A bit about me:

- Specialist Speech and Language Therapist working with Adults with Learning Disabilities and Dysphagia (problems with eating, drinking and swallowing).
- Work for a community team within the NHS.
- Part of a multidisciplinary team of SLTs, nurses, OTs, Physiotherapists, Psychologists and Psychiatrists.
- Special interests are end of life care and reflux.

Learning Disabilities and Health

- People with LD have poorer health than the general population – some examples:
  1. Twice as likely to die from stomach and bowel cancers
  2. Obesity is 25 times more common than in the general population
- Increased morbidity with decreased life expectancy
- Increased risk of co-morbidities associated with old age ie dementia
- Heavy reliance on resident care, support staff and family when faced with terminal illness

Some facts about the Learning Disabilities population

- Research indicates that a significant number of people with LD have some degree of dysphagia.
- At least 60% people with Cerebral Palsy (CP) have difficulties with chewing and/or swallowing.
- People with CP show deterioration in oral motor skills and dysphagia in their early 30’s.
- Dysphagia more likely in older adults (common in people with dementia).
- People with Down Syndrome can also have problems with eating, drinking and swallowing due to low muscle tone.
- People with Autism can have issues with eating and drinking ie specific preferences for foods like colour, taste, texture etc - sensory integration issues.

Dysphagia in Adults with Learning Disabilities in the community

- Dysphagia is an impairment or absence of the ability to swallow food, fluid, saliva and medication.
- Swallowing is part voluntary, ie transporting food/drink to mouth, chewing
- Part involuntary - swallow reflex which is controlled by the brain.
- Many of the problems that arise are associated with the fact that the respiratory and digestive tracts share part of the same tracts.
- Dysphagia is very common in people with learning disabilities - 1 in 10 people known to services have dysphagia.
- Common conditions associated with LD and dysphagia:
  - Cerebral palsy
  - Down Syndrome
  - Rett Syndrome
  - Autism

Some figures:

Respiratory disease is the leading cause of death amongst people with LD - 52% deaths compared to 15-17% in the general population.

And another…

• As many as a quarter of the respiratory disease deaths of PLD can be directly linked to aspiration pneumonia

Community Services Commission (2001): Disability, death and the responsibility of care. Sydney:
New South Wales Community Services Commission

WARNING SIGNS OF DYSPHAGIA

• Gagging, coughing and/or choking at mealtimes
• Chest infections
• Change in colour – especially around eyes/mouth
• Increase in breathing rate, noisy breathing
• Gurgly voice
• Watering eyes
• Noisy swallow
• Increased heart rate, sweating
• Grimacing when swallowing
• Weight loss
• Food refusal
• Urinary tract infections

What can go wrong?

• Penetration—Food or fluid enters the airway to the level of the vocal cords
• Aspiration—The entry of food or liquid into the airway below the level of the vocal cords, which may or may not cause coughing or choking.
• Silent aspiration—The entry of food or fluid into the airway with no obvious visible signs, i.e. no coughing

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Associated physical health problems

• Chest infections
• Aspiration pneumonia,
• Choking
• Malnutrition
• Dehydration
• Poor appetite/ weight loss
• Constipation and/or Urinary tract infections
• Gastro oesophageal reflux (GORD): often goes undiagnosed due to difficulties in reporting and communicating symptoms and pain
• Pressure sores and delayed healing
• Difficulties taking oral medications
• Helicobacter Pylori (bacteria in gut).
• People with Learning Disabilities are more likely to have poorer oral care/ health than the general population.
• Drug side effects (xerostomia- dry mouth).
• So as a consequence, people with LD can have a reduced quality of life, recurrent illness and poorer health status.

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Gastroesophageal reflux (GORD)

• Acid from the stomach leaks into the oesophagus – common terms heartburn, indigestion
• 48% of people with a learning disability with an IQ below 50, will have this.
• Of these, 75% have oesophagitis (Bohmer et al 2000)
• Higher prevalence in people with LD due to cerebral palsy, poly pharmacy, scoliosis/ kyphosis, hiatal hernia, poor diet, poor gastric motility, helicobacter pylori- bacteria in the gut linked to stomach cancer and gastric ulcers
• High prevalence in oesophageal and stomach cancers in LD

Choking

• Leading cause of preventable death in people with LD.
• There is a higher incidence of choking in LD population due to:
• Difficulties chewing and or swallowing
• Poor oral health/ dentition
• Effects of medication
• Behaviours ie Pica- eating in- edibles/ non- food items
• Bolting food/ cramming.

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GORD
- 10 times more likely to get than general population.
- Often goes undiagnosed due to difficulties in reporting and communicating symptoms and pain.
- Can be managed with changes to diet and lifestyle, medications or surgery.

Symptoms
- Heartburn/ indigestion
- Pain behaviours - hitting chest, rubbing stomach
- Difficulty swallowing
- Throat clearing
- Breathing difficulties ie newly diagnosed asthma
- Bad breath
- Regurgitation/ vomiting
- Coughing after eating or at night
- Reduced appetite/ weight loss

Capacity
- Ethical issues and risk add to the complexity of managing someone with dysphagia
- Mental capacity and best interests play a key role in management
- Dysphagia is best managed as part of a multidisciplinary team

End of life care planning
- Communication is key
- Working as a multidisciplinary team is important
- Important to do end of life care planning with people sooner rather than later ie where they want to be cared for
- Signposting family and carers to the appropriate support

What role do SLTs have around end of life care?
- Risk feeding
- Support with alternative feeding and oral tasters
- Feeding for comfort
- Support with discussing end of life plans
- Advice about medication format, liaising with GP and other professionals
- Advice about importance of oral care
- Training for carers and family

Thank you for listening. Any questions?