementia to explore advance care planning to ensure people with dementia are able to maintain a voice in their future care. Visual aids, such as Talking Mats, may be useful to support these conversations (Murphy and Oliver, 2013).

Measuring outcomes

Guidance on measuring outcomes can be found on the RCSLT website.

It is important to involve people living with dementia, and those who provide care and support, in goal setting and monitoring of progress. As dementia is a progressive condition, often goals may be aimed at maintenance of skills rather than improvements. When considering the goals of therapy, it can be useful to refer to local and national care standards and indicators, e.g. **Promoting Excellence in Dementia Care** (The Scottish Government, 2021).

There is no one standardised tool for measuring the outcomes of SLT input for people living with dementia and the above guidance can be used to help SLTs to select the most appropriate outcome measurement tool(s). Some of the tools and approaches that may be useful for measuring outcomes for people living with dementia include:

- therapy outcome measures
- goal attainment scaling
- patient reported outcome measures, e.g., aphasia impact questionnaire
- observer reported measures e.g., dementia care mapping
- clinician reported measures e.g., Progressive Aphasia Severity Scale
- patient and / or family / carer experience feedback
- patient stories.

Examples of SLT roles

These case studies have been provided as examples of SLT roles in working with people living with dementia in different settings. All case studies have been anonymised to protect the identities of the people involved.

SLT role examples

Young onset dementia service

My post is funded by mental health services for older people. My role includes working with older people with more complex mental health needs who may have a diagnosis of dementia, and I am the lead SLT within the local Young Onset Dementia (YOD) multidisciplinary service. YOD is a form of dementia that occurs in people under the age of 65. I work with colleagues to support individuals and families in the community, with communication and swallowing needs. I lead a small team and am involved in SLT and MDT wide service development projects.

More specifically my role involves working closely with families to enable them to come to terms with a diagnosis and enable them to find strategies that help with communication and/or eating, drinking, and swallowing. This often includes communication partner training, as well as implementing evidence based and co-produced language therapy e.g., lexical retrieval therapy or script training. I explore AAC options, and support and empower individuals e.g., when jointly undertaking mental capacity assessments. I encourage and enable service users to keep mentally and physically active, and socially included through local group projects.

I also support individuals with more advanced dementia who develop dysphagia, and lead on discussions with families around complex eating, drinking and swallowing decisions and supporting advance care planning and palliative care.

Clinical academic

I had worked as a speech and language therapist with adults with stroke and progressive neurological conditions for several years. I was noticing more and more people being referred to my outpatient and community caseloads who had diagnoses of dementia and who wanted advice on how to support their communication.

When I explored the research evidence, I found very little on language interventions. Those articles that I did find were mostly focused on word practice. I trialled this with several clients, and whilst many people were interested in some word practice, they found it difficult to generalise this into sentences and daily conversations. Additionally, families expressed interest in what they should be doing.

Aside from this, my manager told me it was difficult to appeal for funding for speech and language therapy due to the lack of evidence in this field. This inspired me to start thinking about a clinical academic career and whether I could contribute to the research evidence to improve the care for people with dementia and support the funding of speech and language therapy services in this area in the future.

I contacted my old university lecturers, where I had studied speech and language therapy. I met with a previous lecturer and discussed my ideas. They explained to me how to apply for funding and what my options were. I also spoke to my line manager during my appraisal, to highlight my interest in this field.

Consequently, I applied for funding to undertake a Master of Research, with support from my line manager. The people with dementia and families with whom I worked were extremely enthusiastic about my work and championed my ideas. They were keen to be involved and encouraged me to continue applying for more funding after my Masters. This opened a whole new career path. I continued with my research work 3 days a week, whilst maintaining a clinical contract 2 days a week. Over several years, I was able to become involved in policy development and advocate for funding of clinical services for people with dementia, as well as developing research ideas around communication interventions. For further information on clinical academics please see the **RCSLT research carers pages**.

