Swallowing and Nutrition in HD

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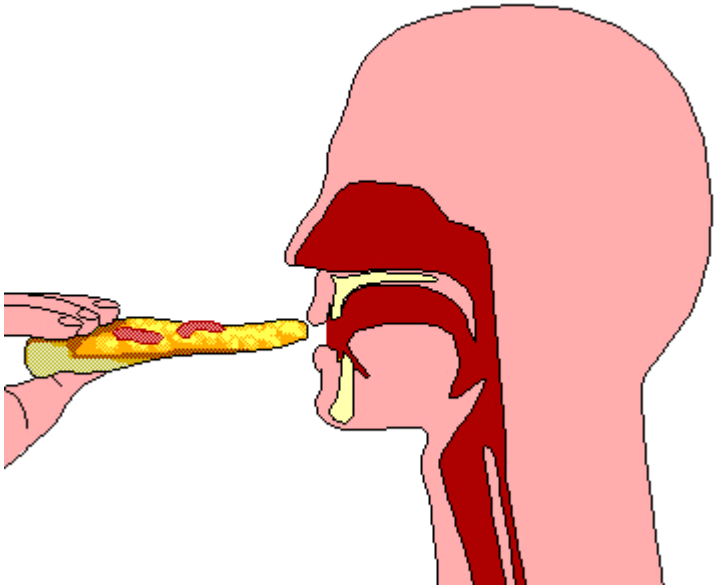
Swallowing

Normal swallow - recap



- Complex process involving many pairs of muscles and nerves.
- Involves chewing and controlling bolus in mouth (voluntary control) and swallowing it (reflex).

Risks

- Chest infections/pneumonia
- Choking
- Poor nutrition and hydration
- Reduced quality of life – social and emotional impact.

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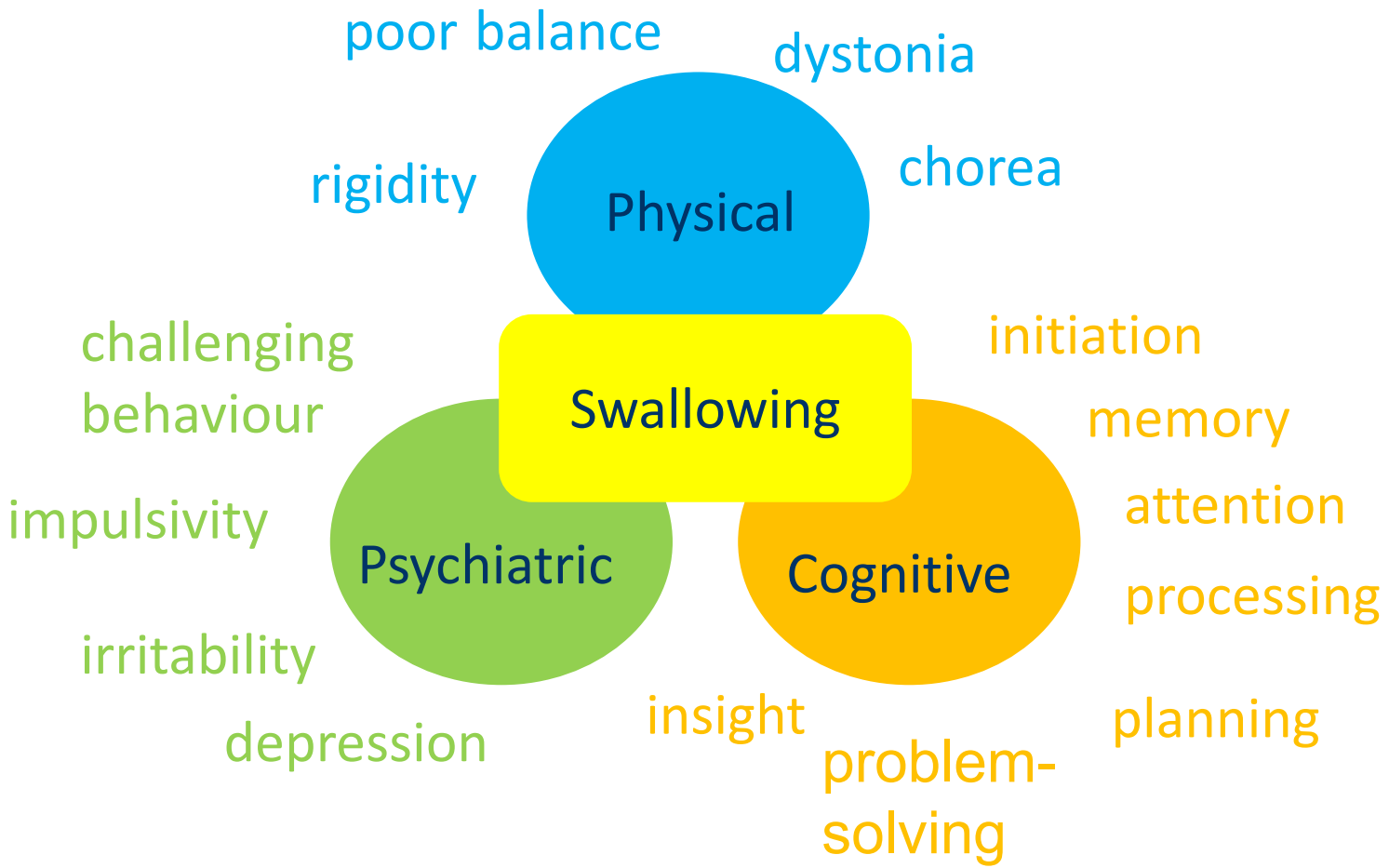
Triad of Impairments



