

## Exploring the evidence around the use of thickened fluids with children and young people with oropharyngeal dysphagia FAQs

This is a list of guestions sent in by attendees at the webinar on 19 June 2025.

#### How does this information link with Eating and Drinking with Acknowledged Risks?

There is a link in so far as any treatment option (including EDAR) requires health professionals and families to evaluate respiratory health, enjoyment of eating and drinking/QOL and adequacy to meet nutrition/hydration needs, to develop a treatment/management plan. However, we are highlighting that that there is uncertainty in the evidence regarding the efficacy of thickened liquids as a treatment for aspiration of fluids. Therefore, there may not be a clear cut "best" treatment option. Rather, using the best available evidence, we should be aware of the potential benefits and burdens when presenting thickened fluids as a treatment option to children and their families and be aware of the other options available which may also balance risks associated with respiratory health, QOL and nutrition/hydration. Not using thickener should not constitute EDAR unless there is clear evidence that it is superior to all other treatment options.

### I was wondering whether any of the studies have compared the differences between type of thickener eg. Carobel vs Nutilis. Are there any differences between outcomes?

Well-designed lab-based studies have looked at how different types of thickener behave in different conditions e.g. type of fluid being thickened, temperature of the fluid, ambient temperature, method of thickening, time etc. In general gum-based thickeners are more stable but there is variability in many parameters. Clinical evidence has shown that Carobel is particularly difficult to use as it lacks stability. There is a good presentation on the PDCEN website from November 2024 which you can access if you are a member. A couple of studies have looked at differences in gastrointestinal impacts of thickeners (e.g. Abdulezer et al, 2022) but, as far as the panel are aware, no studies have compared other outcomes between different types of thickener.



Are we considering recommending cool boiled water more rather than thickener as we have been in the adult population. Are there studies on that in relation to thickener?

There are no specific studies that compare water and thickened liquids in children. Evidence to support this as a treatment option derives from adult literature and animal studies.

#### What are the main risks of VFS?

The main risks of VFSS are associated with radiation exposure. This is a comprehensive paper detailing the risks: Ingleby, H.R., Bonilha, H.S. & Steele, C.M. A Tutorial on Diagnostic Benefit and Radiation Risk in Videofluoroscopic Swallowing Studies. *Dysphagia* 38, 517–542 (2023). https://doi.org/10.1007/s00455-021-10335-y.

In the VF environment where time and attention is limited how would you prioritise assessing pacing/bolus size/thickener to support recs?

As you highlight in your question it is not possible to try all treatment strategies in VFSS. If we consider VFSS an assessment of swallow physiology, which determines the effects of altered physiology on safety and efficiency of eating/drinking then we can apply our knowledge of this physiology to potential treatment options. Understanding *why* aspiration or residue occur, not just that they are present, can help guide treatment planning without the need to try all options in VFSS. However, good clinical assessment and trialling of different options prior to VFSS can also help guide what to try in VFSS. This combined with using VFSS as an assessment of physiology, not presence/absence of aspiration should help prioritise during the VFSS.

Would be interested in the panels' view on recommending thickener when VFSS shows PAS level 2 only. Are there any other factors to consider around swallow function which may indicate thickened fluids would help? Would you do a trial and see if this improves chest health?

This is often a clinical conundrum! Evidence from a recent paper by Miller et al (Miller AL, Miller CK, Fei L, Sun Q, Willging JP, de Alarcon A, Pentiuk SP. Predictive value of laryngeal penetration to aspiration in a cohort of pediatric patients. Dysphagia. 2024 Feb;39(1):33-42.) indicates that frequency and depth of laryngeal penetration impact the likelihood of aspiration – infrequent, shallow penetration was less likely to lead to aspiration than frequent, deep laryngeal penetration. However, there is certainly a lack of evidence to guide management. Using the best available evidence, it would be valuable to consider each individual case, weighing up VFSS results, clinical assessment results, respiratory history, other risk factors/causes for respiratory compromise and discuss with the family and MDT to determine the benefits of a trial of thickener.

For a child eating and drinking with acknowledged risk (no safe textures identified on VFS) would they be better on thin fluids because they are aspirating anyway?

This is a very difficult question to answer. This should be a MDT and family discussion of all the risks/benefits. Consideration of the volume of aspiration might be an important consideration, along with what the child is drinking.



### Can you explain why thickeners may mask signs of silent aspiration rather than eliminate the risk? is it true for children too?

