



Myotubular Trust

Workshop forum: Feeding

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The assessment and management of feeding and swallowing

- Needs multi professional team work with parent and child partnership
- Must be done with a full case history
- Assessments need to be individualised to aid accurate decision making
- No two families or children are exactly the same despite having a unifying diagnosis



Myotubular myopathy and feeding

Swallowing may be affected due to:

- Oral and facial muscle weakness

Difficulties can present early in life e.g:

- Need for suction as not swallowing saliva
- Naso gastric tube feeding due to risk of aspiration



Signs of swallowing problems

- Coughing/choking when swallowing to stop food/drink going the wrong way (being aspirated)
- If the cough is weak airway protection may be more difficult
- If there is no cough it is called silent aspiration
- Aspiration can cause recurrent chest infections and weight loss



Swallowing assessment

- Take a history of symptoms
- Mealtime observation
- Looking and listening



Videofluoroscopy (VF) assessment

X-ray of swallowing
food and drink with barium added

Important to:

determine “safety” of swallow, see any
aspiration

try a range of consistencies and strategies that
may help make it better



Videofluoroscopy findings

- Weak swallow
- Residue remains in the pharynx/ throat after swallowing



Advice for weak swallow with residue

- Avoid distractions when eating
- Not to talk and eat at same time
- Avoid fatigue (30 min mealtimes)
- Dry swallowing
- Stay upright after meals
- No force feeding

- Important that all carers know how to manage choking



What if swallowing is unsafe? there is aspiration

NB This advice is tailor made to the individual patient's VF results

- Continue to eat and drink the volume and consistencies that are safe
- Modify the diet e g thicken fluids
- avoid chewable solids
- Avoid mixed consistencies
- Use a "safe" route for fluid or nutrition



Progression of swallowing problems

- May be improvements in the neonatal and “early” period
- Can repeat VF if symptoms have changed and/or it will help inform a change in management
- It is a risk v benefit decision as it involves a dose of X-rays



What if nothing is “safe” ?

- Early positive oral and facial touch helps to avoid hypersensitivity
- Tooth brushing
- Oral hygiene is important for healthy gums, teeth, saliva and chest
- Tastes (in liaison with SLT)



Other things not to miss out on

- Family mealtimes
- The social side of eating
- Parties and friends for tea
- Cooking and shopping
- Smell and touch
- Food play
- Mess!



Tube feeding

- Naso gastric: usually short term due to risks and disadvantages
- Gastrostomy or PEG: longer term option
- Discuss with medical team and dietitian



swallowing is safe but feeding is slow

- Caused by oral facial weakness
- Slow, effortful chewing
- Gagging/choking if food not chewed well
- Mealtimes take over 30 minutes
- Unable to keep up with nutritional requirements for growth



encouragement

- Coaxing, persuading, bribing, negotiating... all done with best intention can sometimes turn into force feeding making meals unpleasant
- “Lazy, Fussy, naughty” or just very difficult for them therefore not enjoyable



Diet modification to help chewing

- Chopped/cut up
- Mashed
- Puree
- Add sauces
- Avoid hard textures (pizza base, red meat)
- Have a drink with meals



Utensils

- Lightweight cutlery
 - Spoon
 - Long handled fork
 - Straws
-
- Discuss with occupational therapy



Supplementation discuss with dietitian

- Fats and oils to food
- High calorie snacks
- Prescribed supplements: juices, milkshakes
- One problem can be that they get bored with the taste or don't like it
- Take it "as a medicine"



Supplemental tube feeding

- Short term NG tube
- Eg if recovering from an acute illness (chest infection) or surgery

- Supplemental gastrostomy feeding
- Take pressure off eating activity
- Time for other things



Tube feeding

The schedule can effect appetite but growth is key

- Bolus
- continuous
- Overnight pump feeding
- + fibre for constipation
- Discuss with dietitian



Other factors that can affect feeding

Gastro oesophageal reflux

- Secondary aspiration if food comes back up from the stomach
- Oesophagitis/ pain/ discomfort if reflux is untreated
- If pain is associated with eating it can lead to behavioural feeding difficulties



Respiratory compromise

- Morning headache/ no breakfast
- Poor appetite

- ↑ energy requirements as working hard to breathe

- Recurrent chest infections
- Failure to thrive



Tracheostomy

- Children who require a trache may have more problems with the muscles in their throat and therefore are more likely to have swallowing problems
- The trache tube may “anchor” the larynx slightly but on its own does not specifically cause swallow problems
- Issues with + ventilation: discuss with respiratory physio as having ventilation into the trache can affect the swallow safety



summary

Safety

Tastes

Texture
modifications

Efficiency

Assessment

supplementation

Safe swallow
advice

FEEDING

Length of
mealtimes

Tube feeding

fatigue

Oral hygiene

Normal "sensory"
experiences

Family mealtimes