Eating, drinking and swallowing guidance

Introduction

Eating, drinking and swallowing (EDS) difficulties can happen to anyone of any age. Speech and language therapists (SLTs) play a key role in assessing and identifying any difficulties.

This includes assisting service users to make informed decisions around eating and drinking to maximise quality of life. The assessment and management of EDS requires person-centred care and involves a multi-disciplinary and multi-agency care approach. The management of EDS is considered to be 'everybody's business' and a collaborative approach supports holistic care planning and comprehensive clinical decision making. Individuals with long-term conditions who have transient, intermittent, persistent or progressive EDS difficulties often remain at risk of associated complications. SLTs have a key role in educating/training others in identifying, assessing and managing EDS difficulties.

Please note: EDS is sometimes used as an acronym for Ehlers Danlos Syndrome, however within this guidance EDS will only be used to abbreviate eating, drinking and swallowing.

The 'normal' swallow needs the respiratory, oral, pharyngeal, laryngeal and oesophageal anatomical structures to function in synchrony, which is dependent upon the motor and sensory nervous system being intact. Difficulties in EDS may also be called dysphagia (adults) or feeding difficulties in children. Difficulties may occur in the pre-oral, oral, pharyngeal and oesophageal stages of EDS.

Throughout this guidance, the word 'feeding' or 'suck feeding' is used to describe early feeding development including breastfeeding/chest feeding, bottle feeding and early weaning. We recognise other terminology may be preferred and this should be discussed with families to ensure the language used by professionals is inclusive.

EDS difficulties can result from many conditions and are often secondary to a primary psychological, emotional, neurological, physical and/or developmental condition. However, EDS difficulties may be the first or only presenting symptom of a condition and therefore require careful investigation to help with differential diagnosis. EDS difficulties can result in, or contribute to, malnutrition and dehydration, respiratory infections, weight loss and food aversion or poor growth in infants and children, sometimes resulting in serious adverse health effects and death. They can also result in reduced wellbeing and quality of life for the individual and their wider families. EDS difficulties are also associated with an increased morbidity and an increased mortality.

Difficulties in sensory perception may create sensitivities, difficulties with discrimination, praxis and could also lead to psycho-behavioural difficulties in relation to food and drink. Children and adults may have additional anatomical, learning, communication, sensory, behavioural and physical needs. The nature of their difficulties may be acquired or congenital. In both children and adults, EDS difficulties can present as acute or chronic, and within these categories, be static or progressive in their presentation.

Factors influencing EDS

The ability to swallow can be influenced by several factors including, but not limited to:

- Food related factors e.g. texture of the bolus, bolus size and temperature.
- Individual related factors e.g. coordination and strength of the muscles, posture, cognition, frailty, health co-morbidities, fluctuating alertness levels.
- Issues such as fatigue can also impact on an individual's ability to eat and drink. Some conditions may be present from in utero such as genetic conditions (congenital) or others may occur at different points on the life span (acquired).
- Environmental factors e.g. levels of support and supervision.

EDS difficulties may be associated with different conditions or differences. Although these are separated in the subsequent sections into children and adults, it is important to consider how conditions may be present across the lifespan and how the presentation and the impact of EDS difficulties may change over time.

EDS difficulties in children

EDS difficulties in children can be associated with several different conditions (please note the following is not an exhaustive list):

- **Prematurity** – between 26.8% and 40% of infants born prematurely (Lee et al 2011; Morgan, Ward and Murdoch 2004).
- **Childhood onset disability** – between 21% and 44% of children with childhood onset disabilities e.g. acquired traumatic brain injury, childhood stroke (Arvedson et al, 1994; Morton et al 2002; Taniguchi and Moyer, 1994; Newman et al 2001; Weir et al 2011).
- **Oncology/tumours** – Brain, spinal, and head and neck tumours can result in swallowing difficulties in children.
- **Cerebral palsy** – between 31% and 99% of children with cerebral palsy will experience difficulties with EDS (Calis et al, 2008; Mirrett et al, 1994; Reilly, Skuse and Poblete, 1996; Waterman et al, 1992; Wright, Wright and Carson, 1996).
- **Infectious diseases** – e.g., meningitis, can result in damage to the neural pathways required to swallow.
- **Neuromuscular conditions** – e.g., Spinal Muscular Atrophy (SMA), Duchenne Muscular Dystrophy (DMD). 47.2% of children with neuromuscular conditions have EDS difficulties with 90% having chewing difficulties, 43% having swallowing difficulties and 33.3% having problems with both chewing and swallowing (Kooi-van Es, 2020).
- **Respiratory difficulties** – e.g., chronic lung disease, structural abnormalities of the upper respiratory tract, tracheostomy can impact on EDS particularly breath/swallow coordination.

- **Cardiovascular disorders** – e.g., for those with congenital heart disease, 42.9% experienced feeding and swallowing difficulties with 32.9% experiencing aspiration (Norman et al, 2022).
- **Gastrointestinal difficulties** – e.g., gastro-oesophageal reflux, oesophagitis, oesophageal atresia.
- **Structural abnormalities** – e.g., 50.3% of those with laryngomalacia (Simons et al, 2016) and 92.9% of children with a vocal cord palsy experience EDS difficulties. 57% of those with laryngomalacia show silent aspiration on videofluoroscopy (Irace et al, 2019). Between 17%-55% of children with a repaired oesophageal atresia experience swallowing difficulties (Coppens et al, 2016).
- **Craniofacial conditions** – e.g., 80% of children with a cleft lip and/or palate experience difficulties prior to the cleft being repaired with 14% continuing to experience difficulties afterwards (Alfwaress et al, 2017). 47%-100% of children with Pierre Robin sequence experience difficulties (Paes et al, 2017).
- **Congenital syndromes** – e.g., up to 87% of infants with Prader-Willi will experience aspiration events (Salehi et al, 2017). 89.8% of infants with Down's syndrome experiences oral stage difficulties with 72.4% experiencing pharyngeal difficulties (Narawane et al 2020).
- **Learning disability** – There is limited information on the prevalence of EDS difficulties for children with a learning disability, however data from adult learning disability prevalence studies show it is an important consideration for this population.
- **Sensory processing difficulties** – This can include having different sensory experiences or experiencing differences in sensory feedback or sensory awareness.
- **Psychological and mental health related conditions** – Infants and children have changing anatomy and may need to overcome developmental challenges or alter any pre-learned, aversive patterns and behaviours associated with eating and drinking. Many conditions causing EDS difficulties will persist into adulthood. It is important to consider the transition between services and how conditions causing EDS difficulties may intersect with each other.

EDS difficulties in adults

Dysphagia in adults can occur because of a range of medical disorders (Ribeiro et al, 2024). These include but are not limited to:

- **Frailty and ageing** – There is a high association between frailty in older adults and EDS difficulties (Bahat et al, 2019). Up to 43% of all over 65s admitted to an acute elderly ward may have EDS symptoms (Olesen et al, 2021). For those over 80 years of age, the incidence during acute admission is up to 82.4% (Mateos-Nozal et al, 2020). The complex relationship between frailty and associated general medical conditions e.g. urinary tract infections, needs further research to explore the direction and causality of this relationship.

- **Autoimmune conditions** – Autoimmune neurogenic dysphagia may present as a symptom of an autoimmunity or as the sole presentation (Stathopoulos and Dalaka, 2022). 36-56 % of service users with idiopathic inflammatory myositis can experience EDS difficulties (Labeit et al 2020). Service users with HIV/AIDS may present with a variety of EDS difficulties (Cohen, Seedat and Sawasawa, 2023).
- **Cardiovascular disorders** may have an impact on EDS difficulties (Yuan, 2014).
- **Connective tissues disorders** – 53-58% of service users with conditions such as systemic sclerosis experience EDS difficulties (Galli, 2020).
- **Covid and Long Covid**– 94% of service users in intensive care with Covid-19 experienced dysphagia (Clayton, Freeman-Sanderson, and Walker, 2024) after 12 weeks or more 20% of service users with Long-Covid experienced voice and throat problems (Whittaker et al, 2022).
- **Functional neurological disorders** (FND) – Approximately 21% of people with FND experiencing EDS difficulties (Barnett, Armes, and Smith, 2018).
- **Genetic conditions/syndrome**– The incidence and prevalence of EDS difficulties related to genetic conditions varies according to each specific condition. For example, EDS difficulties are a key symptom of oculopharyngeal muscular dystrophy (Werling et al, 2015). It is important to consider how genetic conditions identified in childhood may impact on EDS over the lifespan and how other acquired causes of EDS difficulties may impact on pre-existing difficulties. New drug treatments for conditions such as Spinal Muscular Atrophy (SMA) type 1 are extending life expectancy; therefore, new protocols for EDS will be required if/when children reach adulthood. Specific conditions associated with learning disabilities can result in both anatomical and neurological precursors to EDS difficulties including Down syndrome, Rubinstein Taybi syndrome and Rett syndrome.
- **Head and neck cancer** – 89% of service users reported EDS difficulties post laryngectomy (Arenaz et al, 2018). 54.9% of service users with head and neck cancer experiences EDS swallowing difficulties (Zebralla et al, 2021).
- **Infection** – EDS difficulties may be secondary to an infection of the nerves innervating the muscles of the head and neck e.g. Ramsay Hunt syndrome (Shim et al, 2011). Up to 66 % of people with Bell's Palsy experience EDS difficulties (Seçil, Aydogdu and Ertekin, 2002).
- **Iatrogenic causes** – e.g. the use of antipsychotic medication (Miaronsa and Rofes, 2018 radiotherapy (Caudell et al 2008).
- **Learning disabilities (LD)** – 8.1% to 11.5% of adults known to learning disabilities services will have EDS difficulties (Chadwick and Jolliffe, 2009; Ball et al., 2011) and 15% of adults known to learning disability services have mealtime support needs (Ball et al, 2011). 43.8% of adults with LD aged over 50 have EDS difficulties (Sanders et al, 2024). 17.3% of adults with LD over the age of 40 have a history of choking (Manduchi et al, 2021). Adults with LD are twice as likely to die from preventable illnesses with EDS ability often playing a pivotal role in preventable morbidity and mortality (Perez et al, 2015). It is important to consider how new or existing EDS

difficulties impact people with learning disabilities and the transition of children from paediatric to adult services. Adults with a LD experience EDS difficulties at a younger age due to the higher prevalence of additional comorbidities such as cerebral palsy. A study by Watkins et al. (2022) found that adults with LD over the age of 40 years have a similar health profile to adults without LD over the age of 65 years. The average age of adults with LD referred to speech and language therapy for EDS difficulties was 53 years, which was 25 years younger than their counterparts without LD referred to the adult community for EDS difficulties (Crocker et al. 2024).

