Speech and Language Therapy Provision for People with Dementia.
IASLT Position Statement, 2016

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Foreword

This position statement has been developed by the IASLT Working Group in Dementia, which is made up of speech and language therapists (SLTs) who are working specifically in the field. This is the first IASLT policy document published in this area of speech and language therapy provision for people with dementia and their families. It highlights the key role that SLTs have and their scope of practice in managing people with dementia within multidisciplinary teams. It makes key recommendations for change and emphasises that speech and language therapy services should be available in an equitable manner to people of all ages living with dementia and to their families.

1. Executive Summary

Dementia is one of the biggest public health challenges facing the current population across the globe (Alzheimer Disease International, 2013). It is estimated that there are over 56,000 people living with dementia in Ireland in 2016 (Irish National Dementia Strategy, 2014). Communication difficulties occur in all forms of dementia and have a significant impact on a person's quality of life, ability to access recreation and /or employment, in their social interactions and consequently it affects a person's ability to form and maintain relationships (RSCLT, 2013).

SLTs have a unique role in identifying the specific nature of communication difficulties for a person with dementia and in reducing the impact of the communication difficulties for the person and for their family members (RCSLT, 2013b). Optimising the skills of the person with dementia as well as their communication partners is key to their empowerment and their ability to live well with dementia. In addition to communication difficulties, feeding, eating, drinking and swallowing (FEDS) difficulties occur across all dementia types (Kindell, 2002), and those with advanced dementia often present with particularly complex needs in relation to oral feeding (Evans, Smith & Morrow, 2009; Easterling & Robbins, 2008). Therefore, the need to assess and manage FEDS difficulties and identify potential risks for aspiration and health related consequences is crucial (NICE, 2006).

The Irish National Dementia Strategy (Department of Health, 2014) was a response from the Irish government to enable people with dementia in Ireland to live well with the right supports in their local communities. Key principles of the strategy include making communication accessible for the person with dementia, staff working with those with dementia are appropriately trained in interacting with people with dementia, provide person-centred care and ensuring that people with dementia are supported to participate in all key decisions relating to their lives. The key priority action areas in the Irish National Dementia Strategy include the provision of equitable services for communication and FEDS difficulties to people with dementia.

This position paper provides guidance on the scope of practice and the provision of speech and language therapy services to people with dementia and their family carers. While the role of the SLT is recognised in supporting people with dementia to live well, there has been a lack of consistency in service development within the Health Service and wide variability in speech and language therapy service provision across Ireland. The IASLT recognises the need to improve access to speech and language therapy services for people with dementia and their families. People with dementia need equity of service provision for their cognitive-communication impairment and FEDS difficulties. There are many benefits of providing a speech and language therapy service for people with dementia which are outlined in section 7.. While it is recognised that all SLTs working in this area will not have access to a specialist team, they should have the required level of knowledge and skills to respond to the specific challenges of managing and supporting this client group.

This position paper makes six key recommendations for change:

1) Equal access to speech and language therapy provision for people with dementia is required, including for those with early onset dementia. This will require adequate resourcing of speech and language therapy services nationally in order to provide quality care for people with dementia.

2) People with dementia require timely access to pre and post diagnostic support, including speech and language therapy.

3) SLTs should provide communication therapy and interventions to improve quality of life for people with dementia and their families as appropriate.

4) SLTs should facilitate assessments relating to decision making capacity to ensure that the person with dementia's communication skills are optimised and therefore, that their capacity is maximised throughout the course of their condition.

5) There are currently no specialist SLT posts in dementia care. This paper recommends that this situation is looked at as a matter of urgency in order to ensure that SLTs are identifying gaps in the evidence base, carrying out research and promoting best practice on an ongoing basis. The IASLT considers that development of Specialist SLT posts in dementia is required.

6) SLTs support the person with dementia, their family and the MDT in end-of-life care planning and management. Dementia is a life-limiting condition and it is recommended that a palliative approach to care is taken from the point of diagnosis onwards. SLTs have a key role to play in supporting people with dementia to understand information provided and to enable them to communicate their choices and decisions, including those relating to their future and end-of-life care. It is recommended that the profession continue to develop competence and confidence in a palliative care approach.

Each of these recommendations will be discussed further within the statement.

