This presentation is a resource developed as part of a face to face education event or workshop.

The target audience is health and social care professionals in roles providing palliative and end of life care

The author has agreed to share the work to enable best practice in the provision of end of life care
Swallowing Difficulties in Palliative Care

Tuesday 9th July 2019
Sarah Thomas & Sam Gregory
Head & Neck Cancer Speech and Language Therapists
Aims

• **What is Dysphagia**
  – Conditions that may cause dysphagia
  – Normal swallowing
  – Signs and consequences of dysphagia
  – How dysphagia is managed

• **Role of SLT**
  – Assessment and management

• **Practical session and scenarios**

• **Risk feeding in end of life care**
What is Dysphagia?

- the medical term for any difficulty, discomfort or pain when swallowing
  - Dys — Greek for disordered
  - Phagia — Greek for eating

- Safe swallowing involves the efficient, timely and coordinated transport of food, fluid and saliva from the mouth through the throat to the stomach.
Conditions That Might Cause Dysphagia

- Stroke
- Dementia
- Head injury
- Progressive conditions – motor neuron disease, Huntington's chorea, Parkinson's disease, MS
- Neurological conditions: Myasthenia gravis, Guillain-Barre syndrome
- Head and neck surgery
- Cancer esp. head & neck, lung, brain
- Cerebral palsy
- Respiratory issues e.g. COPD

- General frail & unwell
- Tracheostomy
- Hypoxic brain damage
- Cardiac conditions
- Progressive Supranuclear Palsy
- Multiple Systems Atrophy
- Muscular Dystrophy
- Vocal fold palsy
- Learning disability
- Physical disability
Normal Swallowing

<table>
<thead>
<tr>
<th>Oral Preparatory Phase</th>
<th>Oral Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>feel hungry, anticipate meal, smell/see food arrive- senses stimulated and saliva</td>
<td>tongue moves food around mouth, to teeth-off again, squashing it against</td>
</tr>
<tr>
<td>is produced</td>
<td>palate mixing it with saliva to form ball called a bolus</td>
</tr>
<tr>
<td>food placed in mouth, lips close breathing continues via nose</td>
<td>when we are ready to swallow tongue moves bolus towards back of the mouth</td>
</tr>
<tr>
<td></td>
<td>when we are ready to swallow tongue moves bolus towards back of the mouth</td>
</tr>
<tr>
<td></td>
<td>When food moves posteriorly swallow triggered</td>
</tr>
<tr>
<td>Voluntary</td>
<td>Voluntary</td>
</tr>
<tr>
<td><strong>Pharyngeal Phase</strong></td>
<td></td>
</tr>
<tr>
<td>----------------------</td>
<td></td>
</tr>
<tr>
<td>vocal folds close – hold breath</td>
<td></td>
</tr>
<tr>
<td>soft palate rises to close off the nose</td>
<td></td>
</tr>
<tr>
<td>epiglottis closes over the larynx</td>
<td></td>
</tr>
<tr>
<td>larynx lifts up and forward</td>
<td></td>
</tr>
<tr>
<td>the tongue retracts - airway is now protected by epiglottis vocal folds. Apnoeic period</td>
<td></td>
</tr>
<tr>
<td>back wall of pharynx pulls inwards to meet the tongue, creating pressure to push bolus downwards</td>
<td></td>
</tr>
<tr>
<td>Involuntary</td>
<td></td>
</tr>
<tr>
<td>Oesophageal Stage</td>
<td></td>
</tr>
<tr>
<td>-------------------</td>
<td></td>
</tr>
<tr>
<td>upward movement of the larynx relaxes oesophagus opening to receive bolus.</td>
<td></td>
</tr>
<tr>
<td>larynx returns to normal position and the airway opens</td>
<td></td>
</tr>
<tr>
<td>bolus moves downwards to stomach</td>
<td></td>
</tr>
<tr>
<td>Involuntary</td>
<td></td>
</tr>
</tbody>
</table>
## Signs of Oropharyngeal Dysphagia