- **Mental health** – EDS difficulties are highly prevalent in mental health conditions, with figures varying from 19% to 46% (Guthrie et al., 2023). When clinicallyassessed, between 32%-45% of people showed signs of EDS difficulties which increased to between 84% and 93% when instrumentally assessed (Affoo et al, 2013). Between 23-31% of individuals with schizophrenia experience EDS difficulties (Regan, Sowman, and Walsh, 2006). For those with a LD, mental health problems may be twice as prevalent as that of the general population (Smiley et al, 2007; Emerson & Hatton, 2007; NICE 2016).
- **Neurological disorders** – EDS difficulties may be experienced by up to: 50% of people post stroke (Cohen et al; 2016); approximately 50% of people with Parkinson's disease (Panebianco et al; 2020); between 30-100% of people with Motor Neurone Disease (Panebianco et al 2020); approximately 31% of people with Multiple Sclerosis (Panebianco et al 2020) and between 16-83% of people with Progressive Supranuclear Palsy (Litvan, Sastry, & Sonies, 1997). Up to 75% of people with Guillian Barre syndrome experienced EDS difficulties whilst in intensive care (Orlikowski et al, 2009). 34.4% of people with a subarachnoid haemorrhage experience EDS difficulties (Kesser et al, 2020). Up to 85.9% of people with dementia (Espinosa-Val et al, 2020) and 27-30% of people with traumatic brain injury (Takizawa et al 2016).
- **Other oncology** – Lung cancer may affect the ability to coordinate breathing and swallowing, the primary tumour may affect the nerves for swallowing innervation or treatment such as radiotherapy may impact EDS difficulties, 85% of people with a brain tumour experienced EDS difficulties for at least 4 weeks (Pace et al, 2009).
- **Respiratory causes** – Cardiopulmonary disorders may cause EDS difficulties. For example, 15-20% of people with chronic obstructive pulmonary disease (Mokhlesi et al 2002) and 11-93% of people with a tracheostomy tube (Skoretz et al, 2020) may experience EDS difficulties ndividuals who are dependent on ventilation can also experience these difficulties i.e. post-extubation dysphagia is present in 3-62% of individuals (Skoretz et al, 2010).
- **Surgery** – To any of the structures related to swallowing can have a significant impact on EDS. Adults aged over 65 who have swallowing difficulties before thyroid and parathyroid surgery are 3.07 times more likely to have swallowing difficulties post-surgery, which can persist up to 6 months post operatively (Crepeau et al, 2024), 19.4% of people experience EDS difficulties post anterior cervical dissection and fusion (Tsalimas, 2023). Research has shown EDS

difficulties post cardiac surgery in up to 52% of cases of which 53% silently aspirated (Plowman et al, 2023).

- **Trauma** – This may be related to the cervical spine, face, brain (Borders et al, 2018) or other insults to the aerodigestive trace e.g. thermal burns (Clayton et al, 2020).

Role of speech and language therapy

Guidelines suggest that people who present with indicators of EDS difficulties should be referred to someone with relevant skills in the diagnosis and assessment of dysphagia (NICE, 2006). SLTs have a unique HCPC recognised and registered role in identifying and managing EDS difficulties associated with a broad range of developmental, neurological and head and neck disorders. There is evidence that interventions (behavioural and other) used by SLTs in the treatment of EDS are effective. SLTs should use **evidence-based practice** or best available evidence to support any aspect of EDS care. SLTs are key members of the multi-disciplinary teams working with both children and adults across the care pathway. SLTs work collaboratively alongside medical and nursing teams, dietitians, clinical psychologists and other professionals. SLTs support early communication, feeding, and swallowing through skilled observation, assessment, collaborative management planning and education (Murphy et al, 2021; Marks, Gordon and Parnell, 2022).

The overall aims of the SLT working with an individual with EDS difficulties include:

- Information gathering which can include discussions with the service user, parents, carers, family members and the multi-professional team.
- Detailed and comprehensive assessment (there may be multiple assessments over time) leading to accurate diagnosis of EDS difficulties which may assist with the differential medical diagnosis and/or the developmental profile. Assessment may be clinical/observational but may also be supported by instrumental assessments such as Videofluoroscopy and endoscopy.
- Reducing risks to how individuals feel, function and survive e.g. reducing risks to health-related quality of life, number of hospitalisations, severity and frequency of infections.
- Balancing any potential risks with quality of life, considering the individual's preferences and beliefs, family dynamics and lifestyle.
- Working with other members of the team, particularly dieticians, to optimise nutrition and hydration.
- Maximising safe and effective EDS skills with oral motor/sensory exercises, swallow techniques, positioning and swallow rehabilitation.
- Working to maintain swallow function for as long as possible in those with progressive EDS difficulties.
- Working collaboratively with the MDT, particularly pharmacy and the medicine management team to support clinical decision-making regarding an individualised plan for administering medication (Blaszczyk et al, 2023).

Prompt intervention in the management of EDS can prevent costly and life-threatening complications, such as aspiration pneumonia (Feng et al., 2019). SLTs have a preventative role in strengthening pre-treatment (prehab) swallow for people receiving surgery or treatments including chemotherapy or radiotherapy. The SLT should have a clear understanding of local and national policies and procedures for safeguarding and mental capacity law in relation to EDS and play a key role in supported decision making.

SLTs also play an important role in advocating for the needs of service users with EDS difficulties. Swallowing awareness day is an annual opportunity to raise awareness of EDS difficulties and how SLTs can support them.

The role of the SLT in managing swallowing difficulties in the oesophagus

Historically, the role of the SLT in EDS was limited to pre-oral, oral and pharyngeal stages of swallowing. However, swallowing does not end once the bolus passes through the upper oesophageal sphincter. Abnormalities in the oesophagus can impact on oral and pharyngeal stages of swallowing, and symptoms can overlap. As our understanding of the interaction between oral, pharyngeal and oesophageal stages of swallow has evolved, so too has the role of the SLT. Protocols for SLT-led instrumental evaluation tools including videofluoroscopy and High-Resolution Manometry may now include an oesophageal screen. Therefore, it is essential that SLTs understand how EDS can be affected by abnormalities at all stages of swallowing, including the oesophageal stage. The SLT can identify signs of possible oesophageal difficulties and know when to refer the service user to gastroenterology or other related specialisms. As with all stages of swallowing difficulty, oesophageal stage swallowing issues should be managed as part of a multidisciplinary team. It is within the scope of practice of the SLT to give advice on management of EDS difficulties associated with any stage of swallowing, including provision of non-pharmacological, non-surgical interventions for difficulties arising from oesophageal stage, in line with their knowledge, experience and skills. The extent of the SLT involvement in the management of oesophageal stage difficulties should be agreed at a local level and may vary depending on clinical area, the members of the MDT, supervision available and individual role.

Vulnerability and risk

With an ageing population surviving longer, the number of people living with major illness is projected to increase by over a third by 2040 (Watt et al, 2023) and with increasing survival rates of pre-term babies, children and young adults with complex health needs living into adulthood, the need to consider EDS decisions in the presence of risk is likely to increase. Decisions are made even in early life for some babies to continue feeding with acknowledged risks. Extensive consideration is taken in relation to benefits and long-term outcomes for the infant and wellbeing of the mother.

An **individual's capacity to take part** in the **decision-making process** with regards to eating and drinking with acknowledged risks, should be considered within the assessment process and the discussion regarding future management options. It is particularly important, where possible, for individuals to be involved in the decision-making process during the last days of life.

The RCSLT has produced **Guidance for healthcare professionals around eating and drinking with acknowledged risks: Multidisciplinary team guidance for the shared decision-making process** (adults). The RCSLT recognises the need for paediatric guidance around eating and drinking with acknowledged risks and will be developing guidance in due course.

Impact of eating, drinking and swallowing difficulties – adults

Difficulties with EDS may have life-threatening consequences and can impact on an individual's quality of life. This may be due to embarrassment, lack of enjoyment of food, or inability to participate in food-related social activities, which can have profound social consequences for both the person and members of the family. EDS difficulties can present in many ways, and the patient may demonstrate one or several of the following symptoms:

- Food spillage from lips
- Taking a long time to finish a meal
- Impaired/reduced chewing ability
- Dry mouth
- Drooling/impaired oral management of secretions
- Nasal regurgitation
- Food sticking in the mouth, throat or behind the breastbone
- Poor oral hygiene
- Coughing and choking or gagging when swallowing
- Regurgitation of food
- Wet voice or hoarseness
- Weight loss or not meeting expected weight gain
- Repeated respiratory infections
- Food refusal or fear of eating
- Feeling of pain or discomfort when swallowing
- Reduced eating and drinking enjoyment
- Difficulty co-ordinating breathing and eating and drinking
- Difficulty taking medications
- Impulsive/impetuous/ risky feeding behaviours including rushing and cramming. These behaviours may differ and have varying impact on EDS during different times of the day.

Individuals who do not have appropriate EDS assessment and management may be at risk of:

- Aspiration pneumonia (Cohen et al 2016; Chang et al, 2023)
- Community acquired pneumonia (Almirall et al, 2013)
- Choking and death (Marik and Kaplan, 2003; Hemsley et al, 2018). Whilst it is recognised that anyone can experience a choking episode, people with dysphagia have a higher risk of choking and the consequences can be fatal. Choking is a serious and under-recognised condition for adults with learning disability (LD), with health, psychological and potentially fatal consequences. 17.3% of adults with LD over the age of 40 years have a history of choking. Eating difficulties, cerebral palsy, visual impairment, being over 65 years old and antipsychotic

use increase the odds of choking history. (Manduchi et al., 2021).
- Poor nutrition and weight loss (Wright et al, 2005; Saleedaeng, 2023)
- Dehydration (Cohen et al 2016; Connolly, 2010;Reber, 2019)
- Compromised general health (Leder and Suiter, 2009)
- Increased caregiver burden (Rangira et al, 2021)
- Hospital admission or extended hospital stay (Low et al, 2001; Patel et al, 2018)
- Reduced quality of life (Nguyen et al, 2005; Smith, Bryant and Hemsley, 2024)
- Reduced health and well-being.

Mental Health

People with mental health conditions and EDS difficulties may have severe negative physical health consequences, such as poor nutrition and hydration, choking and premature death (Guthrie et al., 2023). Studies demonstrate that EDS difficulties can impact on social participation and inclusion, with people reported to have reduced control over decisions, feeling stigmatised, and isolated, which further impacts mental health (Aldridge and Taylor, 2012; McHutchion et al., 2021; Smith et al., 2023).It is generally recommended that an assessment should include a functional EDS assessment during a mealtime rather than a snapshot bedside assessment. The use of videoing within assessment has some potential.

- **Medication side effects** -Many individuals with mental health conditions may be prescribed medications that can affect EDS function. Antipsychotics, antidepressants, anxiolytics, and mood stabilizers can cause dry mouth, EDS difficulties, or changes in saliva consistency, which may increase the risk of aspiration or choking during swallowing. Antipsychotics can also cause changes in muscle tone (reduced) and to alter the level of consciousness (reduced alertness) which can increase the risk of penetration/aspiration and choking. People with a LD are thought to be 16 times more likely and autistic people 7 times more likely to be prescribed an antipsychotic than the general population (NHS England: STOMP).
- **Psychiatric symptoms** -Mental health conditions such as schizophrenia, bipolar disorder, or severe depression can manifest with symptoms such as psychomotor agitation, catatonia, or cognitive impairments that may impact the coordination and safety of swallowing. Assessing the individual's current psychiatric symptoms and their effect on EDS is essential for understanding the associated risks.
- **Emotional factors** -Mental health conditions often coexist with emotional distress, anxiety, or trauma-related responses that can influence swallowing function. Individuals may experience fear or discomfort related to EDS, leading to avoidance behaviours, reduced oral intake, or functional dysphagia. Understanding the emotional context of dysphagia is crucial for effective assessment and intervention. It is important to consider how previous traumas around EDS

may impact on the service user's current presentation including childhood experiences.