Learning Disability service

Part of my role includes the diagnosis of dementia in people with a learning disability (LD). For this to be accurate I work closely with colleagues in LD services. Typically, a nurse or carer who knows the person well will conduct a dementia screen, answering questions about the persons abilities and activities of daily living to help me retrieve baseline information. This also includes information about their communication ability.

After 6 months, I will endeavour to complete the same screen (with input from people who know the person best) to ascertain whether there are any changes, in particular any decline, in function. I assist people to access brain scans as would typically be offered in memory assessment services; I advocate for reasonable adjustments to be made so the person with LD can access an open MRI scanner if they are too claustrophobic in the acute hospital scanner.

After diagnosis I assist with ensuring information about the diagnosis is shared in an accessible way, for example sharing leaflets with pictures and descriptions in and liaising with the person and their carers/family about how to support them with this new diagnosis. We assist the nurses to deliver information about dementia medication in a format the person can understand.

As the dementia progresses, someone may present with changes in behaviour. I work with carers to help them work out what behaviours are being shown and what the person may be trying to communicate through their behaviour.

Case study examples

Mrs Jones: a person living with dementia in the community with eating, drinking and swallowing difficulties

Background: Mrs Jones had a diagnosis of advanced Alzheimer's dementia and depression, and lives at home with her daughter. She was referred to SLT as she had recently become drowsier, with mobility limited to her bed and armchair. She had developed eating, drinking and swallowing difficulties and was experiencing choking episodes at home.

Assessment: SLT carried out several observational assessments, including days where Mrs Jones was more alert and days where she was drowsier and more unwell.

Intervention: Practical advice was given, including modelling of hand under hand assistance, and demonstration of diet texture modification, with both the daughter and regular care staff. A personalised eating, drinking and swallowing care plan was co-produced with Mrs Jones' daughter and given to care staff to follow. Discussions were had with Mrs Jones' GP and the MDT, and she was subsequently referred for palliative care support at home.

Outcome: Mrs Jones' daughter was grateful of the advice provided and valued being included in all decisions around her mum's care to enable her mum to stay at home at the end of her life as per her wishes.

Mr Thomas: a person living with dementia in the community with speech, language and communication difficulties

Background: Mr Thomas was diagnosed with younger onset Logopenic variant of PPA. He and his wife had recently moved to the area to be closer to family and were keen to meet other people and add structure to their week.

Intervention: SLT supported Mr Thomas to access local younger onset dementia groups and third sector support opportunities. Mr and Mrs Thomas engaged in communication partner training, which helped Mrs Thomas in particular to build confidence in her use of total communication in a fun and supportive way. Mr Thomas was able to co-produce a core vocabulary list for lexical retrieval therapy, and the SLT Technician was able to support him to develop a personalised booklet of core vocabulary, as well as supporting the family to start a life story book.

Outcome: Although adjustment to the new diagnosis has not been easy for Mr and Mrs Thomas, they have been able to find new ways of communicating as a couple and have grown their support network in their local area with the support of the health and social multidisciplinary team, and third sector opportunities.

Veronica: a person living with dementia in a nursing home with eating, drinking and swallowing difficulties

Background: Veronica is a nursing home resident, diagnosed with Alzheimer's dementia ten years ago. She was referred for an assessment of her swallow by nursing staff as they were concerned that she was "at risk of aspiration and choking". The lead nurse in the home explained Veronica "doesn't speak very often". All her needs are anticipated as she doesn't ask for things, but they know when she is unhappy as she cries out and shouts. She has been nursed in bed following an unwitnessed fall (no injury). Veronica eats more in the morning, but amounts get less throughout the day. She spits out any bits / fibrous food. The nurse feels Veronica sometimes swallows well but at other times holds the food or fluid in her mouth. Sometimes she will take a few sips or mouthfuls and then refuse to take more, holding it in her mouth for a long time. Sometimes the food/drink dribbles out of her mouth, sometimes she coughs. Staff report Veronica gets agitated at mealtimes. They are taking a long time to feed her and do not feel they have the time or staff. The nurse is concerned Veronica is losing weight and she is at risk of dehydration. Veronica has had no recent /recurrent chest infections and there is no gastroenterology history (e.g., reflux). Veronica is reported to be resistant to mouth care but there were no records of what she was allowing/refusing. She is able to take all her medication orally in a liquid form.

