

Eating and Drinking Assistance for Children with Movement Disorders

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Chailey Clinical Services



Excellent care at the heart of the community

Eating, drinking and swallowing ability

AIM

- How do neurological impairments affect children's eating, drinking and swallowing?
 - What are the consequences for children of limitations to eating, drinking and swallowing ability?
 - What management and treatment options are there to support children and young people?
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What is the problem?

- 22% of identified deaths for people with cerebral palsy resulted from solids or liquids in their lungs or windpipe.

Improving Health and Lives Learning Disabilities Observatory (2010)




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Neurological Impairment and Eating and Drinking

Childhood Neurological Impairments

- Affect whole body including movements required for **safe** and **efficient** eating and drinking
 - Eating, drinking and swallowing involves complex sensori-motor processes
 - Eating and drinking affected by:
 - overall motor control and co-ordination,
 - posture
 - head position
 - oral skills.
- 

Changes in tone- Hypertonia



- body feels stiff
- limbs resist movement
- limited movement in face and mouth
- reduced selective motor control i.e. challenging to recruit muscles with precision, speed or timing

Changes in tone – Hypotonia



- Person is floppy
- Head may flop forwards or to one side
- Mouth may be open – tongue protrudes
- Reduced selective motor control

Changes in tone – Athetoid /Dystonia



- Lots of involuntary movements – all the time
- Affects trunk and head control
- Affects movement in and around the mouth
- Reduced selective motor control

Posture and Positioning affected by:

- Altered muscle tone
- Poor postural balance / righting reactions
- Retained Primitive reflexes

Postural Reflexes

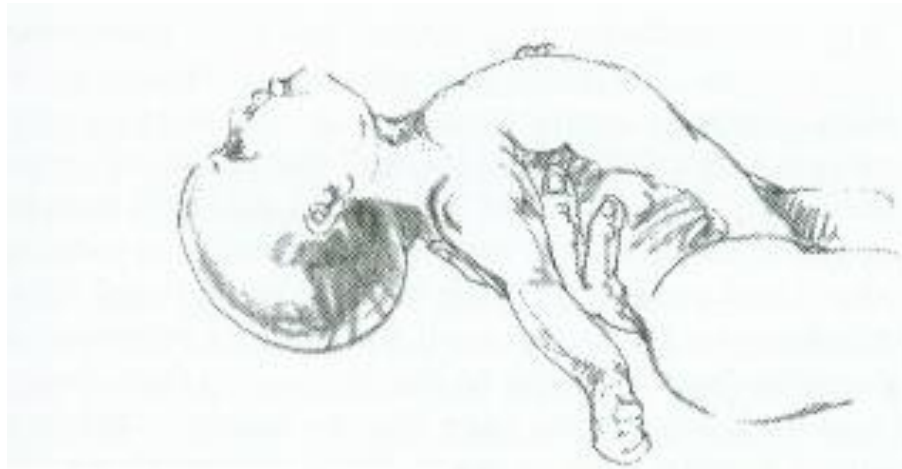
- ATNR - Asymmetrical Tonic Neck Reflex - stimulated by rotation of the head



- Startle Reflex - sudden outward extension of upper limbs
- may be stimulated by noise or sudden movements

Postural Reflexes

- Extensor Thrust (tonic labyrinthine reflex TLR)- child pushes head and trunk back in a strong extension movement



Question?

What happens if you drink

- With your head upright, in midline
- With your head turned as far as you can to one side
- With your head down facing the floor
- With your head tilted back, chin poked forwards.

Positioning – the Person

- stable base - feet supported
- trunk supported and upright
- head in midline
- shoulders and arms forwards
- chin tuck to facilitate swallowing
- comfortable