- **Cognitive functioning** – Many mental and physical health conditions (e.g. TBI, stroke, dementia etc) are associated with cognitive impairments, including deficits in attention, memory, executive function, and problem-solving skills. These cognitive challenges can impact an individual's ability to follow swallowing precautions, adhere to dietary modifications, or use compensatory strategies effectively. They can also have an impact on the individual's ability to take part in swallowing rehabilitation, maintain EDS independence, take part in discussions and decision making, and impact on their understanding of risks and benefits of EDS recommendations. Cognitive functioning can also impact on sensory awareness and lead to disruptive eating behaviours such as under-chewing food, bolting and cramming as well as eating non-food items. Comprehensive EDS assessments should include evaluations of cognitive functioning to tailor interventions accordingly.
- **Social support and environment** – Social factors, such as living arrangements, caregiver support, and mealtime environment, play a significant role in managing EDS difficulties in the mental health population. Individuals with mental health conditions may face challenges in accessing appropriate mealtime support, maintaining a consistent eating schedule, or communicating their EDS difficulties to others (Guthrie et al, 2023). Assessing the social support network and identifying potential barriers to safe swallowing is essential for developing holistic dysphagia management plans.
- **Eating disorders –** The role of the SLT within eating disorder services is evolving to include input for communication and EDS difficulties across both for adult and paediatric services.

Pneumonia

Pneumonia is a major cause of morbidity and mortality after stroke and head injury that can be associated with EDS difficulties. Sellars et al, (2007) in a study of 412 patients determined the key characteristics that would predict patients at high risk for post-stroke pneumonia. These included older-age, dysarthria, severity of post-stroke disability and an abnormal water swallow test. EDS difficulties have been identified as a serious risk factor for developing aspiration pneumonia in frail older people. The pathogenesis of aspiration pneumonia in immunocompetent elderly people has been attributed to oropharyngeal colonisation of respiratory pathogens and subsequent aspiration–inhalation of infectious particles (Rofes et al 2010). EDS difficulties have also been proposed as an independent risk factor associated with community-acquired pneumonia in the elderly (Almirall et al, 2013). Aspiration of secretions is normal in the general population, and immune-compromised status and poor oral health can increase pneumonia risk in the absence of EDS difficulties. However, the presence of EDS difficulties can heighten that risk. Langmore (1998) concluded that dysphagia was an important risk factor for aspiration pneumonia, but generally not sufficient to cause pneumonia unless other risk factors were also present. Dependency for feeding emerged as the dominant risk factor.

Respiratory health

Aspiration related to EDS does not always result in respiratory deterioration and other factors can have a significant effect on the development of aspiration pneumonia e.g. poor oral health, clinically assisted artificial nutrition and hydration and reduced mobility. (Gillman, Winkler and Taylor, 2017; Ball, Meteyard and Powell, 2023). However, certain patient populations who may already be affected by respiratory complications,(e.g. COPD, progressive neurological conditions and stroke) are more vulnerable to further respiratory deterioration if they experience EDS difficulties (Prather et al, 2014; van der Maarel-Wierink et al, 2011; Yuan et al, 2015; Lin and Shune, 2020).

Establishing whether a respiratory complication is directly related to an EDS difficulty remains complex and is often based on clinical hypotheses (rather than investigations such as biopsies of the lungs). Poor oral health is linked to developing aspiration pneumonia (Scannapieco, 2023; Khadka et al, 2021). However, lung health is affected not simply by what is being aspirated but is influenced by a range of interconnected variables that include what is being aspirated (pH of the aspirate) and equally how much is being aspirated, over how long a period of time, and most importantly what the defence mechanisms of the individual are (e.g. cough, mucociliary clearance, immune system function). Increasing evidence suggests that respiratory coordination is key for safe swallowing, thus it can be hypothesised that poor respiratory health could lead to dysphagia (Hopkins-Rossabi et al, 2021).

Choking

The SLT has a key role in preventing choking. 17.3% of adults with LD over the age of 40 have a history of choking episodes with eating difficulties, Cerebral Palsy, visual impairment, being aged over 65 and antipsychotic use increasing the risk of choking (Manduchi et al, 2021). Choking risk assessments may be beneficial for high-risk populations.

The older person

In older people, EDS difficulties can confound existing problems such as diabetes and wound healing (Cheng et al, 2023; Zakaria et al, 2018). Older people are 7 times more likely to suffer food-related choking than a 1-4 year old child, and choking is a significant cause of avoidable death in elderly care settings (Cichero, 2018). In addition to age related changes to EDS, the frail elderly often present with poor oral health, defective, absent dentition, polypharmacy, cognitive impairments and/or neurological disorders that can further impact their EDS abilities. Guidelines produced by the Royal College of Physicians (2021) require the early diagnosis and effective management of EDS difficulties, stating that it has been found to reduce the incidence of pneumonia and improve quality of care and outcomes. Studies suggest that around 30% of older people in hospital and up to 68% of those in nursing homes have EDS difficulties (Wirth, 2016). Sarcopenia is also thought to be a major cause of EDS disorders in the elderly (Abu-Ghanem, Graf, and Govind, 2021). EDS difficulties can cause anxiety at mealtimes: either the individual not wanting to eat alone for fear of choking or feeling embarrassed at their slow and altered eating behaviour (Costa Bandeira et al, 2008).

Impact of eating, drinking and swallowing difficulties – neonates

Respiratory health for neonates

Babies born preterm have an immature respiratory system (Smith et al 2010). Respiratory distress syndrome is a common difficulty for babies born preterm and may lead to requiring some form of respiratory support and potentially surfactant administration e.g. LISA (Yadav et al, 2023, NHSGGC, 2024). The process of lung development can be impaired leading to bronchopulmonary dysplasia (BPD) or chronic lung disease (CLD) (Bonadies et al, 2020).

Babies born at term can have a different physiology of respiratory compromise. These can include congenital diaphragmatic hernia, meconium aspiration syndrome and persistent pulmonary hypertension of the newborn (Gallacher et al 2016). Abnormalities of the anatomy of the head and oesophagus can occur during embryological development leading to infants requiring neonatal care and possible ventilatory support e.g. tracheo-oesophageal fistula, oesophageal atresia, micrognathia and choanal atresia. Structural difficulties can also be caused by trauma during surgery, intubation or as a planned procedure e.g. tracheostomy. These can include vocal cord palsy, subglottic or oesophageal stenosis, laryngomalacia, tracheomalacia and/or bronchomalacia and a high arched palate (Hysinger, 2021).

The impact for communication and feeding for infants with difficulties related to their respiratory health may include:

- delayed, interrupted or inconsistent suck feeding opportunities due to medical status, interventions or surgery
- risk of negative sensory experiences around the face and mouth
- difficulties coordinating sucking, swallowing and breathing during suck feeding
- reduced stamina and endurance for suck feeding
- reduced ability to achieve sucking pressure impacting feeding efficiency
- altered airflow impacting sensory experience within the pharynx and larynx.
- reduced airway protection resulting in aspiration.

For more information see eLearning module: **Speech and Language Therapy in neonatal care: principles of practice**.

Ventilated Associated Pneumonia (VAP)

Ventilated Associated Pneumonia (VAP) is a type of Healthcare-Associated Infection (HAI). It is a lung infection that can develop in an infant in neonatal care if they require for example, repeated and prolonged endotracheal intubation and mechanical ventilation (Bancalari et al 2018, Donn S et al 2020 and Garland 2010). VAP overall is the second most common HAI in neonatal units. Preventative strategies include moving to non-invasive respiratory support, when possible, good hand hygiene and pre-feeding strategies e.g. mouth care with maternal breast milk (MBM) (Klomplas et al 2022).

Feeding and non-invasive respiratory support in neonatal care

There is a lack of guidance and varied opinion in the literature regarding feeding on non-invasive respiratory support. Following a review of the literature, an **RCSLT position paper** was developed which recommends both caution and shared clinical decision-making with parents, carers and the neonatal MDT when considering suck feeding opportunities for infants requiring non-invasive respiratory support. SLT assessment and intervention should consider medical complexity, gestational age, level of respiratory support and/or method, weight, developmental readiness, and suck feeding method(s) within the context of the changing physiological, anatomical, neurological, respiratory, developmental and psychosocial background of the infant who requires non-invasive respiratory support (RCSLT, 2023).

Aspiration of breast milk and formula

Breast milk contains nutritional and biological elements that can protect an infant. Infants who are exclusively feeding with breast milk are at less risk of respiratory illness and hospitalisation (Mineva et al, 2023). Breast milk may result in fewer respiratory consequences if aspirated than formula (Hersh et al, 2022). The protective factors and antibacterial content of breast milk may support recovery from aspiration and prevention of respiratory illness. However, there is minimal research to support or negate this theory. Recent evidence from Duncan et al, 2024 identified infants who breastfeed known to aspirate on video fluoroscopy had increased risk of BAL inflammation and more pulmonary hospitalisations. Continued research regarding the incidence of aspiration and suck feeding, with analysis of the milk type and recovery, may give some further insight into this.

Infants requiring neonatal care

Infants born early, or term infants who are born medically fragile and require neonatal care, may present with feeding and/or swallowing difficulties which could lead to long term eating and drinking difficulties across childhood. This may be evident in a variety of forms:

- lack of/poor reflexes related to feeding e.g. sucking
- Unable to manage own secretions requiring regular suction possibly indicating a delayed or absent swallow
- Unable to latch onto nipple/teat
- Unable to demonstrate suction and compression effectively to remove milk
- Unable to coordinate suck/swallow/breathe pattern
- Coughing, choking or gagging when swallowing

- Respiratory infection
- Poor weight gain

Infants who do not have the appropriate feeding management on the neonatal unit are at increased risk of:

- aspiration
- an increase in medical interventions
- poor chest health
- learnt aversive feeding patterns
- poor weight gain and nutrition
- increased anxiety and distress for their family with significant impact on maternal health
- increased length of stay and readmissions.

Impact of eating, drinking and swallowing difficulties – children

Children

EDS difficulties can impact on a number of physical, social and psychological consequences including:

- poorer quality of life
- poor weight gain and nutrition
- aspiration and poor chest health
- an impact on mealtime enjoyment and interactions.

In children, there are serious implications for both survival and brain development if nutrition is insufficient for developmental needs (Boyle 1991). There is increasing awareness of compromised swallowing in preterm babies. Respiratory disorders caused by aspiration can seriously affect the child's ability to survive or thrive. In addition, EDS difficulties can significantly impact on life, for example the child's ability to participate in mealtime tasks (Morgan et al., 2004, Morgan et al, 2023). This can cause stress for the child and family (Morgan et al, 2012). There is particular need to give support to families of children who are tube fed as it is important to develop systems to have a pleasant feeding/mealtime to establish a good carer-child relationship (Sullivan et al., 2005). Stressful feeding and mealtimes can impact on wellbeing, social interaction and lead to behavioural issues (Tan et al 2022).

Respiratory health

Respiratory needs in children can lead to EDS difficulties as well as being an outcome of them. Structural and physiological issues such as complex airways from TOF-OA, laryngomalacia, tracheomalacia, vocal cord palsy, and laryngeal trauma impact on the mechanism of swallow and breathing co-ordination and airway protection.

Children with a history of prematurity and respiratory needs requiring respiratory intervention such as ventilation or a tracheostomy have a higher risk of aspiration (Sabotka et al, 2023). The impact of poor oral hygiene in ventilated neonate/paediatric inpatients, with subsequent increase in bacterial colonisation of the oropharynx, can also lead to higher risk of ventilator associated pneumonia (NHSGGC, 2024). Chronic lung disease from prematurity can impact on the development of feeding skills which can continue into childhood.

EDS difficulties in children can lead to aspiration, including silent aspiration, which can lead to further respiratory complications such as pneumonia and chronic lung disease. Silent aspiration was found to be prominent in children with neurological based dysphagia (Arvedson et al 1994). Sabotka et al (2023) found that children with chronic subclinical aspiration were at risk of chronic cough, airway inflammation and more severe respiratory infections.