We know from studies looking at the impact of thickeners on aspiration in VFSS that thickeners reduce the volume of aspirated material. If a trace volume is aspirated it is less likely to trigger a cough response than a larger volume aspiration. What is unclear is whether the volume that ends up in the lungs is less i.e. is even a partially effective cough better at protecting the lungs from a larger volume aspiration better or worse than no response to trace aspiration.

### I'm interested to hear the panels opinion on breastfeeding for young children with swallowing difficulties I have heard anecdotal research that there is less risk with breast milk.

Two recent studies have been published which show conflicting evidence surrounding the effect of breast milk aspiration. Hersh CJ, Sorbo J, Moreno JM, Hartnick E, Fracchia MS, Hartnick CJ. Aspiration does not mean the end of a breast-feeding relationship. International Journal of Pediatric Otorhinolaryngology. 2022 Oct 1;161:111263-is a small retrospective study which showed no respiratory symptoms at 3 month follow up. Duncan DR, Golden C, Larson K, Williams N, Simoneau T, Rosen RL. Breastfeeding in infants who aspirate may increase risk of pulmonary inflammation. Pediatric pulmonology. 2024 Mar;59(3):600-8. showed that a small number of infants who breastfed did present with respiratory sequalae, although these were not evident on chest x-ray. This study used a longer follow up period and more robust measures of respiratory outcome. A number of infants who continued to breastfeed did so with no complications. Family and multi-disciplinary discussion is required, given the uncertain evidence.

### When you mentioned a weaning protocol, do you mean slowly reducing thickener until on thin fluids if possible to child abilities?

Yes that is the idea, rather than just sticking to IDDSI levels and jumping down we are suggesting a more gradual decrease. There is a paper by Nikolaus E.Wolter, Kayla Hernandez, Alexandria L. Irace, Kathryn Davidson, Jennifer A. Perez, Kara Larson, Reza Rahbar, A Systematic Process for Weaning Children With Aspiration From Thickened Fluids (2018) JAMAOtolaryngology–Head & Neck Surgery which describes a study of 50 children undergoing a 10% reduction in thickener in their drinks every two weeks. It was mostly very successful and the North East Dysphagia CEN has started adopting this approach, but to make it easier for families the fluid amounts to thickener have been adjusted but have kept to the 10% reduction.

# Would you then advise a VFSS prior to weaning thickener? Also, weaning protocol advised earlier when recommending thickener - what are the indicators to initiate the weaning protocol? Do you include these in your recommendations?

Whether you undertake a VFSS prior to weaning may be a matter of individual assessment. If the child had silent aspiration on a prior VFSS you may be more inclined to consider this, other factors may be access to VFSS. However, one could consider trialling some thinner fluids prior to a repeat VFSS if the intention is to see if they can reduce or come off thickener as we often see that after some time of drinking thicker fluids children have less control of thinner fluids, they may tip the cup more and get bigger mouthfuls that they aspirate on the exam, making it a less 'fair' assessment.



Indications of when to think about a thickener wean can be varied but having a good stable period of no chest infections and signs of development in other areas such as talking are good factors to consider. This is usually more relevant to our idiopathic dysphagic children, ones who have maybe had more structural or respiratory issues than those with neurodisability. Dysphagia symptoms in some cases may only last a short while (Kenny, I et al 2022 Vocal cord dysfunction after paediatric cardiac surgery: A prospective implementation study; Duncan et al (2022) Clinical aspects of thickeners for paediatric gastroesophageal reflux and oropharyngeal dysphagia). We are now finding these children are having no dysphagia signs or symptoms by the age of 5 (for example S Sheikh 1, E Allen, R Shell, J Hruschak, D Iram, R Castile, K McCoy (2001) Chronic aspiration without gastroesophageal reflux as a cause of chronic respiratory symptoms in neurologically normal infants; Casazza et al (2020) Aspiration in the otherwise healthy Infant-Is there a natural course for improvement?) so considering a wean before school is now becoming more common.

Community SALT refer to acute colleagues for VF- 3 month wait so we do trial thickeners, change in equipment, positioning, naturally thickened fluids as we wait for VF appointment and outcome. Once VF completed and advice is to thicken fluids- discharged back to community to manage-should we be referring back to acute VF service to support our decision making as to when to reduce thickener or even stop it? With demand and wait for VF and reluctance to expose the child to radiation- it does feel that community SALTs are given outcome and then are asked to manage and decide when to reduce /stop thickener. Is there guidance on this?