Assessment: Veronica was seen in her room; she was in bed. Veronica was initially agitated (moving around in bed, crying out) but responded to gentle, calm voice (eye contact, stopped moving). She was not following instructions for oro-motor movement instructions but did allow oral care with the speech and language therapist; the toothbrush was shown to her, she was helped to hold it and bring to her mouth. This allowed the speech and language therapist to see some oral movements and check oral hygiene. Her mouth was very dry and she had dried secretions on her tongue and around her mouth, there was a white coating on her tongue indicating possible oral thrush. The care staff didn't have a record of mouthcare but reported she wouldn't always let them clean her mouth.

Lunch observation: Veronica was in bed to eat. The TV was on – the lunchtime news playing very loudly. The curtains were drawn and the light on even though it was sunny outside. The care assistant talked to Veronica quite loudly even though Veronica has no reported hearing difficulties. Veronica was given IDDSI level 4 puree food from a large metal spoon and was fed quickly. After a few large spoonfuls, Veronica stopped opening her mouth and pushed the spoon away. Sips of water were given which sat in her mouth. The sips of water eventually escaped from her lips results in drooling. The SLT then trialled Veronica with some sips of sweet warm tea and cold, sweetly flavoured water. This significantly reduced the amount of time Veronica held the drink in her mouth and a consistent single swallow was triggered each time with no loss of the drink from drooling or coughing. The SLT then turned off the light, opened the curtains, turned off the TV and asked the carer to speak to Veronica at a normal volume, describing the food in a positive way and to ensure that she had swallowed each mouthful before giving the next. The large metal spoon was replaced with a smaller spoon and the carer was prompted to provide hand over hand support to hold it. This resulted in Veronica resuming eating her meal with minimal oral holding and no coughing or drooling. As staff had reported that Veronica spits out any lumps / bits in food, it was decided to continue with IDDSI level 4 diet.

Intervention:

- Referral to physiotherapy and occupational therapy to assess if Veronica could sit out of bed for meals and preferably in the dining room.
- Mouth care chart started to record when mouth care given / refused. Staff showed how to orientate Veronica to the task and include her.
- SLT to contact GP to see if medication was needed for potential oral thrush.
- SLT to reassess in dining room once/if Veronica was able to sit out of bed for meals.
- Mealtime set up; reduce sensory overload: lights off, curtains open, TV off. Orientate to task: sat out of bed (following physio/OT assessment), place table with meal in front of Veronica, discuss the food, hand over hand support to hold the cup and spoon.
- Enhance sensory feedback; sweet, warm tea, cold or flavoured water, smooth/moist puree foods (not thick) – IDDSI 0 fluids and 4 diet.
- Dietitian referral: food diary to gauge food preferences or times of day she eats better.

Outcome:

Veronica was assessed as safe to sit in a Sorrento chair for short periods of time with group supervision (which increased as she built up tolerance). Following reassessment by the SLT, she started to have lunch then dinner in the dining room with other residents which was found to help her orientate to the task and reduced distress.

One to one support to provide hand over hand assistance to help her start eating, she would then remember what to do and continue with only prompts/reminders.

If the cup was placed in front of her, she would sometimes pick it up and independently drink. The Dietitian gave advice on fortifying her diet, encouraging more food and drink in the morning, her best time.

There were no further reported coughing or choking episodes and her mouth returned to being moist and pink.