EDS difficulties have been identified as one of 9 risk factors that contribute to respiratory disease in children with Cerebral Palsy (Gibson et al, 2021), with respiratory causes being a major reason for premature death (Blair et al, 2019). Consideration of management of EDS as part of preventative action for respiratory illness in CP is being developed with the **Association of Paediatric Chartered Physiotherapists in the UK** (ACPC 2024).

Assessment

Adult

Swallow screening is a minimally invasive procedure that determines the possible presence of EDS difficulties. Screening protocols indicate the presence of clinical signs that may be indicators of EDS difficulties. Screening protocols are usually carried out by trained nursing staff or other health care professionals. Screening protocols are most commonly implemented in acute settings where EDS assessment and management is supported by rapid input from members of the MDT. Screening protocols are less common in community settings. There is a wide variability in available screening tools and specific training may be required to administer each tool. SLTs have a role in establishing EDS screening procedures in an organisation. For people with EDS following a stroke, evidence from the Sentinel Stroke national audit programme (SSNAP) shows that delays in the screening and assessment of EDS are associated with an increased risk of stroke-associated pneumonia (Bray et al, 2017).

After completion of the swallow screening tool, if an individual is deemed to have clinical signs of EDS difficulties, a referral should be made for a full clinical swallowing evaluation (CSE). EDS assessment falls within the remit of the SLT. Oesophageal assessment does not usually form part of the routine SLT examination however SLTs should have a good awareness of causes and signs of oesophageal dysphagia which may warrant further investigation by the medical team and how these may affect the swallowing process as a whole. However, oesophageal screening may form part of some assessments e.g. oesophageal sweep during videofluoroscopy. (**See section on role of SLT in managing swallowing difficulties in the oesophagus**)

A CSE completed by a SLT should involve a holistic and service-user centred synthesis of many different sources of information, including a thorough case history covering medical, social, cultural and religious factors, history of EDS difficulties, collaboration with other health professionals, the service user and family/carers and current presentation.One of the aims of a CSE is to identify or develop a reasonable hypothesis of how anatomy, physiology and/or neurology is contributing to the person’s EDS difficulties. A clinical swallowing evaluation should include or consider the following aspects:

- an orofacial and cranial nerve examination
- trials with appropriate volumes and consistencies of diet and fluids
- consideration of the impact on service user’s wellbeing, including the presence of an advanced directive if appropriate
- contextual factors that may impact on an individual’s presentation
- consideration of a risk assessment regarding aspiration, including consideration of **eating and drinking with acknowledged risks**

- health and safety considerations (e.g. infection control, personal protective equipment (PPE), food handling, moving and handling)
- consideration of the need for an instrumental swallow assessment (VF, FEES, Manometry) to provide more in-depth physiological and anatomical information on swallowing that can inform dysphagia intervention and management – see separate RCSLT guidance on these.

Assessment templates and those designed to record case histories such as those developed for the pre-registration EDS competencies online eLearning are a useful starting point in developing organisation specific documentation.

Following completion of a CSE the following outcomes may result:

- diagnosis of characteristics of EDS difficulties and their severity
- recommendations for management/intervention/rehabilitation options that are jointly agreed with the service user
- consideration of the role of clinically assisted nutrition and hydration
- prognosis for improvement, maintenance or deterioration of function
- referral for other services or professionals. Including instrumental EDS assessments.

The SLT should provide sufficient information to the service user to enable them, where possible, to make their own informed decisions. This should include ensuring they understand both potential risk and benefits of suggested recommendations and what alternatives are available. This may result in service users giving informed refusal of the recommendations. SLTs should be aware of local policies and procedures to document this outcome and any further actions required.

Neonates and medically complex term infants

The holistic care of an infant and family requiring SLT assessment is underpinned within family integrated care, trauma-informed care and long-term neuroprotective care. A fully embedded MDT would approach the assessment of an infant and family within the remit of medical stability, readiness and cue based. When infants and families require specialist SLT assessment this will involve:

- general observation, medical history, respiratory status, stability on handling and level of readinesscues
- consideration of parental wishes, concerns
- pre-feeding assessment. Oro facial examination including cranial nerves, mouth care, non-nutritive sucking, skin to skin, supportive tube feeding, management of secretions, level of and maintenance of alert state and state regulation, feeding cues, oral feeding reflexes

- feeding assessment. If breast feeding discussing expressing, milk supply, last expression, skin to skin contact, NNS at recently expressed breast. If bottle feeding consideration of positioning, teat choice and flow of teat. It must be ensured parents are given the first opportunity to experience a bottle feed with their infant. The consideration of multiple feeders needs to be considered for assessment and management.
- consideration of the need for an instrumental swallow assessment (videofluoroscopy, FEES) to provide more in-depth physiological and anatomical information on swallowing that can inform intervention and management (**RCSLT neonatal guidance**). However, the method of feeding should be considered prior to the consideration of instrumental assessment specifically in relation to breast feeding (RCSLT Neonatal Instrumental position paper – currently being finalised).

Quality narrative can be given around the feed and further strategies identified using assessment tools e.g. UNICEF UK Breastfeeding tool, UNICEF UK bottle feeding tool, the Infant Driven Feeding Scales (IDFS) (Waitzman, Ludwig and Nelson, 2014). Other tools include pulse oximetry and cervical auscultation (CA).

Following completion of a holistic feeding assessment the following outcomes may result in

- diagnosis of characteristics of feeding skills/dysphagia within a developmental framework
- recommendations for management/intervention/strategies
- prognosis for development of feeding skills
- referral for other services or professionals.

Children

SLT assessment of children with eating, drinking and swallowing difficulties may need to consider several areas. All assessment should be underpinned by person-centred care and consideration of the child's own health, wellbeing and lifestyle. However, it is acknowledged that assessment protocol may differ in different settings and services. Assessment may include, but is not limited to:

- general observation. This may need to take place in a variety of settings including hospital, neurorehabilitation/care facilities, the child's home and education settings.
- comprehensive case history, including consideration of developmental milestones, gross motor skills and history of EDS skill patterns and behaviours.
- caregiver interview, including consideration of ongoing support caregivers may require in relation to the child's EDS.
- oral examination, including assessment of oral structures and dentition.
- discussions around oral care, including existing oral care, use of equipment such as toothbrushes, toothpaste and tolerance to oral care.

- observation of mealtime, including the child's management and tolerance of all texture consistencies and level of assistance/support required.
- cervical Auscultation (CA) and pulse oximetry.
- instrumental assessment if appropriate e.g. videofluoroscopy, FEES, manometry.
- consideration of eating and drinking with acknowledged risk (EDAR), requiring liaison with paediatrician.

Paediatric Feeding Disorder (PFD)

PFD is a diagnosis that sits within the International Classification of Functioning, Disability and Health and is coded within the ICD-10. It is defined as '*impaired oral intake that is not age-appropriate and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction*'. All children with oropharyngeal dysphagia could be described as having a PFD, however there are a significant number of children who have PFD that do not have pharyngeal dysphagia. For example, a child with a long history of reflux (medical dysfunction cause) may have PFD affecting all four areas, impacting oral feeding development, although having a typical swallowing mechanism. There is a central role for the SLT with assessment and treatment of paediatric feeding disorders (PFD). The role of the SLT within PFD is to assess and treat the skills related to feeding and eating (oral sensory-motor skills, swallowing and communication at mealtimes) and the impact this has on the child's development and functioning. The SLT should operate within an MDT framework, to ensure medical, nutritional, skill-based and psycho-social drivers for the feeding difficulties are addressed. The SLT has a role to play in educating and supporting MDT awareness and understanding of paediatric feeding disorders as a developmental condition that is more common in children with neurological and developmental differences, providing adaptations and adjustments to tailor the therapeutic MDT approach to individual need. The SLT has a role to play in training caregivers and those who work with children and young people (CYP), with specific strategies to support communication and interaction at mealtimes.For optimal outcomes, speech and language therapy input should be offered within the above framework, however it is recognised that there is variation with service provision across the country.

Avoidance, restrictive food intake disorder (ARFID)

There is a growing awareness of the role of the SLT working with ARFID. It is a diagnosis within the DSM-5 and is defined as 'an eating or feeding disturbance as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following: significant weight loss (or failure to achieve expected weight gain or faltering growth in children); significant nutritional deficiency; dependence on enteral feeding or oral nutritional supplements and marked interference with psychosocial functioning'.

There are often additional complexities around unmet/unidentified needs in terms of neurodiversity such as Autism, language difficulties and selective mutism (sometimes known as situational mutism). Both children and adults can experience ARFID. The role of the SLT within ARFID is not only to rule out structural/anatomical difficulties alongside an education element, but to support MDT awareness, understanding and identification of the language and communication needs of the individual, the impact this is having on their day-to-day function and how these hidden needs may be driving some of the ARFID presentation. Alongside assessment and support, any intervention needs to be MDT led and should consider psychoeducation work around the individuals presentation. For optimal outcomes for people with ARFID, speech and language therapy input should be funded so that services are embedded within the MDT.

Considerations of equality, diversity and inclusion

Conducting and synthesising information gathered during an EDS intervention plan can be challenging because clinicians must take into consideration multiple factors. For example, a clinician must consider the medical history/diagnosis, the prognosis, as well as individual viewpoints and wishes such as food preferences, cultural background, overall wellbeing and quality of life, to provide equitable person-centred care.

Although eating and drinking are essential for obtaining the vital nutrition that the body needs, they are also integral parts of cultural identity, social interaction, participation and inclusion. As previously described, EDS difficulties not only impact physical health, but they can be detrimental to wellbeing, impacting the mealtime experience, independence, inclusion and social participation. That is not only due to the physical manifestations, but it can also be a result of the EDS intervention methods, such as food and fluid modification, restrictions of certain food types, positioning, environmental adaptations, assisted feeding, and feeding tubes (Krekeler et al., 2018; Egan et al., 2020; Leslie and Broll, 2022). People with EDS difficulties may face multiple barriers when it comes to inclusion and social life fulfilment. For example, difficulties in finding modified food in restaurants impedes social participation and inclusion (Ambrocio and Shune, 2022). In addition, people with feeding tubes often face discrimination and exclusion from public places during feeding time, leading to devastating feelings and moments for the people and their carers (Brotherton et al., 2007; Taylor et al., 2022).

Eating and drinking are recognised to be interwoven with someone's culture and social identity. Culture encompasses patterns of human behaviours that include language, customs, beliefs and values (Riquelme et al., 2023). As the UK population is increasingly diverse, clinicians must be culturally responsive (Health inequalities guidance, RCSLT 2021). SLTs should be culturally competent when treating EDS difficulties because food, drinks and mealtimes can have symbolic meanings for individuals and often represent an individuals' identity. Mealtime adaptations may have a detrimental effect on an individual's personal identity and may affect social inclusion (Ambrocio and Shune, 2022). Similarly, individual religious beliefs, which are part of someone's culture and identity, additionally influence eating and drinking. Food often is intricately tied to religious practices, with some religions having a clear set of dietary laws (Leslie and Broll, 2022). Individual dietary preferences such as a vegetarian or a vegan diet also play an important role in someone's beliefs and identity and must also be considered when agreeing an EDS intervention plan. In order to support clinicians and organisations in providing equitable, inclusive, person-centred care, the RCSLT (2022) provided practical steps and tools in the '**Analysing diversity, equity and inclusion in speech and language therapy' position paper**.