Swallow features (Hamilton at al., 2012)

- Hyperextension of neck and trunk
- Reduced chewing function and tongue control
- Darting lingual chorea (tongue thrust)
- Anterior loss/drooling
- Premature spillage (losing bolus over back of tongue before swallow)
- Oral residue
- Delayed and repetitive swallow
- Prolonged laryngeal elevation
- Reduced/disrupted breath control during swallow
- Phonation (voicing) during swallow
- Belching & swallowing air

N.B. consensus is that cough reflex is often well preserved in HD. But not always!

Other factors to consider

- **Impulsivity** – rate, size of mouthfuls etc.
- **Initiation** – may be reduced.
- **Attention** – distractible
- **Choreic movement** – orally but also limbs/trunk. Base of support.
- **Behaviour** – e.g. levels of agitation.
- **Medication** – e.g. sedative meds, tone meds, meds for choreic movement.

SLT assessment

- Case history including chest infection hx, communication, cognition, behaviour.
- Check if advanced decision in place re: PEG/risk feeding or LPA for Health.
- Assessment at mealtime is usually very useful, observe ward staff assisting/feeding patient.
- Work with MDT
- Consider instrumental assessment
- Education is key role

Just to say…

- Eating and drinking in HD won't always look pretty!
- Key aim is to promote independence for as long as possible whilst managing risks.

Management

- MDT working is key
- Patient needs will change over time
- Need to be creative/flexible

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Food/fluid modification

- Thickened fluids
- Texture modified foods

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Swallow strategies

- ? patient ability to use strategies (given physical and cognitive impairments) e.g. effortful swallow.
- Bolus size
- Placement of bolus
- Pacing
- Individualised

Positioning and Set Up

- Positioning and posture - ? chin tuck.
- Feeding equipment – maroon spoons, control flow beaker, pat saunders straws etc.
- Environment – e.g. side of dining room, in own room. Consider distractions.
- Medication

Level of Help

- Method and level of assistance – needs may vary over course of meal/drink due to fatigue.
- Type of prompting – verbal/gestural/physical.
- Amount/frequency – e.g. ‘little & often’, ? increase intake via PEG if present