I think guidelines listed above are what community teams are ideally situated to monitor and discuss with the MDT that sees the child often. We know VFSS is not the full answer often and a gradual thickener wean may be more effective in measuring how a child copes in the 'real world' and over different times of day and environments.

### Is there a national or RCSLT consensus on the use of thickening products below the licenced age, which is common practice?

No, this is up to the prescriber. It is worth discussing with regional pharmacists for their opinion and that may help in what you suggest to prescribers but there is no current guidance from RCSLT. Like a lot of medications thickeners are not licenced for under 3's and prescribers take responsibility for prescribing them off licence.

#### Is there any research or advice on thickening medicine?

Not that we know of. The thing to bear in mind is whether there are ways of giving this safely since it is such a small amount – how significant is the dysphagia and is it more important that the child has the medication compared to the risk of aspirating it? Can it be given very slowly either off the tip of a spoon or dropped from a syringe?

There were a number of questions around advice or recommendations around discharge when children are on thickener which is not currently having any recognised adverse effects, but when parents are not opting into sessions.



Also, common concerns were raised around discharge of children in a special school who are on thickener which is not currently having any recognised adverse effects, and who are likely to continue to need thickener for the foreseeable future-should we keep them on caseload or can we discharge?

#### Thickened Fluids FAQ document available on the RCSLT website

What is our duty of care to children who are on prescribed thickener? We should not discharge children on thickener because then we would be unable to monitor the use, the impact, and the outcomes relative to the aims for that child. Children are consistently developing and changing. Thought therefore needs to go into the practicality of what is the right time to assess weaning the child off thickener. It is also important to regularly review if the child still needs thickener.

Currently, thickening agents are offered by medical prescription and as such, need monitoring and regular review to allow for rationalisation of medical intervention. The frequency of this review can be determined by each NHS trust and clinically guided by the specific needs of the child receiving the thickening fluids. For example, this could be as part of an annual medical review, as part of an educational review or through patient-initiated follow-up.

#### If the child aspirates thickener, is that more dangerous than aspirating food?

Unfortunately, there really isn't the evidence to be sure that this is the case.

The RCT proposal on thickened fluids in the paediatric population by NIHR may give useful information on this question.

Can I ask the panel about naturally thickening fluids, so not prescribed thickener. How often are these used?

#### From the Thickened Fluids FAQ document available on the RCSLT website:

'Could you discuss the rationale for grouping naturally thickened fluids with commercially thickened fluids? A consensus agreement was achieved within the working group to include both naturally thickened and commercially thickened fluids. When thinking about naturally thickened fluids and commercially thickened fluids, the main difference to consider is their palatability. Palatability is only one factor of the many that interact here. Naturally thickened fluids are far more likely to be acceptable than commercially thickened fluids and being more acceptable will help to improve oral consumption and hydration. Another factor to consider includes feelings of satiety. Increasing satiety reduces the amount of fluids that we consume when we compare it to thin fluids and this can be impacted when using both naturally and commercially thickened fluids. Oral hygiene is important to consider for both naturally and commercially thickened fluids. The bioavailability of medication is impacted by semi liquid or semi solid foods (this includes both naturally thickened and commercially thickened fluids). There are studies also that report on the effect of the electrical charge created by the interaction between commercially thickened products and certain base fluids.'

The use of naturally thicker fluids is always going to be a difficult clinical dilemma, in part due to the associated risks in terms of nutrition and dental impacts. For this reason using only naturally thicker fluids is not usually recommended.



There may be some cases where naturally thicker fluids are used alongside thickened fluids and water for a short period of time where a child is developmentally ready to transition to cup drinking.

Where they are being used, they will always need to be IDDSI assessed for specified level as viscosity varies considerably.

You mention using alternatives to thickener including tube feeding. How would tube feeding be less stressful to parents/less invasive than using thickener?

This is a good point, for some families, the introduction of tube feeding for fluids could be stressful. Clinical decision making around the use of tube feeding for fluids will always be child specific and something for the child's family and respiratory team to consider. Where a tube is already available i.e. in the right context, giving some/all fluids by tube could potentially be the less stressful and therefore preferable option.

#### Is there an evidence base you know of for using carbonation with children?

As so often is the case, there is not yet any research based on using carbonation with the paediatric population. This would make an excellent research project for anyone considering further study in paediatric dysphagia. Until then we can only extrapolate from available adult research.