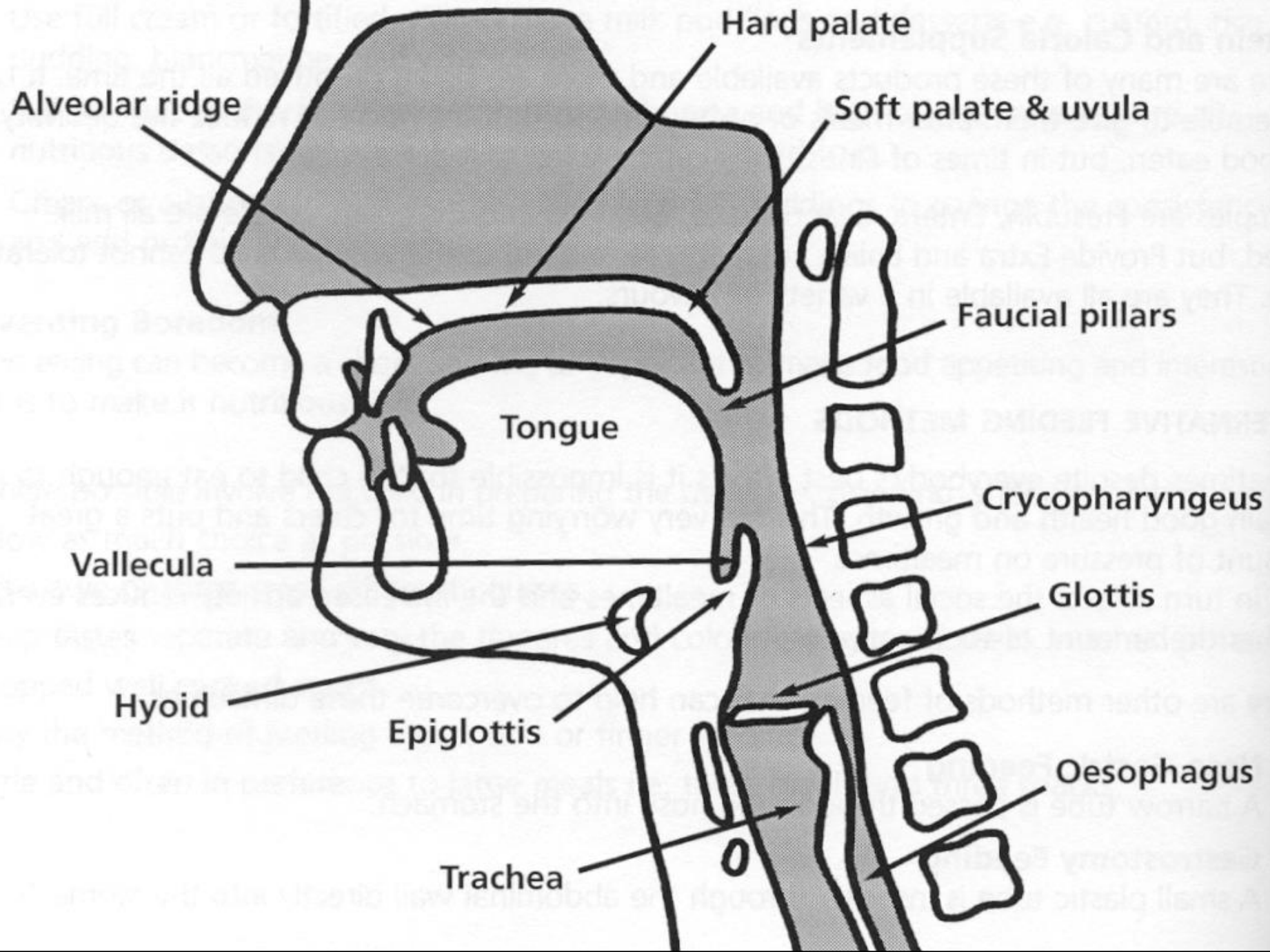
Positioning – the Helper

- Needs to be at the same level or slightly lower than child/adult
- Needs to be comfortable
- Have the food, equipment and cleaning things to hand
- Find a balance between ideal positioning and the need for a positive social experience.

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Respiration, eating, drinking and swallowing




Respiration + eating, drinking, swallowing

- Usual respiratory rhythms interrupted
- Breathing stops during swallowing

Inhale → slight exhale → swallow → exhale

- Other patterns observed in infancy
 - Fine choreography
- 

Neuro-disability


- Disturbed respiratory rhythm
 - Obstructed breathing e.g. Stertor, stridor, pooling of secretions
 - Chronic lung disease of prematurity
 - Weak cough and airway clearance
 - Lack of exercise to induce deep breathing
 - Restricted lung function linked to chest wall deformity secondary to spinal curvature
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Awareness, sensation, perception, communication and cognition

Altered awareness

- Epilepsy including absences
 - Recovering from seizure activity
 - Asleep or tired
 - Impact of pain
 - Effects of illness
 - Unmet personal care needs
- 

Altered sensation and perception

- Sensory loss will not mirror severity of motor deficit
- Tactile perception and integration of sensory input affected
- Long term altered oral and facial sensitivity linked to invasive / traumatic events
- Excessive or low level responsiveness to sensation
- Difficulty integrating information and planning motor responses

Altered communication, cognition and behaviour

- Affects ability to make clear requests or regulate mealtime experience e.g. timing, preferences
- Limited verbal communication and reduced independence can impact nutritional intake
- Ability to express preferences or eat independently may lead to riskier behaviours e.g. increased risks of choking and aspiration.