Saliva management

- Likely to experiences difficulties with this over time
- Positioning
- Medications
- Botox to salivary glands

Mealmats

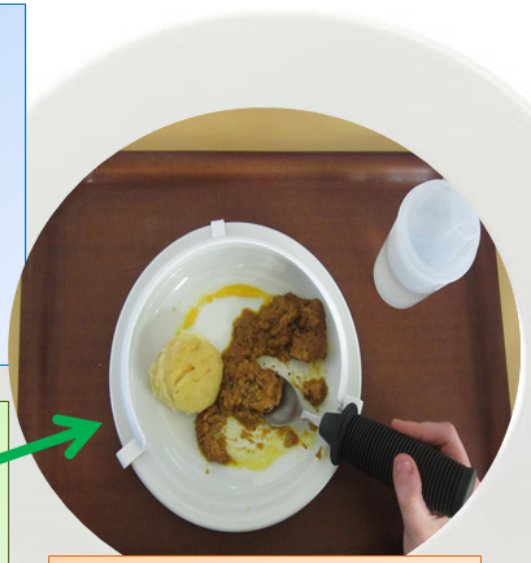
Mealmat: Joe Bloggs

Date: 17.02.15

Fork mashable diet **Syrup fluids**

Positioning and set up

- Upright in chair.
- Meal on tray with plate guard.
- Built up spoon & spouted beaker.
- Sit down next to Joe.



Swallowing strategies

- Prompt Joe to clear mouth before taking next mouthful.
- Encourage two swallows per mouthful.
- Check mouth is empty at the end of meal.

Level of help

- Full set up.
- Prompt Joe to grip spoon
- When tired, help with hand-over-hand assistance.
- Constant supervision.

Communication

- Tell Joe what his meal is.
- Offer him choices e.g. gravy, drink, sauces.

STOP IF THE FOLLOWING OCCURS and advise nurse in charge:

Repeated Coughing; Episode of choking; Chest Infections

Nutrition

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Weight Loss

- High risk of rapid weight loss through all stages
- Cause is multifactorial
  - Increased energy expenditure
  - Decreased oral intake
  - increased metabolic rate/altered metabolism
- Can impact on function and medical stability

Reduced Intake

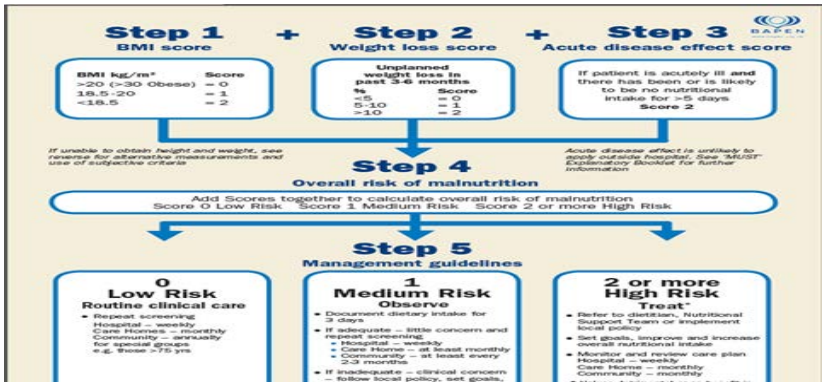
- Reduced ability to prepare meals
- Reduced ability to self feed
- Dysphagia
- Vomiting/reflux
- Depression/anxiety
- Medication side effects
- Communication
- Cognitive decline
- Behaviours that challenge
- Dental issues
- Sleeping pattern
- Constipation

‘Protective Weight Management’

- Recommendations from EHDN specialist group
- Maintain a BMI of: 23-25kg/m^2
- weight loss intervention not started until BMI 27-30kg/m^2 with comorbidities, or above 30kg/m^2 without comorbidities
- Using target weight ranges
- To be discussed with MDT

Identification of MaInutrition

- Use validated screening tools e.g. MaInutrition Universal Screening Tool (MUST)



- Diet history regardless of screening outcome

Nutritional Recommendations

European Huntington's Disease Network Standards of Care recommendations.