Moreover, vulnerable populations, such as those with learning disabilities (LD) and those in institutionalised care settings (both adults and children), are often excluded from the decision-making process and can face health inequalities in accessing appropriate care, as has been described in the **RCSLT Learning Disabilities position paper (2023).** Adults with a LD live with high health inequalities and die on average 15-20 years earlier than those without (LeDeR, 2020). The RCSLT report demonstrates that children and adults with LD are often treated unfairly and excluded by health and care professionals from the decision-making process, leaving them to feel powerless. In general, patient adherence in EDS management, was found to be affected by the influence that individuals have over treatment decisions, such as food modification (Smith et al., 2024). In their systematic review, Krekeler et al., (2018) demonstrate that patient adherence to an EDS intervention plan is influenced by the ability of the patient to remain independent and by the influence they have over decision making processes.

Access to healthcare services for vulnerable communities is frequently impeded. **The RCSLT Health inequalities guidance** (2023) highlights how health inequities are more likely to be experienced by those from 'under-served' or marginalised groups, such as black and minority ethnic groups, those who identify as lesbian, gay, transexual, queer/questioning, intersex and asexual plus (LGBTQIA+), groups with specific social and economic status (e.g., employment, religious beliefs, stigmatised populations, etc.), health status (e.g., people with LD), and those living in socio-economically disadvantaged areas. The guidance additionally highlights the SLT's role in reducing health inequalities and health disparities, as well as the responsibility of both individuals and organisations to understand and recognise the communities they serve.

Witham et al., (2020) in their study demonstrate that underserved populations are often excluded from study trials. For example, in the scoping review of Hirschwald et al., (2024) authors describe that the underserved in EDS and Parkinson disease were groups of younger people (under 50), older people (over 80), and women, etc. According to the National Institute for Health and Care Research (NIHR), failing to include a broad range of participants is impacting the generalisability of findings. To address inequalities in health and care studies, NHIR developed the INCLUDE project, which healthcare researchers are advised to consult when setting a research project.

According to the government (**GOV.UK 2022**), health inequalities and health disparities are sometimes used as interchangeable terms. This has been described by them and The King's Fund (2020):

"Health inequalities are unfair and avoidable differences in health across the population, and between different groups within society, while 'health disparities adversely affect groups of people who have systematically experienced greater obstacles to health"

The RCSLT's commitment to equality diversity and inclusion, aims to support diversifying the speech and language therapy profession and to provide equitable person-centred and holistic care to those with speech, language, communication, and swallowing difficulties. As it is highlighted in **Analysing**

diversity, equity, and inclusion in speech therapy (RCSLT, 2022), ‘It is the moral and legal obligation of speech and language therapists to provide equitable service to everyone.’ This report outlines the six calls to action which are the practical steps to initiate a plan to promote equity, diversity and inclusion, in the speech and language therapy profession, to the services provided to service users, organisations including HEIs, and the wider community.

Practical steps

This is a non-extensive list of recommendations. This list hopes to inspire clinicians to further promote equality, diversity and inclusion in their practice. Please see the **resources page** for further resources.

- SLTs must put service users at the centre of the intervention plan and decision making. SLTs must take into consideration service user viewpoints, preferences, wants and needs and work in partnership with service users and their families or carers. Clinicians must empower service users in decision making.
- Develop strategies to increase cultural competency. Clinicians should dynamically demonstrate cultural humility, which is the lifelong commitment to self-evaluation and self-critique of biases and to take practical steps to tackle them. Clinicians must dynamically assess and reflect upon their conscious and unconscious biases to avoid discrimination.
- Dysphagia researchers should take into consideration the ‘roadmap’ and the recommendations of the **NIHR INCLUDE project** to include populations that are undeserved.

- SLTs should implement specific guidelines such as “Eating and drinking with Acknowledged Risks”, when suitable/appropriate.
- SLTs should provide their recommendations in an accessible format.
- SLTs should provide necessary training regarding intervention modalities to the service users and their carers, to support inclusion, promote participation and to ensure equitable person-centred care.
- Organisations such as hospitals, care homes etc., must make necessary provisions to assure that individual needs will be covered, including religious diets, culturally sensitive diets, cultural appropriate utensils etc.

Health and wellbeing for adults

Understanding the emotional and psychological issues related to EDS difficulties is crucial in supporting the health and wellbeing of service users. When recommending any intervention, you should consider if the treatment creates a burden that outweighs the potential benefit. It is important for SLTs to respect the wishes of the service user and their families/carers, including social and cultural considerations. It is good practice to consider the following aspects to support health and wellbeing:

- physical health impact – e.g. risks of malnutrition and dehydration, weight loss, preventing chest infections, reducing coughing/choking risks, complications associated with tube feeding
- psychological impact – anxiety/fear/embarrassment of eating in public, negative body image
- impact on activity and engagement – impact of EDS difficulties on mealtime experiences, increased length of mealtimes, reduced choice and control, less enjoyment from food, social isolation
- cultural/spiritual impacts – food as a celebration, religious events, cultural identity
- impact on carers – carer burden, stress/fear around food preparation, social isolation, secondary stress i.e. supporting mealtimes
- use of EDS specific quality of life measures as part of the assessment/ management processes
- use of local tools or measures of impact on health and well-being e.g. TOMS (Therapy Outcome Measures).

Infants and families requiring neonatal care

Psychological impact for parents and carers

Parents and carers experience separation and psychological distress which impacts on family mental health, wellbeing and interaction with their infant (Shaw et al, 2013). Mothers with infants in neonatal care are at higher risk of postpartum depression, stress, anxiety and disempowerment. (Muller-Nix, et al 2004, Alkozei et al, 2014 and Aagaard and Hall, 2008). This can have an impact on bonding and infant early interaction skills. Feeding, language, cognitive and emotional development are closely linked to parental/caregiver behaviour, and early negative experiences can impair the development of these early skills and parent-infant relationship (Treyvaud et al, 2009; Treyvaud et al, 2013).

SLT assessment and management for parents and infants is based around current research related to trauma informed care and underpinned by multi-professional working. There is understanding the impact of early trauma has long term impacts on outcomes of those born early or infants born at term but who are medically complex may also have other co-existing conditions. These include necrotizing enterocolitis (NEC), chronic lung disease, Intraventricular haemorrhage (IVH) grade 3-4, Hypoxic-ischemic encephalopathy (HIE), Patent Ductus Arteriosus (PDA), syndromes, and upper airway difficulties. This can lead to poor growth and nutrition, aspiration, sensory based feeding difficulties and long-term medical interventions e.g. oxygen requirement and longer-term tube support (Kamity, Kapavarapu and Chandel, 2021).

Cultural/spiritual impacts

Families and infants requiring neonatal care will have their own individual cultural and spiritual needs. This will include engaging in cultural practices, family celebrations, rituals and religious days. It is important for SLTs to hold understanding and knowledge of different cultural and spiritual needs to support the care, outcomes and experiences for families and infants (MBRRACE-UK, 2024; Ng and Fung, 2023; NHS Race and health observatory, 2023).

Health and wellbeing for children and families

Literature reviews have shown that childhood EDS difficulties can have a significant emotional impact on parents and/or caregivers, particularly increasing stress around mealtimes, negative impact on child interaction and increased feelings of social isolation (da Silva et al, 2023). It is therefore important to consider the needs of both the child and family in management and intervention options for EDS.

Interventions to support feeding, at birth and as infants, may continue to impact on functional EDS as children grow. Trauma, stress caused by a decreased nutritional intake and medicalised experiences of mealtimes can continue to negatively influence the wellbeing of children and their carers. Early intervention for feeding difficulties can also influence sensory needs and experiences with food and drink as children grow.

As well as impacting on respiratory needs, EDS difficulties can have negative consequences for growth, nutrition, hydration and bowels, with an associated impact on skin integrity, immune system support and recovery from illness.

Social activity and participation, along with links to cultural food-based traditions, can also be impacted. Feeding difficulties lead to decreased participation in social gatherings based around food and drink for children and their families (Simione et al, 2020).

Instrumental assessments of EDS difficulties

The most common instrumental assessments within the UK are videofluoroscopy and FEES. Each has its own set of indicators and risks and the treating SLT should be aware of these. Guidance on the use of pharyngeal high-resolution manometry is underway and will be added to this guidance in time.

Videofluoroscopic evaluation of oropharyngeal swallowing function (VFS)

RCSLT position paper: Videofluoroscopic evaluation of oropharyngeal swallowing function (VFS) the role of SLTs (2013). Please note that this position paper had been deemed a priority for RCSLT to update.

The following videofluoroscopy competencies were developed by Greater Glasgow and Clyde NHS trust:

- **VFS competencies: Adult level 1**
- **VFS competencies: Adult level 2**
- **VFS competencies: Adult level 3**
- **VFS competencies: Adult level 4**

The VFS competencies were developed by Annie Aloysius and Imperial College Healthcare NHS Trust (2008):

- **VFS competencies: Paediatric**

During videofluoroscopies, prescription only medications (POMs) such as 'omnipaque' are sometimes used for people identified as high risk of aspiration. It's essential to remember that any administration of POMs should be underpinned by appropriate governance. Appropriately trained and competent SLTs are permitted under current legislation to use Patient Group Directions (PGDs) to supply and administer medicines if these are available and authorised within their Trust. If you are unsure what legal authorisation is in place to administer or supply a POM (or any other pharmacy or general sales list medicine) please speak to your pharmacy or medicines governance team and manager who will be able to advise you. Below are some example PGD's:

Example 1 PGD videofluoroscopy

Example 2 PGD videofluoroscopy

Flexible endoscopic evaluation of swallowing (FEES)

FEES is an instrumental assessment of swallowing used by SLTs, in which a flexible nasendoscope is inserted via the nose to directly view naso-/oro- and laryngopharyngeal structures, secretions, sensory response and pharyngeal swallow function. More about FEES can be found in the RCSLT's **Flexible endoscopic evaluation of swallowing (FEES):** position paper, competency framework and training logs.

SLT led high-resolution manometry (HRM)

High resolution manometry (HRM) is an evidenced based instrumental swallow evaluation and biofeedback treatment tool, suitable for use with service users who present with eating, drinking or swallowing difficulty arising from a wide range of aetiologies in adults and children. RCSLT have developed a **position paper**, **competency framework** and **further resources** to support it's use and wider adoption.

Oral health inadults

Good oral health refers to the promotion and maintenance of a clean mouth including the teeth, gums, cheeks, tongue and palate. Poor oral hygiene can lead to dental caries, periodontal gum disease, the development of ulceration, soreness, cracked lips and fungal infections, and is associated with increased bacteria in the mouth and in saliva (National Clinical Stroke Guidelines, 2023; Ortega, 2014; Scannapieco, 2021).

There is evidence to suggest that the combined effects of poor oral hygiene and EDS difficulties may increase the risks of an individual developing aspiration pneumonia (Khadka et al, 2020, Azarpazhooh and Leake, 2006; Drancourt, 2022; Logemann et al, 2013). As a result of poor oral hygiene, saliva contaminated with multiple bacteria can cause pneumonia if aspirated. Additionally, residuals of microbes may remain in the lower airways due to an ineffective cough reflex and weakened respiratory system. Evidence supports the use of oral health care interventions such as regular tooth brushing, to reduce the frequency of pneumonia and to improve quality of life (Manger et al, 2017; Wu et al, 2022; Remijn, et al, 2022; Tada and Miura, 2012). SLTs have a key role in raising awareness and supporting the training of carers and other health care professionals in this important area.