<table>
<thead>
<tr>
<th>Pre-Oral Phase</th>
<th>Oral Phase</th>
<th>Pharyngeal Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unable to self feed</td>
<td>Poor lip seal</td>
<td>Loss of control of bolus</td>
</tr>
<tr>
<td>Unable to make appropriate choices</td>
<td>Poor tongue movements, leading to:</td>
<td>Inadequate clearing of bolus from pharynx</td>
</tr>
<tr>
<td></td>
<td>-loss of bolus</td>
<td></td>
</tr>
<tr>
<td></td>
<td>-Reduced bolus formation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>-Poor chewing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>-Pocketing of food</td>
<td></td>
</tr>
<tr>
<td></td>
<td>-Long oral phase</td>
<td></td>
</tr>
<tr>
<td>Unable to recognise food and drink</td>
<td>Sensory changes – taste, temperature</td>
<td>Residue collecting in the valleculae/ pyriform fossae</td>
</tr>
<tr>
<td>Drowsy</td>
<td>Food/drink coming down nose</td>
<td>Incomplete opening of the crico-pharyngeus</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Penetration and/ or aspiration of solids/ fluids into the larynx</td>
</tr>
</tbody>
</table>
Aspiration refers to entry of material below the level of the vocal cords”

Anything going the “wrong way”

This includes:

• Food
• Fluid
• Medication
• Secretions
Silent Aspiration

• Occurs when the respiratory mechanism does not respond in any way to the aspiration event
• No cough, no throat clearing, vocal quality is clear
• Some research estimates 40% of patients who silently aspirate are missed on bedside assessment

Signs and Consequences of Dysphagia

- Coughing/choking
- Chest infections/ pneumonia
- Dehydration
- Reluctance to eat & drink due to discomfort
- Poor nutrition/weight loss - impact on success of treatment
- Re-planning of treatment
- Decreased quality of life - long term
- Loss of personal dignity
- Psychological effect
- Social withdrawal (isolation)
- Requirement to have alternative feeding, potentially for life
SLT Assessment

• Manual/ bedside assessment
• Instrumental assessment :
  ✓ FEES (Fibreoptic Endoscopic Evaluation of Swallowing) – Direct view of pharynx/larynx
  ✓ VFSS (Videofluroscopic Swallow Study) – Indirect View using barium. Can also view oropharyngeal and oesophageal Ax
Swallow Management

• Exercises
• Head posture
• Swallow techniques
• Modified diet
• Adapted cutlery
• Alternative feeding
Diet and Fluid Modification

In use from 1\textsuperscript{st} October 2018
0 THIN

- Flows like water and can be drunk through any type of cup, straw and teat/bottle.
Level 1 or slightly thickened fluids are drinks that require a little more effort to drink than thin fluid.

Level 1 drinks will flow through a straw/teat easily.
• **Level 2** fluids are drinks of a slightly thickened consistency that will pour quickly from a spoon, but not as fast as Level 1 fluids.
Level 3 moderately thick fluids and Level 3 liquidised diet:

- Can be drunk from a cup.
- Cannot be piped, layered or moulded on a plate.
- Cannot be eaten with a fork as it will drip through the prongs.
- Can be eaten with a spoon.
- No chewing required – can be swallowed directly.
Level 4 thickened fluids and Level 4 Puree are a thick consistency that needs to be eaten with a spoon.

- It can’t be drunk from a cup or through a straw.
- It doesn’t require chewing.
- It can be piped, layered or moulded.
- It holds its shape on a plate.
- It is smooth and has no lumps.
- It is all one consistency.
- Not sticky - this may be too thick if it doesn’t fall off the spoon when tilted.
- Liquid must not separate from solid.
- A sample will sit in a mould above or fork, and a small amount may flow through.
Level 5 Minced & Moist diet:
• Can be eaten with a fork or spoon
• Soft and moist with no separate thin liquid
• Small lumps visible within the food:
  • Paediatric: 2mm lump size
  • Adult: 4mm lump size – the space between prongs on a fork
• Food can be pressed with a fork and the particles should easily be separated and come through the prongs of the fork.

