Managing Bulbar Symptoms
In A Community Patient With MND

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Outline

- Presentation of a case study to demonstrate the collaborative role of the Speech and Language Therapist and the Dietitian in managing bulbar symptoms related to Motor Neurone Disease.
- To be able to identify when to refer to Speech and Language Therapy and Dietitian.
- To have confidence in providing first line treatment of bulbar symptoms e.g. Implementing safe swallowing strategies, nutrition management alongside other members of the multi-disciplinary team.
G.H

- 82 yr old gentleman.
- Retired and lives with wife.
- Referred to SLT September 2013 with sudden onset of speech and swallowing difficulties.
- Unclear diagnosis – wasn’t diagnosed with MND with bulbar involvement until March 2014.
- Referred to Community Dietetics April 2014, as discharged from hospital on a PEG for handover of dietetic care.
Dysarthria

- Term used to describe a motor speech disorder.
- Research suggests that dysarthria occurs in 80% of patients with MND. Dysarthria as an initial symptom is eight times more frequent than dysphagia (swallowing difficulties) in MND.
- Common characteristics of dysarthria associated with MND:
  - Imprecise articulation (slurred speech)
  - Slow laborious speech
  - Hypernasal speech
  - Strained-strangled voice quality
  - Disrupted prosody: speech can be monotone.
  - Decreased respiratory functioning can lead to a weak (low volume) voice.
G.H

- Initially presented with mild dysarthria.
- By March 2014: Moderate-severe dysarthria - Hypernasal, imprecise articulation, reduced volume, slow rate.

**Therapy Options:**

- Clear Speech Strategies: E.g. Reducing background noise, facing your conversation partner, reducing the rate of speech, over articulation.
- Low Tech AAC: paper and pen, whiteboard, alphabet chart
- Voice Amplifier
# Alphabet Chart

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Voice Amplifiers
October 2014: Anarthric.

Therapy Options:
High Tech AAC Options...
  - ipad:
G.H

Lightwriter SL40 Scanning
Voice Banking

- Joint project with MNDA and The Euan MacDonald Centre for Motor Neurone Disease Research.
- Issue: AAC devices with synthetic voices pre-installed.
- Ideally store a person's voice soon after diagnosis, and before speech has become affected. This voice recording is then “banked” and stored ready to create a synthetic voice for a communication aid if, and when, that person needs one.
The Normal Swallow

- **Pre-Oral Stage and Oral Stage:**
  - Smell and taste of food
  - Motor skills
  - Mastication of the bolus
  - Tongue rises to hard palate and compresses bolus posteriorly, base of tongue drops.

- **Pharyngeal Stage:**
  - Elevation and retraction of soft palate
  - Laryngeal closure and suspension of respiration
  - Bolus moves through the pharynx
  - Bolus enters the esophagus.
  - Larynx returns to normal position and breathing resumes

- **Esophageal Stage:**
  - Bolus passes through the UES, through esophagus into the stomach
Food is chewed

Food and drink stays in your mouth until you are ready to swallow.

Without thought or control...

- Your soft palate lifts and block off your nose
- Your tongue pushes onto the back of your throat
- Your voice box moves up & forward
- Your epiglottis covers your airway
- Your vocal cords shut together
- Your muscles squeeze food down
- Your food pipe opens and food or drinks pass through

Food enters into your esophagus ('food pipe) and makes its way to your stomach
Signs of Dysphagia (swallowing difficulties)

- Coughing when eating and/or drinking
- Wet gurlgy voice
- Difficulty chewing and swallowing food
- Food or fluid leaking from the mouth
- Chest infection
- Unplanned weight loss
- Difficulty swallowing medication
Nutritional Care in MND

Nutritional objectives:

1. To help maintain nutritional status, as malnutrition is an independent prognostic factor for survival.
2. To prevent/minimise risk of dehydration.
3. To support maintenance of oral feeding without risk of bronchoaspiration with change in consistency.
4. To minimise protein catabolism with appropriate provision of macro and micronutrients.
5. To provide counselling and indication of early artificial nutrition support to prevent malnutrition/dehydration and improve quality of life and survival rate.
Malnutrition Universal Screening Tool ‘MUST’

**Step 1**
BMI Score

- BMI kg/m²
  - >20 = 0
  - 18.5 – 20 = 1
  - <18.5 = 2

**Step 2**
Weight Loss Score

- Percent unplanned weight loss in past 3-6 months
  - <5% = 0
  - 5 – 10% = 1
  - > 10% = 2