Barriers to good oral health

Service users can face multiple barriers to achieve good oral health which can include (Hansen et al, 2021; Leggett et al, 2023; Palmers et al, 2022):

Service user barriers

- An individual's physical, mental and cognitive ability to carry out effective oral hygiene, seek dental services and make choices about healthy eating (British Society for Disability and Oral Health, 2001).
- A lack of perceived need, inability to express need and lack of ability for self-care.
- Communication difficulties, particularly difficulties communicating discomfort or pain.
- Fear and anxiety of visiting the dentist.
- Sensory differences or sensitivities.
- Financial or logistical barriers to accessing dental services e.g. a lack of dental services nationwide.
- Side effects of medication or treatments e.g. radiotherapy, chemotherapy.

Carer barriers

- Challenges in providing a recommended healthy and nutritionally complete diet for people with dysphagia.
- Need for high calorie food supplements, sugar based liquid medication, and laxatives may increase the risk of dental cavities.
- Knowledge and skills of carers.
- Time to complete all care tasks including oral care.

Professional service providers (dentists)

- Low confidence and lack of experience of supporting people with e.g. movement disorders, learning disabilities, or mental health difficulties (Komin and Weerapol, 2020*)*.

Physical barriers to accessing oral care

- Mobility difficulties.
- Difficulties attending appointment (e.g. ambulance transfers).

Care setting barriers

- Being in a hospital setting can impact on a person’s ability to easily access cleaning utensils (e.g. toothbrushes).
- Being reliant on others to provide oral care (e.g. in hospital or a care home setting).

Specific oral complications

- Self-Injurious Behaviours (SIB) e.g. Oral self-mutilation or self-injurious behaviour (e.g. biting of lips, tongue and hands). This can lead to infection, scarring and permanent tissue damage.
- Drooling resulting from: impaired oral muscle control (e.g. poor lip seal); a decreased frequency of spontaneous swallowing; side effects of certain medications.
- Dry mouth resulting from: medications; anxiety; drug misuse; radiotherapy; medical conditions e.g. Sjogrens .
- Abrasions or wearing away of the tooth surface due to vigorous tooth brushing, or eating non-food items e.g. coal, soil, pebbles.
- Attrition or wearing down of the biting and chewing surfaces of teeth often because of tooth grinding (bruxism).
- Erosion – non-bacterial chemical process caused by contact with acid (e.g. foods, reflux, excessive vomiting).
- Intraoral prostheses or surgical reconstruction (e.g. obdurators, free flap tissue repair).

Oral health care pathway

If the individual is dependent on others for oral care, it is recommended that an Oral Health Risk Assessment (OHRA) is carried out.

'**Mouth Care Matters (MCM)**' is a Heath Education England initiative to improve the oral health of patients in hospital through education and training. Their resources are available for both children and adults. These include screening and assessment tools, resources for improving oral care and training packages.

Caring for Smiles is Scotland's national oral health promotion, training and support programme, which aims to improve the oral health of older people, particularly those living in care homes.

Oral health care for neonates

Regular oral care for neonates and infants with expressed breast milk (EBM) has demonstrated a reduction in ventilator assisted pneumonia (VAP). Overarching positive oral experiences for all neonates, infants and children is essential.

Oral health care for children

Mini mouth care matters (2019) resources are available for infants and children. An introduction of a toothbrush and fluoride toothpaste should be supported on dental eruption. It also may be appropriate to consider non-foaming (SLS free) toothpaste for children at risk of aspiration.

SLT Intervention and management – Adult

EDS difficulties should be managed following comprehensive clinical assessment of the individual (**see Assessment section**) and the management plan should be agreed with the service user, where possible. If the service user is unable to engage in discussions e.g. as a result of delirium or cognitive impairment, clinical decision making should include the MDT and family/carers. EDS intervention and management should aim to optimise service user's potential for oral nutrition, hydration and participation/quality of life whilst managing and reducing risks of aspiration, choking and other adverse effects on health and wellbeing.

Intervention may include:

- working with an individual to develop a person-centred management plan, taking into consideration aspects such as the safety and efficiency of a swallow and clinical presentation. This may include education about normal swallowing, the nature of the individual's EDS difficulties, and counselling around potential for improvement or trajectory of change.
- determining when there may be a rationale for clinical intervention to support swallow rehabilitation and improved swallow physiology.
- considering additional factors in relation to EDS aside from the anatomical/physiological presentation to support an individual (e.g. posture, environment, support staff).
- promoting nutritional intake and hydration.
- being aware of the mental capacity legislation and how this may play a role in EDS intervention.
- contribution to EDAR discussions and planning.

Intervention and management may be direct or indirect and may involve rehabilitation and/or compensatory strategies.

Therapeutic strategies and interventions

Selection of the recommended treatment options should be based on clinical rationale and assessment hypothesis, taking into consideration points such as underlying aetiology and expected progression (e.g. progressive or non-progressive), the current evidence base and the service user and their caregivers' views and the presence of any advanced directives.

Any EDS treatment plan must always put the service users' viewpoints at the heart of any decision-making process. Clinicians need to take into consideration service users' opinion, perspectives, goals, culture and overall wellbeing, before setting any therapeutic plan as described in the HCPC standards of practice. Poor adherence to EDS recommendations is often associated with reduced control over decision making and not considering their wants/needs among others, such as lack of proper training about EDS compensatory strategies, and reduced social participation (Krekeler et al., 2018; Smith et al., 2023).

SLTs should be aware of the contraindications for intervention/management strategies for a specific condition as well as harms that could occur for an individual. (Cheng et al 2023).

Treatment options may be rehabilitative or compensatory. Rehabilitative techniques such as exercises (Expiratory Muscle Strength Training, Masako, resistive lingual isometric exercises) aim to make a lasting change to the individual's swallowing by improving underlying physiological function. Biofeedback is an effective tool for some service users to help stimulate physiological change (Benfield et al, 2019; Albuquerque et al, 2019; Battel, Calvo, Walshe 2021; Archer, Smith and Newham, 2021; Hou et al, 2024).

Compensatory strategies generally alter the swallow when used but do not create lasting change e.g. head rotation, chin tuck posture. They can include modifications to diet and fluid consistencies including changes to bolus size, presentation, texture, taste, temperature and/or sensory properties.

Adaptive equipment and environmental modifications should be considered when appropriate. This could include working with other members of the MDT e.g. occupational therapy (Guthrie et al, 2023).

The published evidence base for many interventions, including optimal recommendations for dosage, is growing, but more high-quality research is needed. Clinicians should apply the principles of **evidence-based practice** when planning dysphagia intervention. **Advances in the Treatment of Dysphagia in Neurological Disorders: A Review of Current Evidence and Future Considerations – PMC (nih.gov)**.

Innovative Dysphagia rehabilitation methods

Several innovative techniques are available, with varying levels of evidence, and these methods generally aim to improve swallow function. These include interventions such as Neuro-muscular electrical stimulation, pharyngeal electrical stimulation, IQORO, respiratory muscle strength training, McNeil Dysphagia Programme, Biozoon, sensory input tools, chewy tubes, and Ora-light tools. Other devices may aim to develop and maintain oro-motor skills alongside swallowing with the use of 'bridge devices' such as silicone/netted feeders. Please refer to the **section on new devices**.

Texture modification

Modifications to diet/fluid texture may include changing the viscosity of liquids and/or altering the texture of solid foods as well as other sensory properties. RCSLT recommend the use of the standardised terminology set out in the **International Dysphagia Diet Standardisation Initiative (IDDSI)**. It is important to remember that IDDSI is a communication tool and not an intervention plan.

When recommending modifications to an individual's diet and fluids, consideration should be given to the following:

- the impact of the modified consistency on the individual's swallowing physiology and function
- aspiration risk
- increased risk of malnutrition and dehydration
- preferences of the individual and their families and/or care givers and the impact on quality of life
- consultation with the inter-professional team including the dietitian and pharmacist to help ensure that the service user's nutritional and medication needs continue to be met
- the **capacity** of the individual to consent to the treatment/management plan.
- For more detailed information refer to the **RCSLT position paper** on the use of thickened fluids.

Sitting upright after meals

One of the most characteristic features of normal gastric emptying is its large variability, depending on the chemical composition of the food. The effect of different foods on gastric emptying is in large part due to the hormones released from the gastrointestinal tract that provides feedback regulation of gastric emptying (Goyal, Guo & Mashimo, 2019).

There is a lack of robust evidence regarding the time it is recommended to sit upright after eating and drinking. Gravity is thought to aid in the digestion of foods and sitting upright may help to reduce gastrointestinal discomfort and reflux.

It is generally recommended that, if possible, an adult is positioned in an upright position for 30 minutes after eating and drinking. For babies, holding the baby upright after feeding for 10-15 minutes may help the stomach more easily digest the milk or formula they have consumed. However, the time recommended should be person specific and factors such as ability to maintain upright position, skin integrity, pain/discomfort, sitting balance safety and service user cooperation should be considered.

SLT Intervention and management – Neonates

SLT management is delivered as part of the MDT underpinned by developmental care and family integrated care frameworks. All decisions are made within a family centred approach with aim to support and develop oral suck feeding. Approaches to feeding support are cue-based and responsive. All feeding experiences should be positive for both infant and parent/carer.

Pre-feeding interventions

Early pre-feeding support is key to the development of feeding skills (British association of perinatal medicine: toolkit 1, 2020). These include:

- skin to skin/early positive touch
- buccal colostrum within first six hours
- mouth care with EBM
- non-nutritive sucking
- supportive tube feeding.

Breastfeeding

Maternal breast milk (MBM) is the optimal form of feeding for preterm infants and is associated with significant short and long-term benefits (British association of perinatal medicine, toolkit 2, 2022). Supporting the establishment of expressing to produce a sustainable milk supply is essential. Management includes:

- skin to skin
- expressing regularly at cot side, in skin to skin
- non-nutritive sucking (NNS) at recently expressed breast/dummy dips
- positioning and effective latch
- express initially, pacing
- time limits
- consideration of nipple shields.

Supportive bottle feeding

Families choose expressed breast milk or formula during feeding.

- responsive cue-based feeding (White and Parnell, 2013)
- consideration of choice of bottle/teat
- milk flow rate (Bell and Harding, 2019)
- pacing

- positioning – Elevated Side lying (Raczynska, Gukczynska and Talar, 2021)
- volume limitation and/or time limitation
- use of thickener should be considered by the full MDT with caution in this population (Gosa and Corkins, 2015: Beal et al, 2012; Koo et al, 2019)
- the consideration of multiple feeders needs to be considered.

Infants born premature and/or with complex medical conditions may present with persistent feeding and or swallowing difficulties. These infants will require long term tube support with continued pre-feeding management strategies to aim to promote development of oral and pharyngeal skills within a developmental framework.

Training and the environment

The **environment** should be appropriate to ensure neuro-protective care is optimised within a developmental care framework. Ensuring an environment is created to promote early pre-feeding skills and cue-based responsive suck feeding will have a significant impact on the feeding journey. It is key that the impact of the neonatal environment is considered in the development of feeding skills .

Delivery of **training** and education is underpinned by the principles of neonatal models of care e.g. developmental care, family integrated care, UNICEF Baby Friendly Initiative and Trauma Informed Care. Training can be offered to all members of the multi-professional neonatal team, to SLTs and AHPs new to neonatal care and to parents and families. Training is required to support parent and family interaction and involvement with their baby's neonatal care, early communication development, early feeding development, breastfeeding support, bottle-feeding support and feeding and swallowing difficulties which will involve supportive strategies including pacing, positioning and equipment.