Examples:
• Finely mince meat or finely mashed fish in a thick, smooth, non-pouring sauce/gravy
• Finely minced or chopped vegetables (smaller than 4mm)
• Thick and smooth cereal with soft small lumps (smaller than 4mm)
Level 6 Soft & bite sized:

- Can be mashed/broken down with pressure from a fork. You should be able to easily cut into this texture with just the side of a fork.
- Chewing is required before swallowing. Tongue strength and control are needed to move food around and to swallow.
- Soft, tender and moist throughout but with no separate thin liquid
- Bite-sized pieces to avoid choking risk:
  - **Adults: 1.5 x 1.5cm (the size of an adult thumbnail),**
  - **Paediatric: 8mm x 8mm pieces**

  Eg. Cooked, tender meat or soft fish cut/broken into pieces no bigger than 1.5cm x 1.5cm (size of adult thumbnail) – if cannot be served like this, serve mince & moist.
  - Casseroles must be have thick liquid and no hard lumps
  - Steamed/boiled vegetables cut in 1.5cm x 1.5cm pieces
  - Mashed fruit with fibrous skins removed and excess juice removed
  - Smooth cereal with soft tender lumps no bigger than 1.5cm x 1.5cm with excess milk drained
  - Rice which is not grainy, sticky or glutinous
  - No bread unless assessed as suitable by SLT
- Normal everyday food of various textures
- Foods may be a range of sizes
- Includes hard, chewy, tough, fibrous, stringy, dry, crispy, crunchy, or crumbly bits.
- Includes pips, seeds, pith and husks
- Can contain mixed consistencies ie cereal with milk

Eg.
- Bread and sandwiches/toast
- Salad items
- Grapes
- Nuts & crisps
- Chewy meat
How to use thickener:

1. Ensure the cup is dry, with a flat bottom

2. Measure 200ml of prepared hot or cold drink

3. Ensure a level scoop of powder, using the scoop in the tin

4. Add the powder to your cup. Use the correct number of scoops for the prescribed consistency

5. Pour the measured drink on top of the powder quickly and immediately stir briskly for 1 minute (hot drinks will take longer)

6. Wait 1 minute and check the consistency before serving
Practical Session:

- Take some food and drink and get into pairs. Follow the written instructions
Tips for feeding people well...

• Make sure they are **awake** and **alert**!
• Ensure **mouth is clean** before feeding
• Enable **independent feeding** where able
• Feed **one person** at a time
• Sit them as **upright** as possible, preferably in a chair
• Create **calm, relaxed environment** - turn off television/radio
• Use **recommended textures**
• **No lidded beakers** (unless individually assessed)
• **Avoid straws**
• Use appropriate **utensils**
Tips for feeding people well...

- Feed from in **front**, ensure you are **level** with the person
- Maintain **eye contact** (unless not appropriate for that person)
- **Tell them** what they’re eating
- Go **slowly**
- Encourage/**watch** for swallow
- **Check mouth is clear** before proceeding to next mouthful and at the end of the meal. Clear mouth if necessary.
- **Sit out** for 20 minutes after feeding.
- Maintain a **clean and healthy mouth**.

*NB: REMEMBER, ALWAYS SUPPORT A PERSON TO SELF-FEED IF THEY ARE ABLE, so long as this does not place them at increased risk.*
Active vs conservative management

- Establishing appropriate goals
- Compensatory vs rehabilitatory

- Pre-morbid lifestyle and health?
- What is the patient prognosis?
- Quality of life?
- Patient input/past wishes
- Resuscitation status
End of Life

• Communication

✓ Provide supportive strategies enabling the patient to express their end of life goals eg. communication charts/ E-tran/ Lightwriter / apps for phones/ Ipads/ pen & paper etc
Oral vs non-oral feeding