2. Defining Dementia

"Dementia is a syndrome characterised by progressive cognitive impairment and is associated with impairment in functional abilities and, in many cases, behavioural and psychological symptoms. There may be memory loss, usually related to short-term memory, communication difficulties, changes in personality or mood and problems with spatial awareness" (Irish National Dementia Strategy, 2014 pg. 10).

There are a number of different types of dementia with Alzheimer's disease (AD) being the most common followed by Vascular Dementia (VaD). There are other less common types including mixed dementia, Dementia with Lewy-Body (DLB)

and Frontotemporal dementia (FTD). It may also occur alongside progressive neurological conditions such as Parkinson's disease (PD), Korsakoff's syndrome and Huntington's disease. Mild Cognitive Impairment (MCI) is early cognitive decline in people who do not have dementia (Sperling et al., 2011). MCI is the most commonly caused by AD but can also be caused by the other subtypes of dementia (Bayles & Tomoeda, 2014). The MCI classification should be viewed as a transitional state, encompassing heterogeneous cognitive profiles, with multiple 'forward' and 'backward' outcome possibilities. Other clinical data, such as age, baseline cognitive performance, MCI subtype and diagnostic stability, should be taken into account when assessing the risk of progression to dementia (Diniz et al. 2009)

3. Demographics and Policy

3.1 The International and National Context

Dementia is the biggest global health challenge facing our generation (Alzheimer Disease International, 2013). There are about 35 million people worldwide with dementia, about nine million of whom live in Europe. Dementia affects approximately 1.55% of the European population (Dementia in Europe Yearbook, 2013), which equates to 49,469 Irish people. Over the age of 65 the prevalence rate for dementia nearly doubles every five years (Lobo et al., 2000). The Irish National Dementia Strategy figures estimate that by 2016, 54,793 people in Ireland will have dementia. These figures are likely an underestimation given the difficulties many experience obtaining a diagnosis and the figures are expected to grow given our ageing population and population growth. The estimated cost of care per person with dementia annually in Ireland is €40,500, with the bulk of care for people with dementia being provided free of charge by family caregivers (Irish National Dementia Strategy, 2014).

Dementia is not solely a disease of old age. There are significant numbers within the overall dementia population with early onset dementia. Currently, in Ireland it is estimated that there are approximately 4,000 people under the age of 65 years with dementia (Irish National Dementia Strategy, 2014). It can be more challenging for people with early onset dementia to access a timely diagnosis

and appropriate services, given that they typically must access services within the existing paradigm, which is tailored to the needs of older people.

Based on the Central Statistics Office (2013) Population and Labour Force Projections, it is estimated that by the end of 2016 there will be 54,793 in Ireland living with dementia. (Irish National Dementia Strategy, 2014). Some 25% of people admitted to hospital over the age 65 have dementia (Cahill et al., 2012a) and estimates indicate 50-66% of nursing home residents are thought to have dementia (Cahill & Diaz-Ponce, 2010). Dementia is three to four times more common in older people with intellectual disabilities than in the general population, particularly in people with Down Syndrome (Sinai et al, 2014).

Given the increasing profile of people with dementia in Ireland (Cahill et al., 2012b) speech and language therapy services should be available to all people with dementia and families who require help with FEDS and cognitive-communication difficulties.

3.2 Irish National Dementia Strategy

The growing prevalence and cost has prompted governments around the world to develop national strategies for dementia. The Irish National Dementia Strategy came into effect in December 2014. This strategy" seeks to progress the dual and overarching principles of personhood and citizenship by enabling people with dementia to maintain their identity, resilience and dignity and by recognising that they remain valued, independent citizens who, along with their carers, have the right to be fully included as active citizens in society" (Irish National Dementia Strategy, 2014 pg. 12). One of the key principles of the strategy is that those providing services/care to people with dementia should be appropriately trained and that all communication should be accessible and easy to understand for people with dementia. Additionally, this National Strategy advocates that people with dementia have timely access to diagnosis and intervention with person centred, flexible and responsive services.

Given the prevalence of dementia in nursing homes, there is an increasing focus on the quality of care. The Health Information and Quality Authority (HIQA) are commencing a thematic inspection programme on Dementia Care in 2016. This

will evaluate care planning and service delivery to older people in residential settings on a range of topics including, facilitating communication, decision-making and emotional and social well-being.