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Movements of Eating and Drinking

The Normal Swallow

<https://www.nature.com/gimo/contents/pt1/images/gimo95-v2.mp4>

From **GI Video 2 - Interpretation, normal.**

How to perform video-fluoroscopic swallowing studies

Gary D. Gramigna

GI Motility online (2006)

doi:10.1038/gimo95

Eating and Drinking


Think about it in four stages:

- Before food/drink in mouth - ANTICIPATORY
- Food/drink in mouth - ORAL
- Food/drink in throat - PHARYNGEAL
- Food/drink from throat to stomach - OESOPHAGEAL

What could go wrong at each stage?

Before food/drink in the mouth

ANTICIPATORY STAGE


- choose
 - look, feel, smell, taste
 - know, think
 - hand to mouth
 - salivate
 - co-ordinate breathing
- 

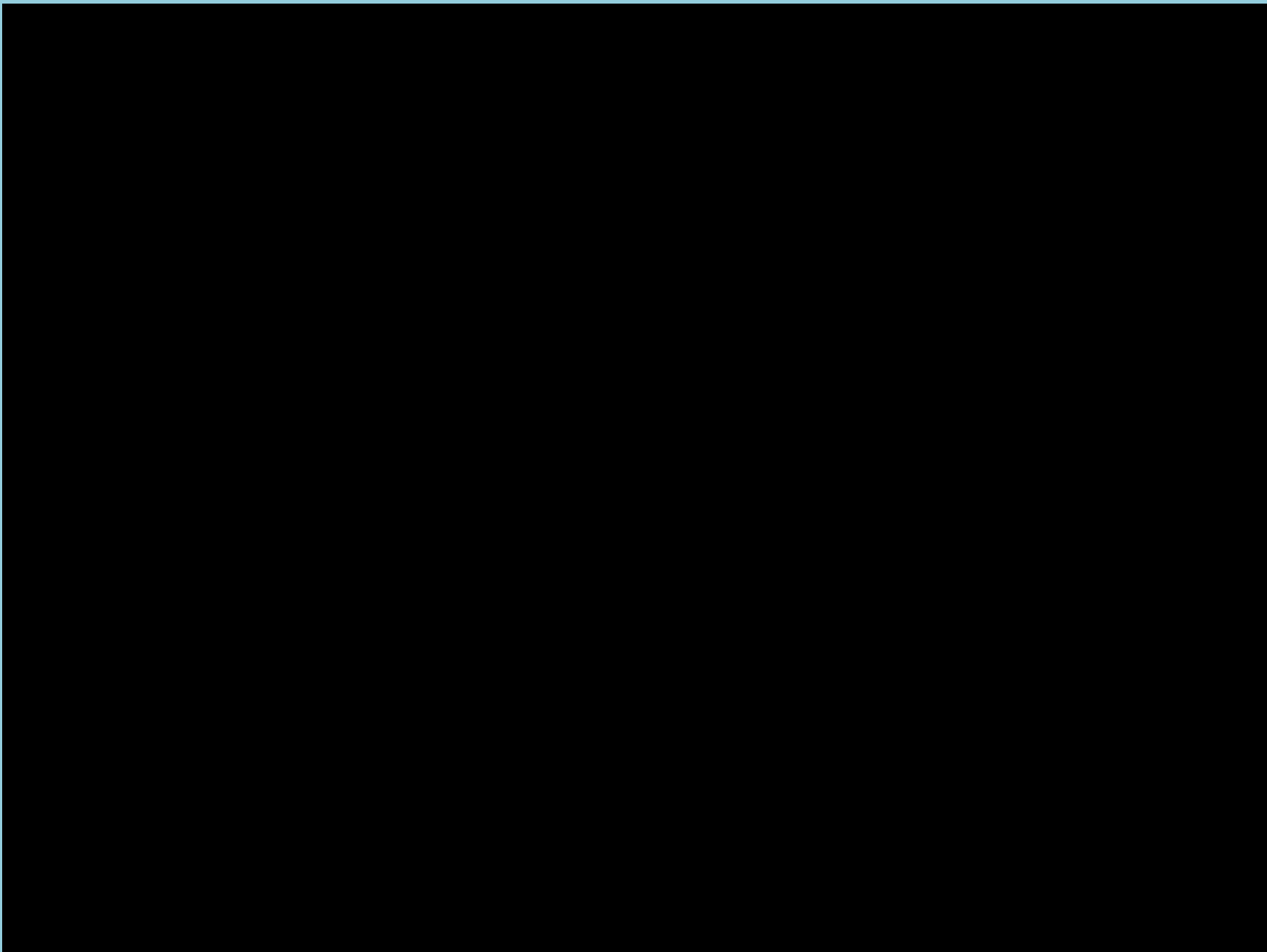
Disturbances - Anticipatory Stage

- Altered sensory information affects anticipatory movements
- Problematic if dependent upon others
- Limited sensory feedback through hands of food/drink
- Timing of mouth opening affected
- Risk of choking and asphyxiation – eating and drinking at speed
- Aspiration or choking linked to altered awareness
- Memories and associations
- Mistiming with respiration

Food/drink in mouth

ORAL STAGE

- control breathing
 - salivate
 - bite, dislodge, transfer
 - lip seal
 - taste, lick, chew
 - suck, squash, sort
- 




Disturbances – Oral Stage

- Limited co-ordination of movement of lips, jaw, facial muscles and tongue:
 - Lips and jaw – remain closed
 - Clamped jaw on spoon
 - Tongue thrust
 - Initiation of swallow affected
- No suction to draw liquid into mouth
- Transfer food/drink front to back or side to side challenging
- Spillage anterior and/or posteriorly
- Limited biting and chewing
- Increased risk of choking / aspiration
- Inefficient intake

Food/drink in the throat

PHARYNGEAL STAGE