- Some patients are able to have modified diet and fluids safely (eg – level 6 soft and bitesized diet and level 1 thickened fluids)

- Some patients do not have a safe swallow across consistencies.
Alternative Feeding

• Multifactorial
  - Tube insertion prior to radical treatment with the aim to remove post treatment
  - Tube insertion to prolong patient’s active life
  - Balance between tube feeding and oral intake which should be regularly monitored by the MDT

• Tube insertion within the elderly and frail population has not been proven to improve nutrition; maintain skin integrity; prevent aspiration pneumonia or improve functional status
SLT Role in EOL Care

• Identification of a patient presenting with severe chronic dysphagia or intractable aspiration and when recovery of the swallow is not anticipated
• Maximising the patients swallow function which aids in maintaining their pulmonary health and support impaired nutrition
• Provide consultation for the patient, their families, the MDT regarding the patients communication and swallowing difficulties
• Ensuring the patient is as comfortable as possible when eating and drinking
• Promote positive feeding interactions for the patient, their family members and care staff

SLT Role in EOL Care

- Patient is at the centre of the care plan
- Quality of life vs ‘risk’
- ‘Comfort feeding only’ identifying the stopping point when it becomes distressing for the patient
- Promote continued interaction with the patient at meal times
  - Mouthcare
  - Communication
  - Therapeutic touch

Palecek et al (2010)
SLT Role in EOL Care

• Therapy offered should be proportional to the level of stress caused by the intervention

• Palliative phase incidence of dysphagia was found in 79% of patients
  – Coughing
  – Loss of appetite
  – Decreased oral secretions

Royal College of Physicians (2010)
Risk feeding

• Palliative approach
• Enhance quality of life
• Provide support to enhance safe feeding techniques
• Educate family and carers
• Might be candidates for yanker suctioning

N.B – thickening drinks do not always make a swallow safer!!
End of Life: ‘Comfort Feeding’

• There is growing evidence that people at the end of life don’t suffer from more than transient hunger and thirst, and they can experience comfort from minimal intake of food and drink

• Constant and distressing attempting to encourage eating and drinking should be reviewed and if necessary discontinued

(NICE, 2006)
RISK FEEDING MANAGEMENT PLAN

Name of Patient: NHS No.: 
Date of birth: Hospital No.: 

Is there reasonable doubt re patient’s mental capacity to make a decision about eating and drinking options? YES □ NO □
If yes, a best interest decision will be made with the involvement of all relevant personnel for patients who lack capacity (complete MCA form)

Patient has an LPA for personal welfare or an advance directive: YES □ NO □

NAME AND DESIGNATION OF LEAD CLINICIAN RESPONSIBLE FOR DECISION: DATE OF DECISION:

The above-named patient has had their swallowing assessed by a Speech and Language Therapist (SLT). They are currently at high risk of 'aspirating' food and drink into the lungs when eating and drinking, and may develop medical complications associated with aspiration e.g. recurrent chest infection.

This is because either:
- The patient has severe oropharyngeal dysphagia and they are at risk of aspiration on all food and fluid consistencies
- The patient wishes to eat and drink as they choose accepting that not following speech and language recommendations will place them at risk of aspiration.

A medical team decision has been made to allow the above-named patient to eat and drink orally, accepting the risk of aspiration.

Safest consistency advice may be given by the SLT team with the aim of reducing the risk of food and drink being aspirated into the lungs: see overleaf for swallow recommendations.

Patients on a risk feeding management plan may be medically managed in the community if they develop medical complications, e.g. chest infections, arising from aspiration.