3.3 Approaches to Care

Person-centred and relationship-centred care are recognised as best practice approaches in working with people with dementia. The notion of personhood, with its emphasis on preserved ability and well-being encourages the belief that all people with dementia at all stages have something to communicate about (RCSLT, 2014).

Relationship-centred care places emphasis on the need to support both the person with dementia and those who care for them (Nolan et al., 2004). Optimising the communication skills of both the person with dementia and their carer is a central theme to good quality relationship centred care.

When planning services for people with dementia it is important to consider a social and community approach working towards Dementia Friendly Communities (Goodchild,. & Rippon, 2011).

4. How Dementia affects Communication and Swallowing Ability

4.1 The Impact of Dementia on Communication.

Changes in cognition, language, and behaviour over the degenerative trajectory of most dementias lead to limitations in communication and functional behaviours (Bourgeois & Hickey, 2009). While different types of dementia are characterised by different patterns of language breakdown, changes in cognition and language throughout the disease lead to impairedcommunication and functioning across all the dementias (Gorno-Tempini et al., 2011).

Communication skills are integral to relationships, at the core of social interaction and key for quality of life. Cognitive-communication difficulties emerge in the early stages of dementia. These difficulties can have significant social and emotional consequences for the person with dementia and their family-caregivers. Lack of social contact and depression may be related to these declining skills. This can pose a threat to their identity and relationships (Bryden, 2005). Barnes (2003) emphasises the importance of providing support to carers suggesting that by providing training, advice and support on communication and memory difficulties, carers are enabled to continue in the caring role for longer. Therefore, it is critical that SLTs provide early intervention for people with dementia in order to maintain functional communication and reduce communication breakdown.

4.2 The Impact of Dementia on Feeding, Eating, Drinking and Swallowing (FEDS) .

FEDS refers to the total process of feeding, eating, drinking and swallowing. When a single aspect of the swallowing process needs to be identified then the appropriate term will be employed e.g. feeding (RCSLT, 2006 cited in IASLT 2012). FEDS can be a result of behavioural, sensory, or motor problems (or a combination of these) and is common in individuals with neurologic disease and dementia. Across all dementia types, increasing cognitive decline results in progressive difficulty with swallowing (dysphagia) and an increase in behaviours which can lead to difficulties with eating and drinking, including impulsivity, reduced ability to self-feed, and oral stage difficulties (over-chewing; holding food) (Kindell, 2002; Bourgeois & Hickey, 2009). Morris (2006) reports that up to 60% of individuals with dementia have dysphagia, with all individuals inevitably developing dysphagia and/or difficulties with oral nutrition in the advanced

stages of the disease (Evans, Smith & Morrow, 2009; Easterling & Robbins, 2008).

FEDS difficulties associated with dementia can have a significant impact on day-to-day life for the person with dementia and their caregiver. Perceived inappropriate mealtime behaviour and dysphagia often lead to the cessation of popular social activities such as eating out, or entertaining friends (Gillies, 2011). Dysphagia in dementia can contribute to malnutrition, dehydration, weight loss, choking episodes, repeated chest infections, pneumonia, and recurrent hospitalisations - all of which can be challenging for the person with dementia and their caregiver (Hudson et al., 2000; El Solh et al., 2004; RCSLT, 2014)

5. The Role of the SLT.

SLTs can support the person with dementia and their families to live well in spite of FEDS, communication, memory or cognitive difficulties. SLTs are recognised as key professional members of the multidisciplinary team, who work with persons with dementia, and their families or caregivers. The practice of speech and language therapy includes the assessment, diagnosis, identification and rehabilitation of individuals presenting with communication and swallowing disorders (IASLT, 2010). A key focus in providing quality dementia care is person centeredness and hearing the voice of the person with dementia (; Cahill, O'Shea & Pierce, 2012). All input should be designed to promote independence and maximize the person with dementia's retained abilities (NICE, 2006).

Interventions target the cognitive aspects of communication, including attention, memory, sequencing, problem solving, and executive functioning and developing treatment plans for retaining and maximising functional cognitive-communication abilities.