- 25-35Kcal/Kg/day
- 0.8-1.5g protein/kg/day
- Fat, carbohydrate and fibre as general population.
- Micronutrients as general population.
- Factor in clinical presentation

Nutritional Management

- Involve patient and carers/family members
- High energy/high protein diet
- Regular meal pattern & snacks
- Early threshold for food fortification & nutrition support
- Oral nutritional supplements
- Facilitating eating and drinking
- Individualised Nutrition Care Plan

Monitoring

- Essential as behaviour/mood/physical abilities can change rapidly
- Weight checks on fortnightly/monthly basis
- Food and fluid records
- Mealtime clinics
- MDT approach

Oral nutrition support


Fresubin Crème

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Obesity

- Can be challenging to manage
- Decreased mobility
- Obsessive behaviours
- MDT intervention & consistent approach
- Capacity assessment, education, contracts
- Regular monitoring is vital due to high risk for rapid weight loss

Enteral Feeding-Challenges

- Pump vs. bolus feeding
- Positioning
- Feed tolerance – reflux, vomiting, gastric emptying, chorea of the gut
- Pulling at tube –abdominal binder

Summary

- Nutritionally high risk group
- Optimal nutritional screening
- Be aware of protective weight management
- MDT approach to maximising nutrition status
- Liaise with your local dietitian

Future Feeding Planning

Future Feeding Planning

Why is it important?

- To avoid decision made at ‘crisis point’
- To give the patient the opportunity to make the decision themselves (or at least contribute!)
- To allow adequate time for education of patient and family/NOK and for them to consider options fully.

Pros and Cons

Risk acknowledged eating and drinking

versus

Feeding Tube

Steps in RHN pathway

1. Liaison with doctor, MDT and NOK. Checking for legal documentation.
2. Communication and cognitive assessments
3. Education sessions and mental capacity assessment.
4. Final decision.
5. Formal documentation.

Mental Capacity Act (Northern Ireland) 2016

- Capacity is the ability to make a decision. It is issue-specific.
- Key principles of the MCA:
  - A person must be assumed to have capacity unless proven otherwise.
  - A person should be given all possible help/support to make their own decision.
  - A person has the right to make an unwise decision.
  - If a person lacks capacity, decisions made on their behalf must be in their best interests.
  - Decisions made in best interests must be 'least restrictive' option.

MCA continued...

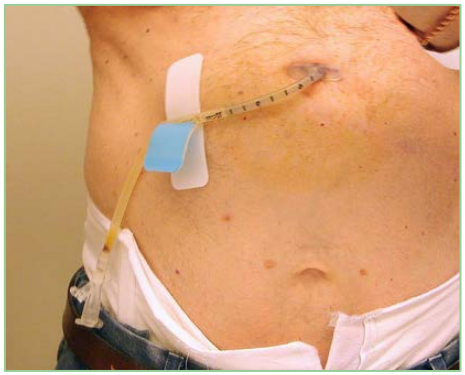
A person has capacity if they can:

- ✓ Understand the information relevant to the decision
- ✓ Retain that information
- ✓ Weigh up that information
- ✓ Communicate their decision (through any means)

If they cannot do one or more of these then they do not have the capacity to make the decision.