- inhibit breathing
 - protect airway
 - close off nose
 - swallow (involuntary)
 - cough (voluntary or involuntary)
- 



Disturbances – Pharyngeal Stage


- Delayed initiation of swallow
- Repeated attempts to swallow
- Throat muscles reduced in strength or asymmetrical affecting movement of food/fluid
- Back flow into naso-pharynx
- Pooling in pharynx
- Penetration of food/fluid into larynx
- Aspiration of food/fluid into airway past vocal folds
- Altered sensation – adverse effects on swallow safety

Food/drink throat to stomach

OESOPHAGEAL STAGE

- upper oesophageal sphincter opens
- peristaltic transfer of food to stomach
- sphincter prevents regurgitation
- hiccup
- burp
- Vomit

Disturbances to Oesophageal Stage

- Delayed upper oesophageal sphincter opening
 - Reflux
 - Gastric pain
 - Slow gastric emptying
 - Swallowing air
 - Aspiration risk
- 

Oral Reflexes

- Rooting
- Tongue protrusion
- Bite
- Swallow
- Cough/ gag

These movements are triggered by specific sensations and are not under someone's conscious control.

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Aspiration and Choking

What is Aspiration?

“**Aspiration**” is when food, drink, saliva or stomach contents enter the wind pipe and lungs.

“**Silent Aspiration**” is when there are no observable signs of this happening



Videofluoroscopy

- <https://www.youtube.com/watch?v=1sFNMk87558>
- VFSS clip of aspiration from YouTube

Signs of Aspiration

- **Coughs – weak or strong cough**
- **Noisy / wet / gurgly upper airway sounds**
- **Wet voice quality**
- **Changes to breathing pattern**
- **Signs of panic in facial expression**
- **Prolonged blinking or eye watering or widening**
- **Colour changes to face or lips**
- **Repeated attempts to swallow**
- **Delay before managing to swallow**
- **Refusal to eat or drink**
- **Chest infections**