SLT Intervention and management – Paediatric

Dysphagia intervention and management should aim to optimise the child's potential for oral nutrition, hydration and participation/quality of life whilst managing and reducing risk of aspiration, choking and other adverse effects on health and well-being.Paediatric dysphagia management should consider the child's current developmental stage, alongside future potential development. Interventions may include:

- working with an individual, families, carers, MDT and education staff to develop a person-centred plan for managing eating, drinking and swallowing difficulties. This should take into consideration aspects such as the developmental picture, maximising nutrition, hydration, growth and the efficiency of feeding, and EDS.
- determining when there may be a rationale for clinical intervention to support the development of EDS skills and providing this intervention within scope of service provision and practice.
- considering external factors in relation to EDS aside from the anatomical/physiological presentation to support an individual (e.g. Posture/positioning, environment, support staff).
- considering compensatory and behavioural strategies which may be required to support a child with eating and drinking e.g. modifying fluid and food textures, feeding techniques like pacing.
- determining whether environmental adaptations or specialised equipment may be required to optimise a child's eating and drinking skills e.g. cups/specialised straws/spoons/plates.
- determining whether there is a need for oral care intervention and provide guidance and support in line with this whilst being aware of aspects such as oral sensation and aspiration risk.
- provide appropriate training and education to parents/carers/education professionals to assist in the intervention/management process.
- being aware of the Gillick Competence, mental capacity legislation and how this may play a role in EDS intervention, considering the context of who decision makers are.

The SLT should be aware of local and national guidance to guide intervention, e.g. Nice guidance NG62 – guidance for management of cerebral palsy in under 25's. Intervention and management may be direct or indirect and may involve rehabilitation, compensatory strategies, and/or training.

Therapeutic strategies and interventions

Selection of the recommended treatment options should be based on clinical rationale and assessment hypothesis, taking into consideration points such as developmental stage, underlying aetiology and expected progression (e.g. progressive or non-progressive), the current evidence base, the patient's and the family/carer views and the presence of any advanced directives.

SLTs should be aware of the contraindications for intervention/management strategies in specific conditions as well as any harms that could occur for an individual.Treatment options may be developmental, rehabilitative, palliative, compensatory and/or modifications to diet and fluid consistencies. Developmental interventions aim to increase eating, drinking and swallowing skills.

Rehabilitative techniques such as exercises (resistive lingual isometric exercises) aim to make a lasting change to the individual's swallowing by improving physiological/neurological function.

Compensatory strategies aim to maximise the effectiveness and function of a person's existing oral or swallowing skills. They alter the swallow when they are used, but do not create lasting change on their own e.g. head rotation, chin tuck posture. However, spontaneous improvement may occur concurrently.

The published evidence base for many interventions, including optimal recommendations for dosage, is growing, but more high-quality research is needed. Clinicians should apply the principles of **evidence-based practice** when planning EDS interventions.

Dysphagia rehabilitation and/or skills maintenance methods

Several innovative techniques are now available which aim to improve swallow function and develop oral skills for eating, drinking and swallowing.

There are varying levels of evidence available for the techniques available and each should be considered on an individual person-centred basis, whilst looking at clinical need and the benefits to the child. Examples of interventions are IQoro, Ora-light, chewy tubes and sensory motor input tools.

Alternative devices also aim to develop and maintain oro-motor skills alongside the swallow with the use of 'bridge devices', such as silicone/netted feeders.

SLTs should work with each individual to understand if or when it is appropriate to use adult interventions. Considerations may include physical and mental developmental level, physiology, growth, and underlying diagnosis, and the SLT should follow the principles of evidence-based practice.

Texture modification

Modifications to diet texture may include changing the viscosity of liquids and/or altering the texture of solid foods and/or temperature/portion size to facilitate safety and ease of swallowing.

RCSLT recommend the use of the standardised terminology set out in the **International Dysphagia Diet Standardisation Initiative (IDDSI).** When recommending modifications to an individual's diet and fluids consideration should be given to the following:

- There is a limited number of thickeners licensed for use with for children under three years old
- the impact of the modified consistency on the individual's swallowing physiology and function
- gut function in neonates and paediatrics
- contraindication of starch-based thickener with macrogol laxatives
- aspiration risk
- increased risk of malnutrition and dehydration
- the preferences of the individual and their families and/or care givers and the impact on quality of life
- the **Capacity** of the individual to consent to the treatment/management plan.

Consultation with the inter-professional team including the dietitian and pharmacist is needed to help ensure that the service user's nutritional and medication needs continue to be met. For more detailed information refer to the **RCSLT position paper on the use of thickened fluids**.

Training and environment

There is a significant level of dependence of paediatrics on caregivers for nutrition and hydration intake. The influence of caregiver and child relationship on EDS has high levels of impact on skills, support and management of eating, drinking and swallowing needs (Aldridge et al 2010, Davies et al 2006).

Consideration of multiple environments that paediatrics may experience should also be part of any assessment and management plan (e.g. home, nursery, school, respite, hospital) and how these can impact on functional eating, drinking and swallowing skills.

Training is required to support appropriate and effective use of strategies, equipment, positioning guidance and texture modification by a range of people in different settings (home, education staff, respite care). Training will include people who are specific to individual care needs (family, carers, 1:1 education support) but may also be needed to develop wider scale awareness of support techniques and signs of clinical concern within education, social care and hospital settings. This is key to facilitating awareness of needs and early referral for specialist support.

Competency frameworks

EDS competency frameworks for SLTs

All pre-registration SLT students graduating from 2026 onwards will be required to complete **pre-registration EDS competencies**. A **suite of resources and supporting documents** is available. As graduates enter the workplace, their role may or may not include EDS. If it includes EDS, they will move to the **Speech and Language Therapist EDS competency framework**. SLTs who are currently EDS trained will transition to the SLT EDS competency framework. This framework is a document to support SLTs working in EDS throughout their careers. Examples of completed frameworks will be added to this page as they are received. This **webinar** gives an overview of the guidance and competency framework with further questions answered in this **FAQ document.**

For carers and other professionals, who are not qualified SLTs, working with people with dysphagia we recommend using the **assessable eating, drinking and swallowing competency framework (EDSCF)**.

EDSCF e-learning

Health Education England e-Learning for Healthcare (HEE e-LfH) has worked in partnership with Sheffield Teaching Hospitals NHS Foundation Trust, RCSLT and industry experts to develop the Dysphagia Guide e-learning resource for those working with people living with dysphagia.

The resource, which was co-developed with care home staff and is relevant to others in the health and care workforce, informal carers and people with dysphagia themselves, can be used to support people working in care to gain the relevant level of competency for their role as outlined in the Eating, Drinking and Swallowing Competency Framework. This resource is also a useful guide for managers in policy and workforce development.

The Dysphagia Guide e-learning resource, which has been adapted by HEE e-LfH, is made up of five sessions that cover the following topics:

- essentials
- food
- quality and safety
- training and resources
- workforce

Visit the**e-LfH website** for more information about the e-learning resource, including access details.

Response times and outcome measures

Response times

Clinicians reserve the right to prioritise referrals in line with their professional judgement, according to the information received and according to local team prioritisation criteria to determine risk and urgency. Classification of whether a referral is urgent or non-urgent needs to be determined at a local level and the organisation should have protocols and procedures to support this decision-making process.

Many speech and language therapy services have service level agreements in place which set out the expected response times to see people with EDS difficulties who are referred for speech and language therapy assessment. Services commissioned to provide rapid response services and who have 7-day services may be required to see individuals who are referred with 24 hours or less.

Based on consensus of expert opinion, the RCSLT recommends the following responses times where a service level agreement does not exist or where the agreement does not state specific response times:

- Urgent patients are seen within 2 working days from receipt of referral irrespective of their setting.
- Acute inpatients are seen within 2 working days from receipt of referral.
- For non-urgent community settings, including educational settings, individuals will be seen within 10 working days in locations where dysphagia services are commissioned and resourced.

It is recognised that under-resourced services may not be able to achieve these response times, however consensus within the SLT profession deems them to be good practice. Services can use the data to support business cases and commissioning to seek increased SLT resources.

A small number of clinical pathways are introducing recommended staffing levels for speech and language therapy services e.g. **neonatal care**. Staffing levels have been agreed nationally for SLT teams working within a **stroke pathway** and for **critical care** teams.

Outcome measures

It is good practice to use outcome measures to measure the effectiveness and impact of any intervention offered. There are a number of outcome measure tools available which can provide both baseline data and show progress or impact of the EDS intervention. Tools can measure severity of any impairment, as well as measuring aspects such as well-being and social participation. Tools can be either generic or condition specific. The use of patient reported outcome measures (PROMS) which show the patient experience of the care should also be considered.

For more details on outcome measures, please see the RCSLT webpages on **outcome measures** and the resources section associated with these pages.

Devices

There are a range of products that claim they may be used in the treatment of EDS disorders. The RCSLT's position on the use of these is the same as for any new intervention. We support the use of new interventions provided that the clinician using them works within national and local governance frameworks and policies. For further guidance, please see our section on the **use of new interventions.**

Transcutaneous Neuromuscular Electrical Stimulation (NMES)

Transcutaneous electrical stimulation involves placing electrodes on a person's neck. Small electrical currents pass through the electrodes to stimulate the peripheral nerve supply of the pharyngeal or laryngeal muscles. The patient carries out an exercise protocol concurrently with the electrical stimulation. There are a number of NMES devices available that use different electrode designs, positions and stimulus intensities. Transcutaneous neuromuscular electrical stimulation (NMES) is usually used as well as traditional swallowing therapy for treating oropharyngeal dysphagia. The aim of NMES is to increase the effectiveness of swallowing therapy by strengthening the muscles involved in swallowing. It also promotes recovery of cortical control of swallowing. Two systematic reviews investigating non-invasive neurostimulation therapies including NMES reported some positive effects on swallowing function and quality of life. (Du et al, 2021; Wang et al, 2021). Similar findings were also reported in recent European Stroke Organisation and European Society for Swallowing Disorders guidelines, although there is a lack of evidence of improvements in other outcomes such as mortality, pneumonia, length of stay or feeding tube removal (Dziewas et al, 2018).

In 2023 the 6th Edition of the National Clinical Guidelines for Stroke included NMES as one of the recommendations. The recommendation states:

'People with dysphagia after stroke may be considered for neuromuscular electrical stimulation as an adjunct to behavioural rehabilitation where the device is available and it can be delivered by a trained healthcare professional'.

In December 2018, the National Institute for Health and Care Excellence (NICE) issued guidance to the NHS in England, Wales, and Northern Ireland on one group of electrical stimulation interventions: transcutaneous neuromuscular electrical stimulation for oropharyngeal dysphagia in adults. NICE recommend that when using a new treatment device or approach that it should be part of service evaluation, audit or research. Thus, gathering data associated with its use is suggested.

Current evidence on the efficacy of transcutaneous neuromuscular electrical stimulation (NMES) for oropharyngeal dysphagia in adults shows there were no major safety concerns.

NICE Guidance on Transcutaneous neuromuscular electrical stimulation for oropharyngeal dysphagia in adults. Interventional Procedure Guidance (IPR634).

An update to this guidance is expected in 2026. The RCSLT recommends carefully reviewing and following this guidance if you are considering using this approach. For questions on indemnity cover while acting on the NICE guidelines, please refer to the **use of new interventions** section for more information.

Pharyngeal Electrical Stimulation (PES)

Pharyngeal electrical stimulation involves a catheter being passed through the nose and into the pharynx. The catheter delivers small amounts of electrical current to the pharynx. The electrical current travels to the brain and stimulates areas involved in swallowing. The aim is to reduce aspiration and improve secretion management and quality of life. In 2024, **NICE issued guidance** around the use of PES.

