

The importance of identifying and managing Dysphagia

Difficulty with eating, drinking and swallowing (dysphagia) results in significant negative health consequences for people with learning disabilities, including aspiration pneumonia, choking, malnutrition, poor hydration, reduced quality of life or enjoyment of eating and drinking. As well as food and drink, ability to swallow medication and manage oral secretions must also be considered.


LeDeR reports consistently identify aspiration pneumonia as one of the leading causes of death of people with a learning disability and through early recognition of swallowing problems/dysphagia we can help people to stay healthy and reduce the need for hospital admissions. Nationally 17% of deaths of people with a learning disability are due to aspiration pneumonia, in Somerset this was 18% over the past 3 years.

How someone is eating and drinking, the consistency of their food and drink and their posture while eating all play a part in ensuring someone is as safe as possible. Sometimes if swallowing food and drink becomes unsafe a person may receive nutrition and hydration via a tube/PEG.



Watch [these videos](#) to see the impact dysphagia can have on a person's life.

What is Dysphagia and Aspiration Pneumonia?

A definition of dysphagia is "disorders that can occur in the oral, pharyngeal and oesophageal stages of eating, drinking and swallowing. This includes positioning food/drink in the mouth, oral movements (including sucking and chewing) as well as the process of swallowing". Aspiration pneumonia may be associated with breathing in food, liquid, saliva, or vomit instead of it being swallowed down the food pipe into the stomach.  [3D Animation](#)

Dysphagia in people with learning disabilities typically occurs alongside other health conditions e.g. cerebral palsy, epilepsy, and certain genetic syndromes. In addition people with learning disabilities may have acquired conditions that result in dysphagia e.g. stroke, dementia, head/neck cancer, head injury, Parkinson's Disease, respiratory conditions, reflux. Watch this [TEDx Talk](#) (first 4min).

Signs of Dysphagia include...

- Coughing or choking when eating or drinking
- Problems swallowing or being unable to chew food properly
- Changes in usual eating and drinking behaviour, including any that might be due to medication changes
- A sensation that food is stuck in your throat/chest
- Changes in breathing during eating and drinking
- Bringing food back up
- Repeated chest infections
- Persistent drooling of saliva
- A 'gurgly' wet sounding voice when eating or drinking
- Any unexplained weight loss

Click [here](#) to read more on dysphagia.

Making a referral...

If you have concerns about someone with a learning disability, please refer them to the LD Specialist Health team at CTALDHealthReferrals@somersetFT.nhs.uk

Click [here](#) if your concern is for an Adult without a learning disability.

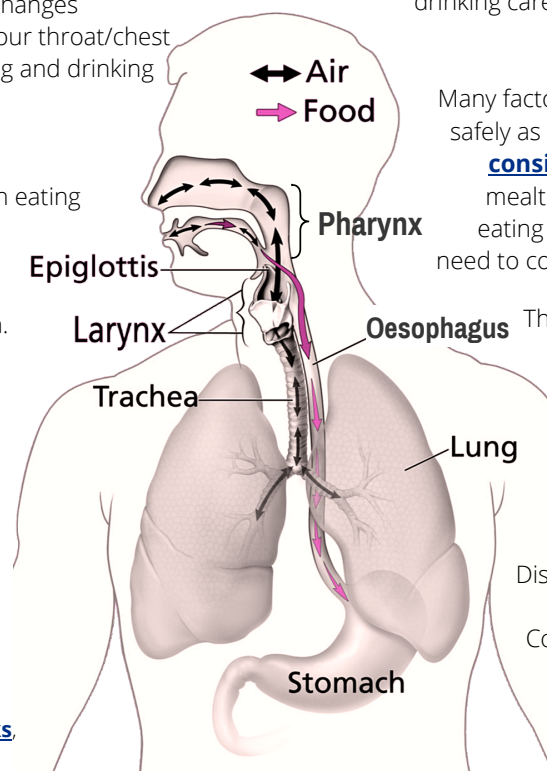
Developing a care plan...

Speech and Language Therapists (SLTs) provide assessment, diagnosis and treatment for people with learning disabilities who have swallowing difficulties. Following assessment, an eating and drinking care plan will be written by the SLT with family, carers and the person's involvement.

Many factors contribute to someone eating and drinking as safely as possible e.g. their ability to chew and to swallow, **consistency of food/drink**, positioning, environment, mealtime behaviours such as overfilling their mouth or eating too quickly, side effects of medication. Care plans need to consider all of these, click [here](#) to view an example.