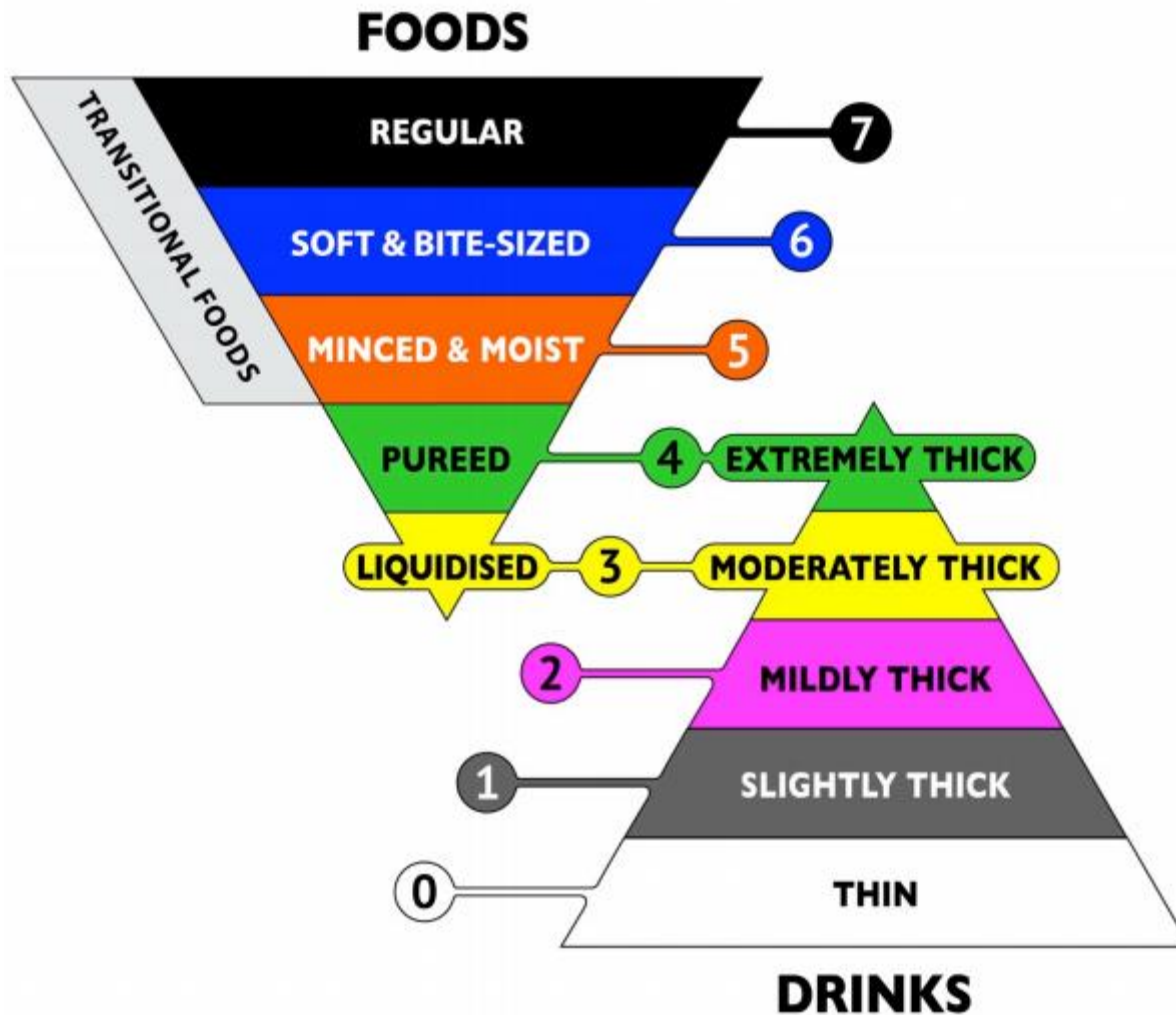
What is choking?

- Choking is a blockage of the upper airway by food or other objects, preventing effective breathing.
- Shape and texture of food will increase risk of choking e.g. round shapes, chewy sticky textures, fibrous foods or floppy foods



IDDSI

International Dysphagia Diet Standardisation Initiative



Regular textures include:


- ***Firm bite and effortful chew textures*** e.g. tough meats, molluscs, hard nuts, crunchy fibrous fruit and vegetables
- ***Mixed textures*** combining different food textures and fluid consistencies e.g. lumps of food in thin soup, watery puree, meat and salad sandwich
- ***Slippery textures*** challenging to control in mouth e.g. melon or grapes
- ***Sticky foods*** difficult to clear from mouth e.g. nut butters, tahini, toffee
- ***Hard chew textures*** effortful strong co-ordinated movement e.g. raw fruit and vegetables, meat, crackers, crusty bread
- ***Soft chew textures*** less effort, strength and co-ordination to eat e.g. well cooked non-fibrous vegetables, ripe peeled fruit no seeds, soft cake