Patients on a risk management plan will not normally undergo further SLT swallowing intervention unless the patient or family/carers wish to reconsider the decision, or it is felt that the patient's swallow status has changed.
**Name of Patient:**

**NHS No.:**

**Date of birth:**

**Hospital No.:**

<table>
<thead>
<tr>
<th>DATE ADVICE GIVEN:</th>
<th>DISCUSSED WITH:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th><strong>CONSISTENCY OF FOOD:</strong></th>
<th><strong>CONSISTENCY OF FLUIDS:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Normal Diet</td>
<td>□ Normal Fluids</td>
</tr>
<tr>
<td>□ Level 6 soft &amp; bite sized</td>
<td>□ Level 1</td>
</tr>
<tr>
<td>□ Level 5 minced &amp; moist</td>
<td>□ Level 2</td>
</tr>
<tr>
<td>□ Level 4 Purée</td>
<td>□ Level 3</td>
</tr>
<tr>
<td>□ As patient chooses</td>
<td>□ As patient chooses</td>
</tr>
</tbody>
</table>

**SWALLOW STRATEGIES:**

Patient needs full supervision with all eating and drinking, and must be sat upright with head in the mid-line.

Take small mouthfuls of food/sips of fluid.

Use a teaspoon for eating/drinking

Allow x2 swallows per mouthful.

Pause between mouthfuls to allow clearing swallows to occur/ feed slowly.

Give verbal reminders to the patient to swallow.

First aid training to manage the risk of choking is advised.

Patient only likely to tolerate small amounts of food and fluids at a time; offer small, frequent meals and snacks.

Stop if oral intake causing distress or discomfort and re-attempt at a later time.

**OTHER ADVICE/LEAFLETS GIVEN:**

Should you require further advice or support please contact your local SLT team on 01626 324545

**SLT Name and date:**

**Signature:**
Mouthcare

• Why is it important?
  – Maintains comfort
  – Improves communication
  – Easier chewing/ swallowing
  – Decreases sensation of dry mouth, dehydration
  – Enhances quality of life
• What does it involve?
  – Keep mouth and lips clean, moist
  – Remove debris, dried secretions
  – Clean the tongue
  – Every two hours
  – Every 15-30 minutes during last days of life
Scenario - What might happen?

You are looking after a 95 year old lady with advanced dementia.
She usually takes Level 4 puree diet and Level 3 thickened fluids but is now coughing all the time on this intake.

What might we all think about for managing this situation?
<table>
<thead>
<tr>
<th>Question</th>
<th>Comments</th>
</tr>
</thead>
</table>
| 1. Is it appropriate to feed this lady in any other way e.g. NBM and tube feed? | • Highly unlikely  
• Not normally clinically indicated |
| 2. Can we make the food and drink any safer?                            | • Safest oral intake already given  
• Ensure all safe feeding strategies are being used |
| 3. Should we all continue to feed and accept the risk i.e. ‘risk feeding’? | • Think about quality of life...and of death  
• What would you want if this were your relative? |
| 4. Can she make the decision herself?                                  | • Unlikely, therefore a mental capacity assessment must be done to demonstrate that this is in her best interests |
| 5. Is the decision documented everywhere?                                | • Use risk feeding forms to communicate the decision made to **prevent unnecessary hospital admissions**. |
You are working with a man with motor neurone disease who is safe swallowing Level 4 puree food and Level 2 thickened fluids....he is refusing to have thickener in his drinks and will only drink thin fluids.

What might we all think about for managing this situation?
Think about....

1. Has he written an advanced directive?
   - People may have made their wishes known in advance

2. Has he got capacity to decide for himself?
   - If he can demonstrate capacity by understanding and expressing the risk and outcome, he can make an unwise decision

2. Has this decision been documented?
   - Use risk feeding forms to communicate the decision made by the team to other teams to prevent unnecessary hospital admissions

3. Are you happy to give him thin fluids?
   - Think about how you would feel if it were you making the choice. Remember quality of life...and death.
## How to Contact SLT

<table>
<thead>
<tr>
<th>Acute SLT Team</th>
<th>Torbay Hospital</th>
<th>01803 654931</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community SLT Team</td>
<td>Newton Abbot Hospital</td>
<td>01626 324545</td>
</tr>
<tr>
<td>Head and Neck Cancer SLT Team</td>
<td>Torbay Hospital</td>
<td>01803 654949</td>
</tr>
</tbody>
</table>
Thank you!
References