The **Mental Capacity Act (MCA)** must be followed when decisions related to eating, drinking and swallowing are being made. Risk and quality of life are always considered. Read more about supported decision-making and MCA [here](#).

Management and support of dysphagia involves multi-disciplinary team work, with the Learning Disabilities SLTs playing a central role. Sometimes, a decision might be made by Gastroenterology Consultants that nutrition and hydration should be non-oral. e.g. via a PEG.



Service User Story - Kate

Kate is a 68 year old lady with mild learning disabilities who lives alone with some daily staff support. Kate had never experienced any difficulty with eating and drinking until last year when she experienced 3 choking incidents in close succession. Assessment indicated that Kate had difficulty chewing her food and controlling food in her mouth – she lost control of food and choked. The SLT worked with Kate and her Care Provider to change the consistency of the food that she ate and increase the support she had at mealtimes – these were very significant changes for Kate. Over time, Kate has shown that she is able to prepare food so that it is the right consistency, eat in a more mindful manner and demonstrate how to use an alarm if she gets into difficulty. Kate has an easy read Care Plan. Kate's staff support is now gradually being reduced during mealtimes so that she can be more independent again but remain as safe as possible.



Learn More

If you want to find out more about eating, drinking and swallowing, watch the LD Specialist Health Team's e-Learning video [online](#). This short film includes normal eating, drinking and swallowing, what can go wrong, mealtime support, texture modification/IDDSI, use of thickeners, oral care and how to make a referral to the Learning Disabilities Speech and Language Therapy team.



There is also a practical workshop available that complements the e-learning and the team is also developing a Dysphagia Link Worker role. If you have any queries on accessing Learning Disability dysphagia training, email LDTraining@SomersetFT.nhs.uk

Somerset is currently looking at how the new national [eating, drinking and swallowing competency framework](#) could be implemented across the care providers and could effect future training.

Medicines

As part of an eating and drinking assessment the SLT will ask about how the person manages their medication and what format it is in. Although the SLT can make a recommendation about this it is always the prescriber who must be contacted and who must decide about the format of medication for an individual. See this [IDDSI factsheet](#) on pills, capsules, tablets, choking and aspiration. Remember that some medications may effect a person's ability to eat, drink and swallow safely and it is essential to contact the prescriber/SLT in these cases.

LeDeR Reviews Continue...

It is even more important that we continue to receive notifications and information from health and social care providers when someone with a learning disability has died.

[Notify us of a death online](#) or by calling **0300 777 4774**

Your Local Contacts

Local Area Contact for Somerset
Karen Taylor, karen.taylor38@nhs.net

Co-ordinator for Somerset
Lisa Jones, lisa.jones81@nhs.net
01935 381945



Myth Busting

Using thickeners in drinks is always a good idea. NO!

Historically, thickeners were used commonly with people with LD and we thought they were helpful. Nowadays though, best practice is to only use them when absolutely necessary – the SLT will advise about this as there can be risks attached to using thickener.

Puréed foods are always safest for a person to eat. NO!

A person's eating and drinking care plan is not a "one size fits all" so we can never say that a particular texture of food and drink will always be safer than another; each care plan is bespoke to the individual. This is why assessment by a SLT is key to supporting people with dysphagia as safely as possible.


We can prevent someone from ever choking. NO!

We are all at risk of choking but people with learning disabilities have an increased risk. By following care plans and supporting them as safely as possible we aim to minimise that risk but the risk cannot be eliminated altogether. See the learning from Hampshire on [reducing the risk of choking for people with a learning disability](#). Help Stop Choking resources are available [here](#).

Best Practice

The [RCSLT mealtime poster](#) gives pointers for best practice for support at mealtimes and can either stand alone or be read alongside the eating and drinking care plan. SALT care plans should not be changed when transcribed onto records/notes, see this [CHC bulletin](#) for information.

Visit [IDDSI](#) for guidance on food and fluid texture modification. Also, see this [Patient Safety Alert](#) about safe storage and management of thickening powders.

People with swallowing difficulties are at increased risk of infection, watch this [video on recognising deterioration and the Somerset Soft Signs Escalation Tool](#). 

Making reasonable adjustments...

Guidance from Public Health England on providing support and reasonable adjustments for people who have swallowing difficulties can be found [here](#).

Easy read information on swallowing difficulties from [EasyHealth](#) supports understanding of the condition.