Chen: a person living with dementia in a nursing home

Background: A nursing home contacted our community SLT service for support with a 77-year-old gentleman placed in their care. He was Cantonese and had a diagnosis of dementia.

Chen's first language was Cantonese. He had previously spoken minimal English and would currently say greetings in English e.g., 'Hello'. We knew little about his cultural needs and social preferences. There were no other Cantonese speakers in the nursing home, and he had no visitors. A communication assessment in Cantonese had not previously been undertaken to establish if he had any communication impairment. Staff reported he was able to understand situational cues e.g., he was able to get dressed if they selected clothes and laid them on his bed.

We were unaware of how dementia was viewed within the Cantonese culture or within his religion. We completed research on his culture and looked through his records for family contacts. For a proportion of Cantonese people, dementia can be seen as a mental illness and shameful, something that should not be disclosed outside of the family and was linked to views of it being a punishment for previous sins. Chen's family were of this belief and were unwilling to provide further information on his previous communicative abilities and social preferences.

Assessment: Our organisation did not have access to a Cantonese interpreter who could visit Chen in person therefore I was able to find a bilingual support worker in a local charity whom we trained on the fundamentals of interpreting within the context of a communication assessment. We completed a joint visit to carry out an initial informal assessment of Chen's speech, language and communication.

Chen showed some difficulties with understanding spoken words in Cantonese but he was able to understand basic vocabulary and phrases in a written format which he could read aloud. The written form was used to support comprehension and expression. He showed no difficulties with spoken Cantonese.

Intervention: We made a bilingual communication chart for care staff to use with him. I transcribed the sound of the Cantonese words in the English alphabet so that staff could say them as well as point to the symbol and word for Chen and understand when he said them aloud.

Outcome: The communication chart helped the communication between Chen and care staff which reduced his levels of distress. He was able to express his basic needs and relations with staff improved because they could engage with him better. To enable improved social interactions, the charity is looking for a volunteer visitor who speaks Cantonese. We are currently working on how he can access medical appointments and be supported to participate in more activities in the nursing home.

Albert: a person living with dementia in the community with progressive supra nuclear palsy

Background: Albert has a diagnosis of progressive supra nuclear palsy. He was referred to the community neuro rehab team for a mobility assessment – he was falling regularly when trying to get to the toilet, he would sit in wet/soiled clothes all day as he couldn't make the bathroom in time, he was refusing to wear incontinence pads or to let carers wash him. He was at high risk of developing pressure sores and injury from falling. The physiotherapist and occupational therapists asked the speech and language therapist for support as they were having difficulty understanding him due to dysarthria. They wanted a capacity assessment around his decision to reject care.

Assessment: Dysarthria profile and Language assessments were completed. Albert had difficulties understanding lots of verbal and written information. He couldn't always think of the word he wanted to say and was inconsistent with his yes and no responses. Pictures didn't help his understanding but seeing single written words or short sentences in large, bold type / large handwriting did. Listener strategies such as giving him time to answer and repeating back what is understood further helped as did the use of a yes/no board.

Using these strategies, Albert was able to explain he was having bladder urgency (knew he needed to go with not much warning) so he had to rush to the bathroom, often forgetting his frame. He didn't like the pads as they made him feel "like a baby". He has always washed in the evening. He is a private person and feels embarrassed that people want to wash him.

Intervention: With the occupational therapist, he agreed on changing his room around, so he sat nearer the door, a riser recliner chair made getting up easier and rails were placed in the hallway for him to hold on to. He practiced moving from the front room to the bathroom with the physio. GP referred him to urology and the incontinence teams. Adult Social Care arranged for a carer to support Albert to wash himself at the end of the day.

Outcome: With input from the multidisciplinary team, Albert was able to be much more independent with going to and from the toilet, had a reduction in incontinence and a reduction in the number of falls. Albert also felt listened to and more in control of his continence.