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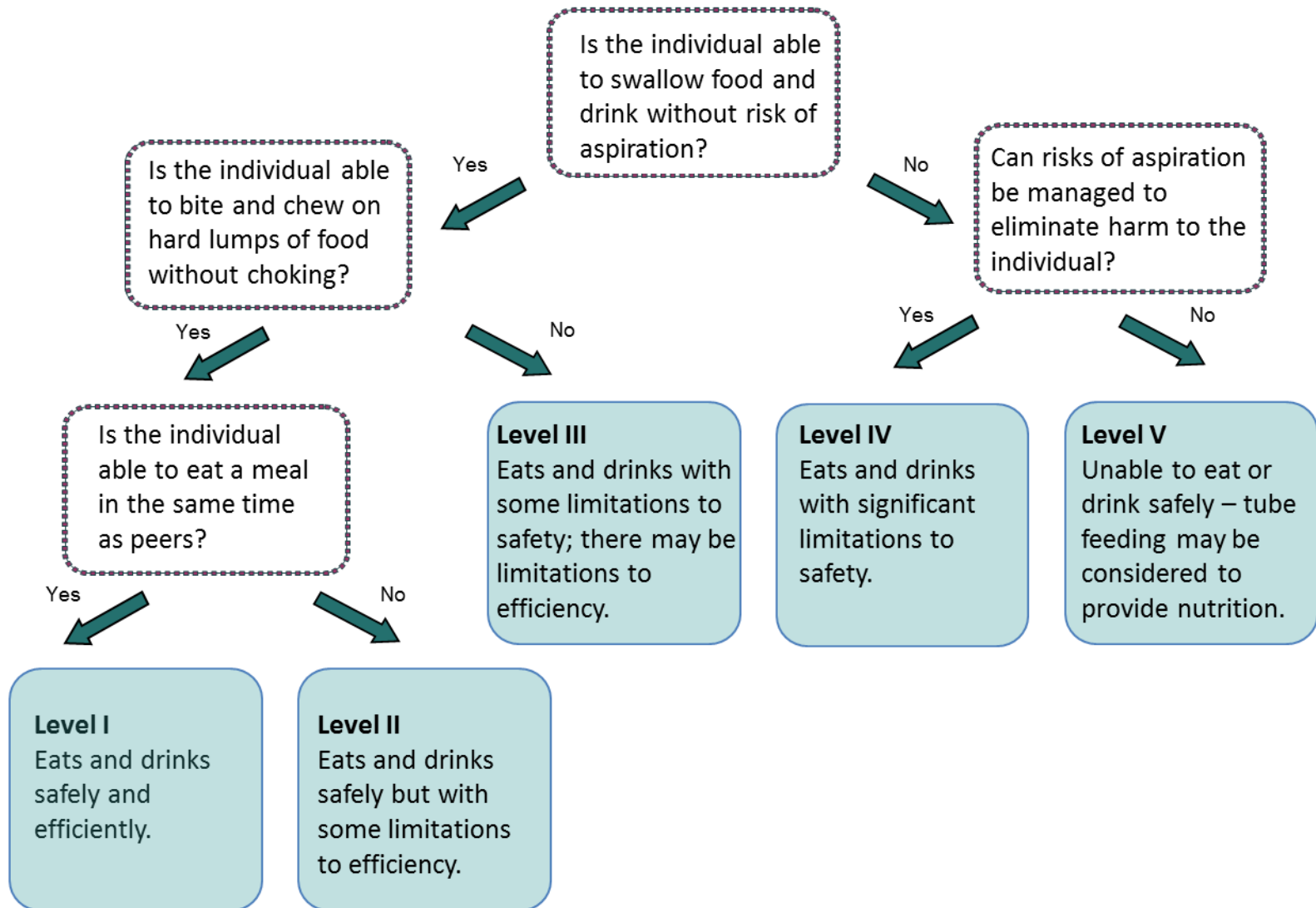


Management and Treatment options

Assess, understand and plan

- Understand nature of person's eating, drinking swallowing limitations
 - Identify what can be changed – cure is not possible
 - Identify appropriate management and treatment options
 - Agree approach with key people: child, family and multi-disciplinary team
 - Communicate this clearly to those who need to know
- 

Eating and Drinking Ability Classification System





RISKS

Becky gets all the calories and drinks she needs through her gastrostomy. She is at risk of aspirating whenever she eats and drinks. Becky understands this risk and only has tiny tastes of food and drink.