Assessing capacity – what we do

- 2 Healthcare Professionals – usually SLT with Dietitian or Psychologist
- Usually at least 3 sessions
- Provide education information
- Use visual materials
- Talking mats
- Structured yes/no questions



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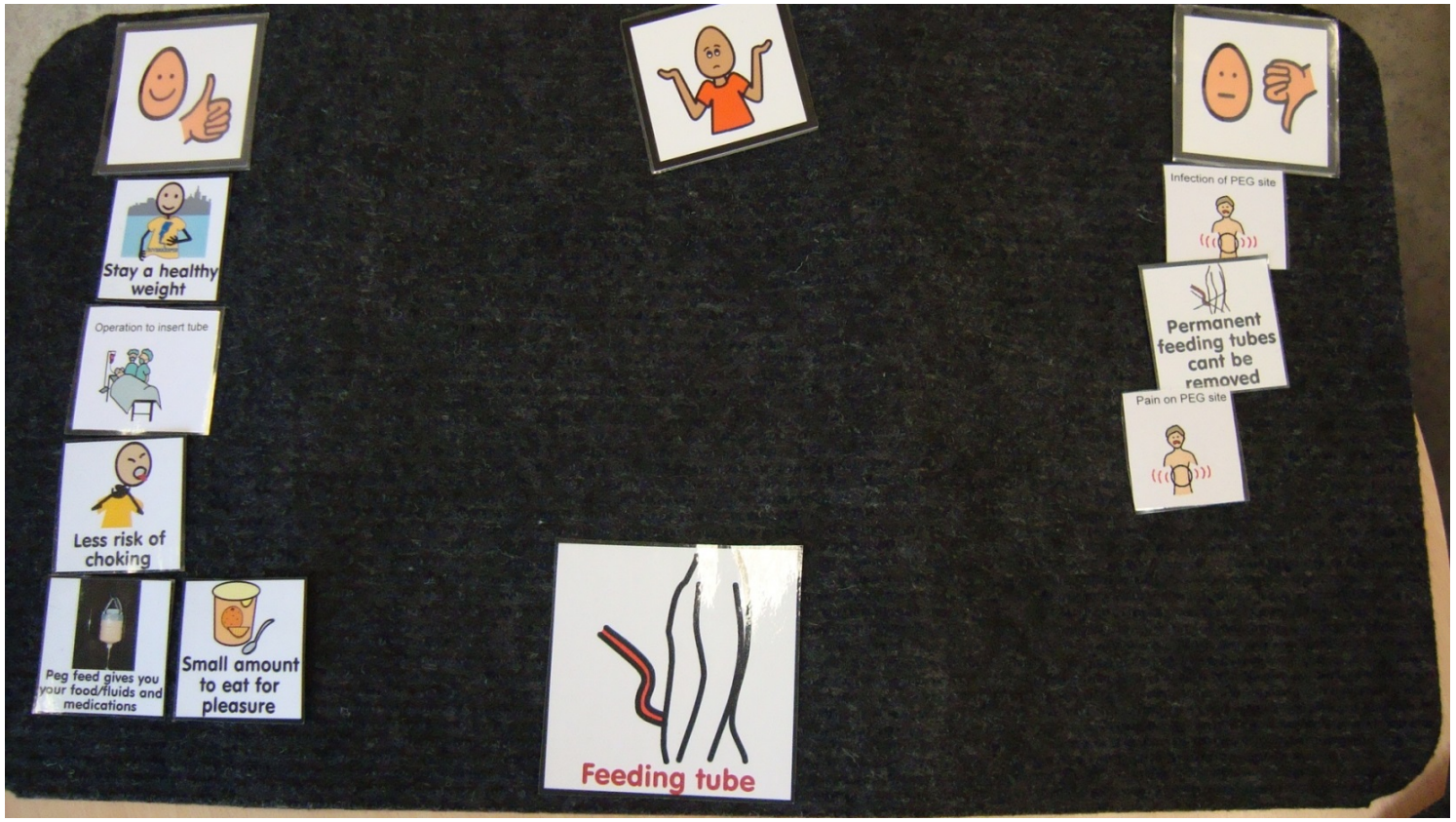
TM – Feeding Tube



TM – No Feeding Tube

What next…

If patient has capacity:

- Patient makes decision
- Clear documentation

If patient lacks capacity:

- Best Interests Decision
- Clear documentation

Case example – MDT working

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