As dementia is a progressive condition, deterioration is likely to occur across all domains (Cahill et al., 2012a). Therefore, people with dementia require access to a range of quality services, including speech and language therapy, on an ongoing basis throughout their journey with dementia.

5.1 Scope of Practice

Working with people with dementia demands a flexible and creative approach from SLTs, supporting the person and their families, working within the person's daily environments and working to raise awareness and support inclusion within the wider community. SLTs are required to continue to develop their professional knowledge and skill base in working with people with dementia to ensure the delivery of high quality evidence based practice.

SLTs work in a variety of settings to contribute to the care of people with dementia, including community teams, hospitals, intellectual disability settings, memory services, care homes and mental health settings. The specific competencies required by the SLT will depend on the clinical setting. For example, there may be a large focus on FEDS in the acute setting, but in a domiciliary setting speech and language therapy interventions may focus on promoting functional communication. Core clinical competencies in the assessment and treatment of FEDS and cognitive-communication impairments will be drawn on to provide a quality service to people with dementia as their care needs evolve. SLTs specialising in dementia may be more involved in memory clinics, research, advocacy, building capacity and life-long psychosocial support including community based initiatives like Alzheimer's Cafes and carer support groups. (RCSLT, 2014).

Due to the progressive and life limiting nature of dementia, SLTs have an ethical responsibility to provide appropriate services that will benefit the individual and maximise their communication at all stages of the disease (ASHA, 2015). The Palliative Care Competency Framework (2014) outlines key domains of competence required of all SLTs.

Core domains of competence for all healthcare staff are:

- Principles of Palliative Care
- Communication
- Optimising Comfort and quality of Life
- Care Planning and Collaborative Practice
- Loss, Grief and Bereavement
- Professional and Ethical Practice in the Context of Palliative Care

Finally, SLTs should be familiar with the IASLT Scope of Practice (2016) for a full description of the clinical, management and educational services provided by SLTs as well as the frameworks within which they operate

5.2 Assessment

The role of the SLT in the assessment of the person with dementia will include the following:

- Assessment of body functions and structures which may be contributing to communication and/or swallowing disorders (Moorhouse, 2010; IASLT, 2010)
- Informal and/or formal assessment of communication and swallowing to clarify the severity and nature of deficits. Findings from this assessment may contribute to the multidisciplinary team based differential diagnosis of dementia in relation to other cognitive-communication disorders, or differential diagnosis of dementia subtype (RCSLT, 2014). This may involve assessment for language disorders or speech difficulties.
- Develop a profile of skills and difficulties with communication as well as the resulting challenges. This may include the psychological and social impact of these difficulties on the person with dementia.
- Engage in the assessment of the capacity for decision-making where the person with dementia presents with language difficulties.
- Assessment for the presence and severity of any FEDS difficulty as well as assessing any risk of aspiration. This will include clinical bedside assessment and/or mealtime observations.
- Objective assessment of swallow (e.g. videofluoroscopy and/or fiberoptic endoscopic evaluation of swallowing (FEES).
- Monitoring of FEDS difficulties to prevent adverse outcomes and reduce unnecessary hospital admissions (RCSLT, 2014).
- Assessment and evaluation of the person with dementia's activities, participation, environmental factors and personal factors relating to communication and FEDS (Moorhouse, 2010; IASLT, 2010). This may include examining the person with dementia's communication environment, observing interactions with communication partners,

exploring mealtime environment, and food/drink preferences. This assessment will help to identify priorities for intervention (in collaboration with the person with dementia and their caregivers, where appropriate).

5.3 *Intervention*

A key focus in providing quality dementia care is person centeredness and hearing the voice of the person with dementia (Marsh & Begley, 2009; Cahill et al., 2012). The exact focus will depend on the specific communication and FEDs abilities and the needs of the person with dementia and their families.