A small group of specially trained people help with tastes. **Do not give Becky anything to eat or drink unless you have been trained.**

Becky chooses who gives her tastes. Training can be given by Josie Bennett (SALT), Fred Johnson or Rosie Garcia, who have been trained by SALT.



Food

Texture – soft chew (see Texture Guidelines)

Becky says:

- *I like tiny tastes of food in the side of my mouth so I can taste flavours that I really like.*
- *Do not put anything in the front of my mouth.*
- *Ask me if I would like something*
- *If yes, break off the tiniest amount (smaller than a currant) and put it in the side of my right cheek.*
- *Give me time to enjoy the flavour and swallow. Do not talk to me*
- *I will look at you when I'm ready for more.*



Drinks

Consistency – thin fluid (see Texture Guidelines)

Becky says:

- *I like to have tiny flavours of drink put into the side of my mouth. Use tiny syringe for drinks.*
- *Put 1ml of fluid in syringe. Put syringe in the side of my right cheek (not in my mouth). Gently squeeze the syringe to give me the tiniest amount of fluid.*
- *Give me time to get organised to suck and then swallow.*
- *I will look at you when I've finished swallowing then check if I want more.*



Equipment

- Do not use a cup with Becky.
- Use a small plastic spoon to put the tiniest taste of food in the side of Becky's mouth.
- Use a 1 ml syringe to give Becky tiny tastes of drinks.
- Paper towels to protect clothes



Position

Becky says:

- *I sit in my wheelchair in the upright position*
- *I need my headrest on.*
- *I need my middle chest strap done up*
- *Sometimes I need my supermarket straps on my wrists. I will tell you when by looking at my wrists.*
- *My assistant needs to stand or sit on a high stool on my right side. You need to be able to see my face clearly.*



Assistance required

- Give Becky time to adjust her movements to taste food and drink
- Keep calm
- Wait for Becky to swallow and cough if needed. This could take a few minutes.
- When Becky is not ready it does not mean she wants to stop
- Pay close attention to Becky's communication signals.
- Becky chooses if she tastes food/drink.
- Ask Becky if she wants her face wiped

Tastes can take between 5 and 30 minutes.



Environment

Becky needs a quiet, predictable environment to taste food and drink.

People need special training to assist her.

People who have been trained are:

**Rosie Garcia
Fred Johnson
Jane McDonald
Amanda Loughton
Nicky Burrows
Harriet Martin**



Likes

Becky says:

- *Foods that work well for me include: the tiniest piece of soft cake, ¼ of a chocolate button, cream, yogurt, tiny crumb of cheese/ soft cheese.*
- *I also enjoy segments of lemon, lime and oranges. Hold the segment between my lips so I can suck the juice out.*
- *Some of the drinks I enjoy include: orange squash, coke.*



Dislikes

Becky says:

- *I will tell you what I like and don't like*
- *I don't like it if you ask my friends questions about me*
- *I don't like it if you use a spoon or a cup at the front of my mouth as this makes me move my tongue backwards and forwards really quickly so I really can't swallow anything*
- *I don't like it if you miss my communication signals*



Communication

Becky says:

- *I understand everything you say – don't talk to me as if I'm a baby*
- *Ask me if you're not sure*
- *I say YES by nodding my head and NO by shaking my head*
- *I have a CCS book. Read instructions in the front to know how to use it*
- *I have a Tellus communication aid*
- *I find it hard to swallow and communicate so don't ask me questions when I am swallowing*
- *I will look at you when I have finished and am ready to chat*



Things to look out for

Look out for coughing, panicked facial expressions, changes in skin colour, gurgly voice, chest infections.

Contact the SALT if you are concerned or observe any of these things.



Contact details

Josie Bennett – SALT
Tel: 01825 722112 EXT 7721
Email: josie.bennett@nhs.net

Chailey Clinical Services

This information is written for use at Chailey Heritage Foundation by staff who have attended Eating and Drinking training provided at Chailey Clinical Services



Date: 7.9.2017

Nutrition

Body factors:

Limited oral skills
Reflux
Constipation
Reflexes
Aspiration
Altered muscle tone

Environment:

Seating
Food / Fluid Textures
Equipment
Distractions and loud noises
Unfamiliar or untrained carers
Distorted view of portion size