**Step 3**
Acute Disease Effect Score

- If patient is acutely ill and has been or is likely to be no nutritional Intake for 5 days or more Score 2

Stage 4: Overall risk of malnutrition. ‘MUST’ Score. Add scores together to calculate overall risk of malnutrition

0 Low Risk
- Routine Clinical Care
  - Repeat screening if there is a clinical concern
  - Care homes monthly
  - Community annually

1 Medium Risk
- Observe
  - Or treat if approaching high risk or if rapid clinical deterioration anticipated
  - Advice patient on how to fortify every day foods and give written information, leaflet “Food First” leaflet
  - Repeat screening monthly. If patients score is 2 or more and there is no improvement proceed according to high risk pathway

2 or more High Risk
- Treat
  - Reinforce dietary advice & give written information on how to fortify every day foods
  - Prescribe a supplement depending on patient’s preference i.e. milk, juice, or pudding style
  - Repeat MUST monthly and record progress. If no improvement or deterioration after 2 months, refer to Dietitian
  - Unless detrimental or no benefit expected e.g. imminent death
First Line “Food First” Dietary Advice for ‘MUST’ Score 1, 2 or more...

**Food first dietary advice: Suggestions for a poor appetite**

If you are experiencing a poor appetite & or are losing weight unintentionally this list will help you increase the calorie & nutrient content of what you eat normally.

- Eat little and often of “what you fancy” Eat three small meals a day
- Eat small and frequent nourishing snacks in-between meals and before bed
- Avoid drinking with meals
- Eat more high energy foods, adding sugar (unless you are diabetic) to cereals, desserts & drinks
- Enrich at least one dish at each meal with extra butter, margarine, double cream, grated cheese, evaporated milk, condensed milk, honey, jam or sugar
- Have full fat products daily rather than “diet” “low fat” or “health eating” products
- Add 5 tsp of semi skimmed milk powder to a pint of whole milk (blue top) and use as normal every day.
- Have milk based drinks e.g. milky coffee, hot cocoa & milkshakes.
- Get some fresh air - this can often help to stimulate your appetite

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**Nourishing Snacks**

Slice of pizza, medium sausage roll, cereal bar, pot of rice pudding or custard, scoop of ice cream, handful of dried fruit & nuts, pot of thick and creamy yoghurt, individual cheesecake, slice of fruit/sponge cake, 2 cream crackers with cheese, chocolate bar, handful of peanuts (50g), crumpet, half a teacake, pot of trifle, doughnut, small flapjack, half a scone with jam and cream

**Use butter & margarine generously on your snacks**

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**High calorie, protein (fortified) diets**

You can fortify your meals by adding cream, milk powder or butter to increase the overall nutritional content, without increasing the portion size, which means every mouthful you eat, will be full of nourishment.

Foods that you can add to your dishes are:

- Milk powder (1 heaped tbsp)
- Double or whipping cream (1-2 tbsp)
- Butterscotch/jam (1 tsp)
- When you add milk powder to your dishes, make a paste with milk so that it mixes better.

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**Nourishing Drinks**

Try having drinks which contain lots of calories, rather than tea and coffee, try to drink one to two nourishing drinks during the day. You can try the recipes below or you can buy ready made drinks like, Mars, Mars Extra, Mars Active, Yarows, Galaxy Avo, Elenor flavoured milk or smoothies and milkshakes.

- Hot chocolate marshmallows drink
  - 150mls white milk.
  - 1 tsp milk powder.
  - 2 tbsp double cream.
  - 3 tbsp hot chocolate/malted drink powder.

- Fruit smoothie:
  - 300mls of white milk.
  - 1 pt of thick and creamy yogurt or large scoop of vanilla ice cream.
  - 1 tbsp milk powder.
  - 75g of soft fresh or frozen fruit in syrup.
  - Liquidise all ingredients for 10-15 seconds.

- Nourishing smoothie:
  - 200mls white milk.
  - 1 tbsp of milk powder.
  - Packet of dried soup powder heat milk until simmering, mix with soup and milk powder using a mini whisk.