The role of the SLT in the intervention with the person with dementia will include the following:

- Direct individual therapy aimed at rehabilitating or maintaining function (e.g. naming therapy (Bier et al., 2009); spaced retrieval training (Hopper et al., 2005); validation therapy (Neal & Barton, 2009); cognitive interventions (Hopper et al., 2013).
- Group therapy input aimed at rehabilitating or maintaining function or activity and participation (e.g. reminiscence therapy groups (Cotelli et al., 2012; Huang et al., 2015).
- Introduction of compensatory strategies with the person with dementia aimed at maintaining or maximising activity and participation (e.g. memory aids to improve verbal communication (Egan et al., 2010)).
- Supporting the person with dementia and their carers to implement programmes to maximise the person with dementia's participation in communicative interactions, such as life storybooks and communication passports (McKeown et al., 2010; Moos & Bjorn, 2006).
- Incorporating the person with dementia's specific communication needs into their care plan.

- Work with carers and the person with dementia in clinic, at home and in community settings to enhance communication facilitation of the use of communication strategies (RCSLT, 2014).
- Train families, carers, staff and other members of the multidisciplinary team (MDT) in supporting communication (Zientz et al., 2007a; Eggenberger et al., 2013) (SLTs ? should? refer to the Guiding Framework for Education and Awareness in the development of person centred dementia care, HSE, 2012).
- Promoting and supporting decision-making, inclusion, enablement, validation and rehabilitation of the person with dementia.
- SLT's who manage FEDS difficulties can make recommendations, advice, support and train carers to support safe swallowing (Kindell, 2002). SLTs can also assist with future planning of FEDS as well as assisting carers in the decision-making process regarding FEDS (Gillick & Mitchell, 2002).
- Research and development; SLTs may work to improve the evidence base and promote best practice in service provision and develop appropriate care pathways for people with dementia (RCSLT, 2014).

5.4 Palliative Approach to Care

Dementia is unique as it is recommended that a palliative approach be taken early on in the course of the disease, ideally soon after diagnosis when the person can meaningfully engage in discussions about their future care (The Irish Hospice Foundation and the HSE, 2008, Clayton et al. 2007, Regan et al., 201).

SLTs have a key role to play in facilitating communication between the person with dementia and their family, carers and other staff in order to ensure that their personhood is promoted and that their values, will and preferences are upheld throughout the course of their condition. This includes supporting and facilitating communication and the management of swallowing problems as the symptoms of dementia progress towards the end of life. SLTs may be involved in education and support for carers and families using a consultative and collaborative approach, which focuses on quality of life.

SLTs working with people with dementia should be familiar with:

- Common ethical principles underpinning dementia care at end of life (IHF, 2016).
- The National Palliative Care Competency Framework (2014).
- Health Service Executive (2012). *A guiding framework for education and awareness in the development of person centred dementia care for Nurses and Care staff working across all care groups in the HSE*

See scope of practice section of this document for further detail.

5.5 Capacity and Consent

The Assisted Decision-Making (Capacity) Bill 2015 which is due to be enacted provides a modern statutory framework to support people with dementia to make their own decisions relating to their life and their care. There are a number of guiding principles within the act to safeguard the autonomy and dignity of the person with dementia. These are:

- There is a presumption of decision-making capacity unless the contrary is shown.
- No intervention will take place unless it is necessary.
- A person will be treated as unable to make a decision only where all practicable steps to support that person to make a decision have been unsuccessful.
- Any act or decision made under the Bill must be done or made in a way that is least restrictive of a person's rights.
- Any act done/decision made under the Bill in support of or on behalf of a person with impaired capacity must give effect to the person's will and preferences.

In order to be demonstrate capacity, the person must:

- Understand the information given to them (this may require that information needs to be made accessible for the person).
- Retain the information.
- Be able to balance the risks versus benefits.
- Use this information to communicate a decision.

(HSE National Consent Policy, 2014).

It is the position of IASLT that SLTs are uniquely qualified to assess and support a person to understand and then communicate that understanding for the purposes of establishing their capacity for decision-making. This is an essential component of the work of SLTs in this area, in order to ensure that individuals continue to exercise choice and control in their daily lives (RCSLT, 2014).

5.6 Role of the Specialist SLT in Dementia

SLT's have a unique understanding and insight into speech, language and communication and swallowing disorders. This insight is integral to accurate diagnosis and supporting other professionals in the management of people with dementia. In addition to service delivery for people with dementia on general caseloads, there is a need for specialist SLT posts in dementia care. The specific competencies of the specialist SLT include:

- Serving as an integral member of an interdisciplinary and MDT team working with people with dementia and their families/caregivers.
- When possible serving as a case manager or coordinator to ensure appropriate and timely delivery of a comprehensive management plan.
- Consulting and collaborating with other professionals, family members, and carers to develop individual care plans.
- Working across a range of clinical settings including specific memory clinics and centres for research.
- Keeping abreast of research in the area of dementia and helping advance the knowledge base related to the nature and treatment of dementia (ASHA, 2015).