LIMITED NUTRITIONAL INTAKE LINKED TO

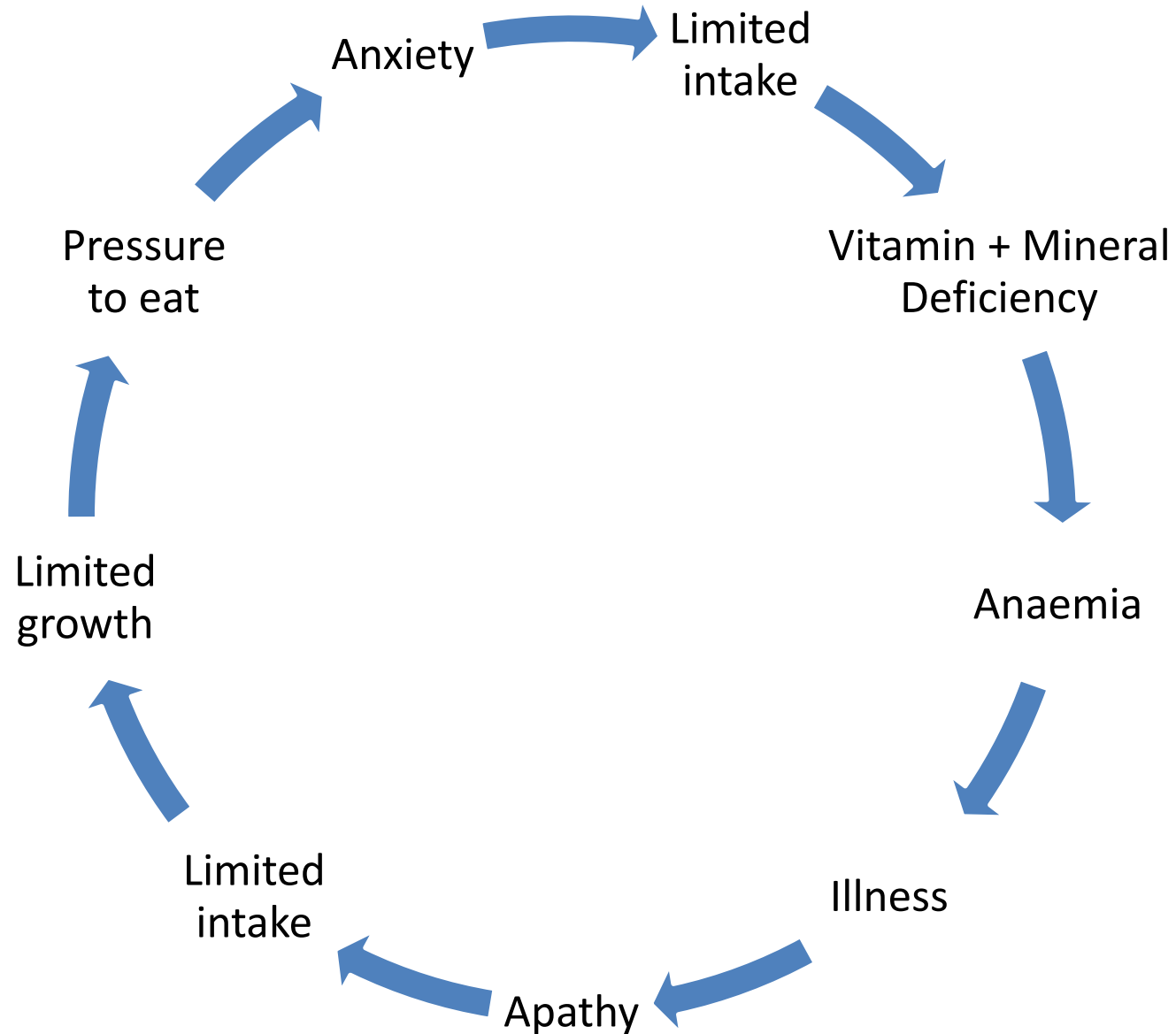
Health Conditions:

Illness
Seizures
Medication
Reflux
Gastric emptying
Altered muscle tone


Personal factors:

Anxiety
Apathy
Time taken
Discomfort or pain
High or limited parental concerns
Self help skills

Effects of poor nutrition



Assessment of Nutritional Intake

- **3 day food diary** – quantity in tablespoons
 - **Body Measurements** – weight, height, knee-height, mid-upper arm circumference
 - **Calculate Requirements** – children have unique needs which change over time
 - **Nutritional deficiencies** – blood tests may be needed
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**Any questions or
comments?**