Gloria: a person living with advanced dementia in the community with speech, language and communication difficulties

Background: Gloria is 96 years old and has complex physical health and cognitive communication changes secondary to dementia. Gloria is bedbound, very frail, has fluctuating alertness and experiences hallucinations. Gloria was referred to SLT for support with communication difficulties. Full-time family carer, Harriet, reporting no meaningful communication with Gloria, which the family were finding a distressing loss. Gloria also called out frequently for their family carer, which was reported to be worse when Gloria has an infection, which is frequent.

Assessment: Using communication partner training to support conversation where a person has communication difficulties, I observed interaction between Gloria and Harriet including the communication 'turns' between them, their non-verbal communication, timing of responses and what were identified as 'facilitators' to communication. Gloria was noted to sometimes respond to Harriet's comments but often with a longer pause.

I observed how Gloria and Harriet were communicating with each other in the 'here and now' e.g., Gloria pointing at a chair and saying the word 'chair' and Harriet recognising this and interpreting and extending it to support the communication 'oh chair! You want (SLT) to have a chair! Yes ok – Here we are!'

Intervention: I was able to talk to Harriet about how 'short bursts' of communication, like the one above, were still good communication and Harriet's skill in facilitating when Gloria is trying to communicate a need/want/request. I also reflected on how 'one-sided' conversation can feel for Harriet and how it can be quite 'task-based' e.g., about offering food/drink/care for Gloria. We talked about offering comments as well as requests / questions with longer pauses to give time for Gloria to respond.

Outcome: On review, I noted that Harriet was using fewer questions and more comments with pauses, giving Gloria more time to respond. Gloria was reported as more content. With my input for Gloria and Harriet, it was possible to change Harriet's perception of 'there's no communication', and introduce an alternative interaction approach, which appeared to reduce carer distress. Taking a communication partner approach, looking at communication between Gloria and Harriet, illustrated that even in a situation of deteriorating health, supporting conversations has value for people with communication difficulties and their caregivers.

Mrs Wilson: a person referred to SLT with suspected Primary Progressive Aphasia

Background: Mrs Wilson, a 61-year-old teacher, noticed she was having difficulties thinking of her students' names in class occasionally. This was very unusual for her, as she had always prided herself on knowing children's names. Her husband also commented that he had noticed she was having trouble when they were socialising in groups occasionally. Mrs Wilson became quite anxious about this, and eventually her husband persuaded her to go to the GP. Initially the GP dismissed the symptoms as a mood issue, but after returning to her GP several times he referred her to a memory and cognitive disorders clinic. At the clinic she described feeling hesitant when speaking. This had led to a decline in social outings.

Assessment: The neurologist asked me to assess Mrs Wilson, as they were unsure whether she had a Logopenic or nonfluent Primary Progressive Aphasia. During the in-depth case history, Mr and Mrs Wilson described that Mrs Wilson often reversed yes and no. Mrs Wilson explained that she knew what words were, but they just wouldn't come out. Mr Wilson also mentioned that she spoke less overall and sometimes, when tired, her speech sounded slurred or distorted.

Outcome: On assessment, Mrs Wilson presented with a mild apraxia and difficulties with naming objects. This informed the diagnosis of nonfluent Primary Progressive Aphasia. We are currently working with Mrs Wilson to establish person-centered goals for continued intervention.

Mr Green: a person living with dementia in the community with Primary Progressive Aphasia

Background: Mr Green was referred to the community SLT service having been given a diagnosis of semantic dementia. He was newly retired and struggling to maintain community connections due to his word finding difficulties. He lived with his wife who felt they were struggling to come to terms with the diagnosis. He had significant word finding difficulties which caused frustration and they both felt rather helpless.

Assessment: I carried out a non-verbal semantic assessment to identify his level of semantic deficit, but this revealed his semantic knowledge was very good. Comprehension was also good. It turned out his semantics had been assessed using a word-based assessment, and he had been unable to explain the links between words and concepts due to his word finding difficulties. Further informal assessment of reading and conversation confirmed the diagnosis as Logopenic variant Primary Progressive Aphasia. Mr Green had previously been very confused by the diagnosis, but this fitted his symptoms much better.