6. The Benefits and Risks of Speech and Language Therapy Provision

6.1 Benefits of Providing a Speech and Language Therapy Service

- Specific analysis of language disorder to inform differential diagnosis of dementia and its subtype. A detailed speech and language assessment can help to identify the presence and nature of dementia (Snowden &

Griffiths, 2000) and in some cases facilitate early diagnosis (Garrard & Hodges, 1999).

- Specialist assessment of FEDS, which can facilitate informed, effective management of difficulties, in order to maximise function and minimize the risks associated with FEDS difficulties in dementia.
- Provision of specific programmes to maximise and maintain communication function and support the maximising of independence in communication and FEDS.
- Enabling carers to care by providing support, which maximises knowledge, skill, self-efficacy and quality of life and minimises carer depression and anxiety. (Thompson et al, 2007).
- Supporting and promoting ongoing interpersonal relationship between the individual with dementia and carers through use of communication strategies to promote connection.
- Contribution to interdisciplinary problem solving and care planning with regard to assessment of capacity to consent to different aspects of care.

6.2 Risks of Not Providing a Speech and Language Therapy Service

- SLTs have a crucial role in differential diagnosis, particularly where a language/speech difficulty is prominent (RCSLT, 2014). Delay in access to speech and language therapy as part of the MDT, may result in delayed and/or incorrect diagnosis.
- Given the communication difficulties that occur in dementia, without assistance to support effective communication (Orange and Ryan, 2000), the person with dementia may experience barriers to accessing and communicating with other professionals.
- Availability of communication strategies at a community level is required to support person with dementia, particularly those with a predominant language/speech impairment as otherwise they are vulnerable to isolation and social exclusion.
- Without appropriate SLT support to target and maximise function in relation to communication and FEDS, the person with dementia may experience an increased level of dependence at an earlier stage.
- The loss of meaningful interaction and conversation places increases pressure on the caring relationship (Nolan et al, 2002).

- FEDS if not managed in a timely manner can lead to multiple hospital admissions, choking, dehydration and malnutrition and avoidable deaths due to aspiration pneumonia (Hudson et al., 2000).
- The person with dementia may be excluded from decision-making and service planning if they are not supported to maximise their communication ability.
- Where communication and FEDS are impacted the person with dementia can experience a decrease in quality of life, wellbeing, sense of personhood and quality of relationships for both the person with dementia and their carers.
- Responsive behaviours may be misinterpreted/misunderstood by those supporting the person with dementia. This may lead to increased use of pharmacological interventions to manage behaviours.

7. Recommendations for change

This position paper makes six key recommendations for change:

1) Equal access to speech and language therapy provision for people with dementia is required, including for those with early onset dementia. This will require adequate resourcing of speech and language therapy services nationally in order to provide quality care for people with dementia.

2) People with dementia require timely access to pre and post diagnostic support, including speech and language therapy.

3) SLTs should provide communication therapy and interventions in addition to the management of FEDS, to improve quality of life for people with dementia and their families as appropriate.

4) SLTs should facilitate assessments relating to decision making capacity to ensure that the person with dementia's communication skills are optimised and therefore, that their capacity is maximised throughout their journey.

5) There are currently no specialist SLT posts in dementia care. This paper recommends that this situation is looked at as a matter of urgency in order to ensure that SLTs are identifying gaps in the evidence base, carrying out research and promoting best practice on an ongoing basis. The IASLT considers that development of specialist SLT posts in dementia is required.

6) SLTs support the person with dementia, their family and the MDT in end-of-life care planning and management. Dementia is a life-limiting condition and it is recommended that a palliative approach to care is taken from soon after the point of diagnosis onwards. SLT have a key role to play in supporting people with dementia to understand information and to communicate their choices and decisions, including those relating to their future and end-of-life care. It is recommended that the profession continue to develop competence and confidence in a palliative care approach.

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