In summary, the guidance states that ‘For people with neurogenic dysphagia who have a tracheostomy after stroke, pharyngeal electrical stimulation can be used in the NHS while more evidence is generated. It can only be used with special arrangements for clinical governance, consent, and audit or research. There are no safety concerns about pharyngeal electrical stimulation, but the clearest evidence on clinical efficacy is for people with neurogenic dysphagia who have a tracheostomy after a stroke.’

The RCSLT recommends carefully reviewing and following this guidance if you are considering using this approach. For questions on indemnity cover while acting on the NICE guidelines, please refer to the **use of new interventions** section for more information. A single blind randomised controlled trial RCT (Dziewas et al, 2018) showed that the use of PES to aid decannulation in patients with a tracheostomy and dysphagia after stroke was effective. In this trial, PES significantly increased the number of patients who were ready to be decannulated compared to sham stimulation.

In 2023, the 6th Edition of the National Clinical Guidelines for Stroke included PES as one of the recommendations: ‘Patients with tracheostomy and severe dysphagia after stroke may be considered for pharyngeal electrical stimulation to aid decannulation where the device is available, and it can be delivered by a trained healthcare professional’.

IQoro

In March 2019, the National Institute of Health and Care Excellence (NICE) issued a **medtech innovation briefing** about the use of IQoro for stroke-related dysphagia. These briefings are designed to support commissioners and healthcare professionals who are considering whether to use a new medical device or technology and thus they particularly consider safety issues.

NICE's briefing describes key evidence around the product but does not provide specific guidance or recommendations. It concluded that swallowing therapy is the usual treatment for dysphagia after a stroke. The company claims swallowing exercises can be more accurately and effectively done using IQoro. No similar technologies are currently recommended in care guidelines.

IQoro has also been used with a small paediatric case study cohort with reported improvements in saliva control (Hagg and Morris, 2022). However, there is no indication as to any other interventions that were also being used to manage saliva (medication, other therapy interventions). The authors acknowledged that further research is required. Key uncertainties around the evidence are the lack of high-quality, randomised studies and the unclear effect of IQoro compared with NHS standard care or spontaneous improvement.

More detail on NICE's overall assessment of the evidence can be found in the **clinical and technical evidence chapter of the briefing.** We recommend careful consideration of this guidance, as part of an evidence-based approach to practice when considering usage of this device. NICE recommend that when using a new treatment device or approach that it should be part of service evaluation, audit or research. Thus, gathering data associated with its use is suggested.

Iowa Oral Performance Instrument (IOPI)

The IOPI is a device that measures tongue and lip strength and endurance and can be used for biofeedback for oral motor exercises.

A systematic review carried out in 2020 suggests that there is positive evidence in terms of impact on tongue pressures, along with mixed results for swallow safety and efficiency (Smaoui, Langridge and Steele, 2020).

Expiratory Muscle Strengthening Training (EMST)

EMST is a device-facilitated rehabilitative exercise that aims to increase the force generation capacity of expiratory and submental muscles by forcibly blowing into a handheld device with built-in resistance. (Chiara, Martin & Sapienza, 2007)

The strength of resistance is adjustable through a one-way spring-loaded valve. In patients with dysphagia secondary to PD, studies showed that 4 weeks of EMST reduced dysphagia severity and improved upper oesophageal sphincter function (Troche et al, 2010), with the improvement sustained for at least 8 weeks post-training (Claus et al, 2021). EMST is included as a recommendation in the **NICE Guidance NG71 Parkinson's disease in adults** 2017. The recommendation states:

‘Offer speech and language therapy for people with Parkinson’s disease who are experiencing problems with communication, swallowing or saliva. This should include:

- strategies to improve the safety and efficiency of swallowing to minimise the risk of aspiration, such as expiratory muscle strength training (EMST)’.

A systematic review (Brooks, McLaughlin & Shields, 2019) suggested that EMST may be effective in improving airway protection in patients with dysphagia associated with stroke or PD. However, this finding was based on the results from only 4 RCTs. There is some limited evidence to suggest that improvements to maximal expiratory pressure translate to an improved functional swallow for service users, after receiving radiation treatment for head and neck cancer (Hutchison, 2018). Therefore, the evidence for the clinical efficacy of EMST remains limited.

Please note that the RCSLT does not endorse any commercial intervention or medical device.

Biozoon

Although Biozoon is not considered a medical device per se, it is an intervention that is used by some patients with severe EDS difficulties. Biozoon turns liquid into flavoured foam bubbles. The foam bubbles can be placed in the mouth where they dissolve without the need to swallow leaving the individual with a taste of the flavour.

Although the evidence base is limited for Biozoon, the approach can provide some comfort and may improve quality of life for individuals who are nil by mouth due to severe EDS difficulties.

Oral stimulation for promoting oral feeding in pre-term infants

The evidence base is limited to support structured programmes for intra-oral stimulation for infants requiring neonatal care (Greene, 2023). SLTs would continue to promote pre-feeding interventions such positive oral touch and non-nutritive sucking.

Therabite

Therabite is an intraoral stretching device that aims to improve range of movement (ROM) of temporomandibular function using repetitive passive motion to stretch connective tissue, strengthen weakened muscles and mobilise joints. When used with a stretching protocol it has been found to have a positive impact on the preservation of temporomandibular ROM in patients with Spinal Muscular Atrophy and Duchenne’s Muscular Dystrophy (Morris et al, 2020). The case studies by Morris etc al (2020) cited improvement to feeding function, oral hygiene and reduced fatigue. It has also been shown to have a positive impact on ROM for service users with head and neck cancer (Pauli et al 2013; Karlsson et al 2021; Montalvo et al, 2020).

Transition

The SLT has an important role in the safe transition of service users between teams or settings. Intervention should be timely, with clear communication and expectations between teams. It is important to consider how waiting lists may impact on safe transitions and what steps can be taken to reduce any potential risks.

Transitions for neonates

Families are at the centre of neonatal care and early discussions to support transition experiences during neonatal care is essential. Understanding parents’ and carers’ thoughts and feelings about the transitions they experience during neonatal care (including moving through different levels of care on a neonatal unit, repatriation to another neonatal unit and preparing for home) can enable the neonatal team, including an SLT, to offer guidance for these next steps (Shillington and McNeil, 2021; BAPM, 2023; Deierl et al, 2018; Banerjee et al, 2020).

An SLT can support transitions and repatriation by:

- attending discharge planning meetings arranged by the team with the family.
- providing information about communication and feeding development and how this may progress for their baby as they move through the different levels of care on a neonatal unit.
- providing verbal and written information jointly discussed with family to the neonatal team working in the next level of care an infant and family is receiving e.g. moving from intensive treatment unit (ITU) to high dependency unity (HDU) or moving from HDU to special care (SC).
- being involved early in discussions about repatriation to reassure families that the continuum of care will be maintained. An onward referral to SLTs in a receiving unit is provided when a service is available.
- ensuring relevant care plans are communicated to receiving SLT and/or neonatal unit team. These conversations can be communicated early before repatriation takes place. A written copy should also be provided to support repatriation.
- informing neonatal care outreach team (NCOT) service of feeding recommendations on discharge.
- providing information about local community support services for families once they leave the neonatal unit.
- informing families about available follow-up clinics led by the neonatal unit, including neuro developmental surveillance as per NICE guidelines NG72.
- discussing an onward referral to relevant community SLT team and the process it requires.

Infants who require continued significant medical support e.g. mechanical ventilation and non-invasive ventilation at the end of their neonatal period will transfer to their specialist paediatric setting for further long-term ventilation support (LTV). Continued support in the longer term for these infants and families is essential to support feeding, communication and neurodevelopmental outcomes (Ross and Brown, 2013; Hawdon et al, 2000).

Transitions for Children

Transition refers to a change in care or responsibility for management. Effective handover between teams is a priority, requiring good communication, professional respect and shared understanding of person-centred care. Discharge is the end of an episode of care and may occur when the child is safe on the current EDS recommendations, has reached their goals, or no progress is being made towards goals and ongoing monitoring is not indicated. It is important to consider discharge from the very beginning of intervention and plan appropriately. Both effective transitions and discharges need to consider the following:

- levels of care i.e. will the child move to a different service if their level of care changes
- repatriation to a district general hospital (DGH)
- transfer to Community SLT services
- rehabilitation centres e.g. traumatic brain injury
- if the child can access specific pathways e.g. T21 pathway
- transition to adult services
- transition to education and Education and Health Care Plan (EHCP)
- transitioning between different schools, educational and residential care settings, including respite services
- how the provision of funding may change which service the child is seen by. This may be Local authority, Continuing Health Care or statutory services (if eligible)
- discharge when safely managing current recommendations
- the need for long term follow-up in specific situations e.g. long-term use of thickened fluids.

Points of transition or discharge can be a particularly stressful time for the child and their caregivers. Early and effective communication can help to alleviate this stress.

Transitions for adults

Transition refers to those points in the service user’s journey where responsibility for care transfers from one service to another. Typically, this might be when young adults reach 18 years of age and move from paediatric to adult services, but transition may also refer to movement between acute and rehab settings, hospital to community, respite or nursing care to the person’s home, or across geographical borders to access services. Service users requiring treatment for mental ill-health may need to transfer to acute hospital should they experience a decline in their physical health presentation and vice versa and those detained within the justice system may need to leave secure settings to access specialist support or as part of their rehabilitation to return to the community.

Depending on the individual situation, transition points may trigger new legislation For example, mental capacity legislation and there may be differing expectations regarding service user autonomy, risk management and access to other agencies. SLT goals in EDS management may change following transition as a person's condition improves or declines and their access to more familiar environments, preferred foods, company and setting alters. Levels of risk may increase or decrease with the change in access to monitoring, equipment and other professionals.

Weller et al (2014) and CQC (2022) describe transition points as times of increased risk to service user safety. A lack of shared physical spaces or information systems and unclear boundaries creates the potential for serious adverse events. Effective handover between teams is a priority requiring good communication, professional respect and shared understanding of person-centred care.

Contributors

Lead author

Dr Sue Pownall, Independent Consultant Speech and Language Therapist

Supporting authors

- Anita Smith, Head of Service and Dysphagia Lead Speech and language therapist
- Caroline Weighton, Deputy Head of Speech and language therapy, dysphagia lead
- Dr Gemma Clunie, Lead Clinical Academic for allied health professions and Honorary Clinical Research Fellow
- James Reid, Specialist Advisor Speech and Language Therapist
- Joanne Marks, Professional Lead Speech and Language Therapist and Neonatal Operational Delivery Network Lead Speech and Language Therapist
- Dr Kate Toft, Highly specialist Speech and Language Therapist and lecturer in speech and language therapy
- Katy Parnell, Clinical Lead Neonatal Speech and Language Therapist
- Kim Ferrari, Lead Speech and Language Therapist
- Konstantinos Smaragdis, Highly Specialist Speech and Language Therapist and Clinical Lead for dysphagia
- Laura Banci, Professional Lead Speech and Language Therapist for acute and secondary services
- Lauren Bell, Consultant Speech and Language Therapist
- Lorraine Coulter, Lead Professional for speech and language therapy and Allied Health Professional's manager for children's services
- Natalie Wray, Specialist Speech and Language Therapist
- Sam Bradley, Professional Head of Speech and language therapy

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Experts by experience

Emma Sullivan
Jamie Preece
Kate Ashby-Smith
Sarah Wood

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