- Nourishing milkshakes:
  - 4 tbsp of Nesquik powder or 2 tbsp Crusha syrup
  - 4 tbsp of skimmed milk powder.
  - 200mls of white milk
  - 1 scoop of ice cream
  - 3 tbsp double cream
  - Blend the Nesquik or Crusha with the milk powder with some milk to make a paste then add the remaining milk and whisk thoroughly.
Nutritional Care in MND

1. Change in meal patterns.
2. High calorie and protein diet (normal, soft or puree consistency as per SLT recommendations).
3. Extra snacks and nutritious drinks that are naturally thick as per SLT recommendations.
4. Oral nutritional supplements (ONS) if MUST score 2 or more, or MUST score 1 and rapid clinical deterioration.
5. Artificial nutrition support if weight loss >10% in the past 3-6 months and/or inadequate oral intake despite ONS & high calorie/protein diet or high risk of dehydration or forced vital capacity (FVC) > 50% predicted.
Bedside Ax: Prolonged mastication of the bolus, reduced oral control, delayed swallow trigger, reduced laryngeal elevation, multiple swallows per bolus, coughing post swallow on solids. Fatigues.

Therapy:

- Education about normal swallow and signs of dysphagia.
- Spouted beaker: Effective at reducing rate and quantity of bolus flow.
- Fork-mashed diet
- Safe swallowing guidelines e.g. Sitting upright for all oral intake, reducing bolus size, ensuring no residue in mouth after swallowing, small meals, little and often.
- Importance of maintaining good oral hygiene.
G.H

- Admitted to Charing Cross Hospital.
- Videofluoroscopy March 2014: Moderate-severe oral pharyngeal dysphagia. At risk of aspiration on oral diet.
- MDT discussion in hospital and agreed best interest to insert PEG alongside continuing oral intake for QOL reasons.
- Discharged on syrup thickened fluids and puree diet.

**Therapy:**
- Education on VF and G.H at high risk of aspiration.
- Education that oral intake is for pleasure. PEG being used for supplementary nutrition & hydration.
- Advice on thickening fluids and possibility of purchasing prepared puree meals (Wiltshire Farm Foods).
Nutritional Management of G.H

- Anthropometric discharge data from hospital on 06/04/14 = 85.5kg, height 1.80m, BMI 26.3kg/m2.
- ‘MUST’ score = 0 – low risk/routine clinical care.
- Nutritional requirements to maintain nutritional status:
  2100kcals (Henry equation), 102g protein (1g-1.2g protein/kg body weight) and 2100ml-2600ml fluid/day (30ml-35ml/kg body weight) as baseline.
- Nutrition treatment plan on discharge from hospital:
  1litre Nutrison Energy Multifibre + 1litre water flushes to provide 1500kcals, 60g protein, 15g fibre, full RDA of micronutrients and 2litres fluid per day

Puree diet + syrup consistency fluids orally daytime
Nutritional Management of G.H

- Reviewed 29/04/14, weight 86.6kg (gained 1.1kg), BMI 26.7kg/m², ‘MUST’ score 0.
- Manages 2 puree meals, 1 x dessert and 1200mls fluid orally = approx. 700kcals, 21g protein and 1200mls fluid daily by mouth.
- 1litre Nutrison Energy Multifibre + 1litre water flushes continues overnight with no reported GI side-effects or signs of dehydration.
- Advised to continue with oral diet/fluid intake and 1litre Nutrison Energy Multifibre, but stop the 1litre water flushes to prevent fluid overload.
- To self-monitor weight at home fortnightly and contact dietitian if weight loss occurs.
G.H

- Swallow further deteriorated. G.H not wanting to eat large amounts but also not wanting to be NBM.

- **Therapy:**
  - Tastes for pleasure.
  - Reiterate the importance of maintaining good oral care.
  - Supplementary enteral tube feeding changed to full nutrition + hydration to help maintain nutritional/hydration status in view of change in swallow status.
  - Continue to self monitor weight and ongoing monitoring from dietetics.
Salvia

- We produce around 1.5 to 3 pints of saliva a day.
- Saliva helps to break down food and prevent the mouth from becoming dry.
- Automatic process.
- Watery saliva: Often results in drooling. Particular problem if a person has difficulties keeping their mouth closed or maintaining an upright position.
- Thick, tenacious saliva or phlegm: Difficult to swallow and can be difficult to cough up due to weakened respiratory muscles.

**Treatment Options:**
- Food and drink
- Medical management
Summary

- Bulbar symptoms affect communication, swallowing and nutritional/hydration status.
- On-going monitoring and reviewing of therapy goals is paramount due to the progressive nature of the condition.
- Collaborative working and good communication within the MDT is of great importance.
- Patient-centred therapy is essential.