There is an interesting systematic review by Nagago et al 2022 based on adult research papers. Effects of Carbonation on Swallowing: Systematic Review and Meta-Analysis Ayano Nagano, MSc; Keisuke Maeda, PhD; Akio Shimizu, MSc; Kenta Murotani, PhD; Naoharu Mori, PhD

Would it be possible to see a copy of the Lanarkshire position statement relating to paediatrics. Is there a plan or recommended approach to disseminate this information locally?

From RCSLT position paper on thickeners: 'Dissemination strategies - We all need to share changes in evidence and practice at the local level. It is useful to make a list of stakeholders and key members in the MDT (including adult social care) and map out how you might disseminate information. Each service will need to do this individually as there will be different variables/context to consider.'

Please see below one example of an NHS Trust's response to using thickened fluids with children.

NHS Lanarkshire, Speech and Language Therapy (SLT) Department, Children and Young People (CYP) Service.

Position Statement on the Use of Thickened Fluids in the Management of CYP with swallowing difficulties.

NH5 Lanarkshire

V0.4 January 2024- for review January 2025



#### Introduction

In accordance with the Royal College of Speech and Language Therapists (RCSLT) position paper and emerging evidence base, Lanarkshire Speech and Language Therapists have been reviewing their management of the use of thickened fluids with children over the last two years.

It is important to note that unlike the adult population, the trigger for assessment of swallow function in children is rarely aspiration pneumonia, but potential lung changes or persistent/recurring respiratory symptoms. There continues to be little research in this area specific to children and the impact of thickened fluids on developing oro-motor skills and the developing lung is not fully understood but from the limited evidence available we can apply some benefits and risks.

#### The current situation

In response to new and emerging evidence, the use of commercial thickeners as a tool for managing dysphagia in paediatrics has reduced considerably, and there are now fewer children within Lanarkshire who are using commercial prescribed thickeners on a regular basis.

#### Some advantages of thickened fluids in babies, infants and children include the following:

- Reduced hospital admissions for respiratory problems
- Improved quality of life with increased fluid intake and less resistance to feeding
- Reduced symptoms of coughing, wheezing and apnoea
- Improved oro-motor control at the oral stage of swallowing

#### Some disadvantages to using thickened fluids in babies, infants and children include:

- Links to discontinuation of breast-feeding
- Altered bowel habits and increased risk of necrotising enterocolitis in infants
- High sodium content which needs to be considered within the suggested daily intake
- The impact of thickened fluids on developing oro-motor skills and the developing lung is not fully understood

#### **Current Practice**

The Lanarkshire children and young people speech and language therapy team shall continue to follow the most recent evidence available on the use of thickened fluids in paediatrics.

- 1. All children using thickened fluids will remain open cases with regular reviews using a child and family-centred approach, taking in all of the available information and established risks/benefits (Where appropriate, using the BRAN decision-making tool Benefits, Risks, Alternatives, Nothing). Share with families and colleagues the most recent literature on thickened fluids as provided by RCSLT.
- 2. Establish the safe and effective feeding and swallowing skills in a manner least disruptive to the developmental process of feeding acquisition.



- 3. Remain sensitive to the parent, child and young adults' preferences in considering thickened fluids.
- 4. Actively consider other treatment options. For children and young people this may mean considering changes in flow of fluid through different teats/cups, using different positioning such as elevated side lying in neonates or considering the use of carbonated fluids in older children. This is because the long-term use of thickened fluids is not well researched/documented yet.
- 5. Any thickened fluids used with children will be used judiciously, using the minimal volume for optimal management, following the \*ALARP principle, with the aim of transitioning toward the establishment of normalised swallow function as soon as possible.
- 6. Where the use of thickened fluids is used on a trial basis, we will use outcome measures and risk profiling therapeutic tools specific to each child to monitor progress. We will ensure that children on thickeners are closely monitored with regular opportunities to wean thickeners as soon as possible.

#### References

Royal College of Speech and Language Therapists. Position paper on the use of thickened fluids in the management of people with swallowing difficulties. RCSLT Position Paper 2024. London: RCSLT, 2024

<u>Patient/Carer leaflet / Easy Read Thickened Drinks A guide to help children make choices about</u> thickened drinks RCSLT website 2024

\*The "As Low As Reasonably Practicable" (ALARP) principle, meaning reducing risks to as low a level as reasonably achievable, is a fundamental concept in risk management, particularly in health and safety contexts like NHS Scotland.