Intervention: Mr Green and his wife were able to understand his strengths and difficulties and with support we were able to identify appropriate compensatory strategies. Thanks to strong semantic knowledge, Mr Green was able to use circumlocution effectively. His reading was good, and he was able to use reading from lists and scripts to support his word finding. He had lost the ability to read lengthy or complex material, and missed reading novels, so we introduced him to Quick reads, which he could manage. He also found he could not follow a complex programme on the TV, so we suggested viewing a recording and pausing at regular intervals to talk over what was happening with his wife, which gave him the processing time he needed to keep up with the plot.

Outcome: Mr Green's confidence in his ability to join in conversations increased and he joined the local walking group. With my support, he and his wife explained to other members what helped him participate, and at that point they both felt he did not need further support from me for the time being.

Mr Smith: a person with dementia in an acute hospital setting

Background: Mr Smith, a 77-year-old man, was referred to SLT for an eating, drinking and swallowing assessment after recently being admitted to the acute assessment ward via A&E, as he was observed to be coughing when drinking. Mr Smith has a new diagnosis of Primary progressive Aphasia (PPA). Concerns had been raised by the Dementia Link Worker and Community SLT that he wasn't coping at home alone: he was confused about his medications, his home was in a poor state with basic equipment not working such as heating and the cooker. An ambulance was called on their second visit to rule out a stroke as Mr Smith had high blood pressure, raised temperature, slurred speech & was unable to follow instructions.

Prior assessment: There had been no concerns with eating, drinking and swallowing in the community, but Mr Smith had a mild expressive & receptive language impairment. He hadn't been aware of his PPA diagnosis due to memory issues. The community SLT had found single word / short written sentences helped Mr Smith's understanding. At that time, the Community SLT felt Mr Smith had capacity to make decisions about his home / where he wants to live & how, with support to understand what is being discussed. He had expressed a need for social care support to "feel secure" in his home.

Recommendations handed over for the ward / medical team:

- Keep information short, write key words / short sentences to help Mr Smith focus on what you are saying.

- Leave a summary of what was discussed so he can look back and remember
- Write days / times: 1o'clock in the afternoon not 13:00 or 1pm, Thursday 1st June not 1/6/23.
- If Mr Smith doesn't change the topic, this means he still has things to say about it. Writing what he has said down helps him move forward and not just repeat what he has said.

Eating, drinking and swallowing assessment: Health Care Assistants had been feeding Mr Smith because he wasn't eating much. On observation, they were feeing him very quickly, causing his swallow to become uncoordinated.

Intervention: Recommendations to help him focus on the meal were given – pulling the curtain around his bed during mealtimes to reduce distractions, encouraging him to sit out of bed for all meals, setting a table in front him with 1:1 mealtime assistance to support independence: cutting food up, placing a cup/fork in hand, and prompts to eat. These interventions increased his independence at mealtimes and there were no further coughing episodes.

An MCA was completed re: discharge destination by the SLT and Occupational Therapist. Despite giving the recommended communication support, Mr Smith did not demonstrate capacity to go home alone; he was able to retain information long enough within the discussion and express his wishes but did not demonstrate the ability to weigh up the benefits / risks of going home. He did express a clear wish to go home.

Outcome: A best interests meeting was completed with his sister present. It was decided Mr Smith would go to an interim placement whilst repairs were completed in his home. He would then be discharged home with support to manage personal care, meals and medications and a pendent alarm to call for help in emergencies. Mr Smith remained agitated on the ward as he couldn't remember the plan and was constantly asking to go home. The SLT provided him with written/accessible information regarding this discharge plan. When he became agitated, Staff were advised to show him the written plan to help him understand he would be going home

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We are grateful to the project reference group, experts by experience and all those who contributed to the development of this guidance.

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