Learning Disabilities Mortality Review (LeDeR) Programme

Learning Disabilities Mortality Review (LeDeR) Programme: Fact Sheet 18

Dysphagia and aspiration pneumonia

Key considerations for reviewers

- Did the person experience repeated chest infections (three episodes within 6 months or four episodes within 12 months involving the lower airways)? If so, were these considered in combination to assess whether the person was at risk of aspiration pneumonia?
- Did the person have any risk factors for aspiration pneumonia identified, and a management plan to minimise these risks put in place?
- Did the person have a full swallowing assessment by a speech and language therapist if there appeared to be any difficulties with their swallowing?
- Was the person in regular receipt of oral and dental care?

Introduction

Respiratory disease is one of the leading causes of death for people with learning disabilities. An examination of cause of death certificates by Glover and Ayub in 2012 found that people with learning disabilities are, on average, nine times more likely to die from lung inflammation caused by solids or liquids or foreign bodies in the windpipe than people who do not have learning disabilities. The Confidential Inquiry into Deaths of People with Learning Disabilities (CIPOLD 2013) found that respiratory disorders were the most prevalent immediate cause of death in people with learning disabilities. Difficulties with swallowing (dysphagia) would have contributed to some of these deaths.

Key Principles

Dysphagia

Dysphagia is a medical term for swallowing difficulties; difficulties at any stage of the oral, pharyngeal or oesophageal swallowing process are classified as dysphagia. Some people with dysphagia have particular difficulties swallowing certain foods or liquids, while other people cannot swallow at all. Dysphagia can disrupt the normal process of feeding, eating and drinking and can lead to increased risk of choking, aspiration and asphyxiation, poor nutritional status and weight loss. Dysphagia is therefore associated with increased morbidity, mortality and reduced quality of life.

Dysphagia can originate from anatomical or neurological causes. Conditions such as cerebral palsy, stroke, dementia, or Down's Syndrome can all make eating, drinking and swallowing more difficult. In addition, a range of other causes, including behavioural and related to medication use, have been identified.

The key indicators of dysphagia are:

- Difficulty initiating a swallow or delayed swallowing.

- Difficulty forming food into balls (bolus formation) in readiness of swallowing.
- Coughing.
- Choking.
- Regurgitation.
- Sore throat and hoarseness.
- Dysarthia (difficult or unclear speech).
- Halitosis (‘bad breath’).
- Weight loss.

Management of dysphagia

Nice Guidelines state that anyone presenting with dysphagia should be offered an endoscopy within two weeks, to rule out oesophageal or stomach cancer.

Any one choking should be assessed by Speech and Language therapist within 24 hours.

Dysphagia management should be led by a multi-disciplinary team (e.g. by referral to a Speech and Language Therapist in the community learning disability team, with input from dentist, medical specialists, Occupational Therapists, Nutritionists/Dieticians) whose key responsibilities will include:

- Diagnosis and treatment of dysphagia/swallowing disorders.
- Development of co-ordinated assessment protocols, joint goals and timely intervention.
- Joint management plans with written documentation.
- Multi-disciplinary audit of practice.
- Agreed common approach to the involvement of patients/relatives/carers.

Management plans for dysphagia

Management plans for dysphagia should include:

- Assessment and advice about the safety of a person’s swallowing.
- Accommodation of individual’s needs to maximise optimum and safe swallowing and reduce the risk of aspiration (e.g. provide specialist cup or eating utensils).
- Environmental modifications (e.g. consideration of where, when and how the person is eating).
- Compliance with infection control with regards to food hygiene, hand hygiene and use of utensils.
- Monitoring the quantity of food and fluid intake.
- Monitoring weight and hydration.
- Management of risk of aspiration by modifying oral intake (e.g. modifying the consistency of food or fluids) or, in severe cases, recommending no oral intake.
- Modification of feeding strategies and diet (e.g. alternate small bites of food with small sip of liquid, tube feeding).
- Modification of swallowing techniques (e.g. dry swallow or multiple swallows to clear residue).
- Modification of posture (e.g. head tilt, chin tuck).
- Monitoring of oral hygiene.
- Introduction of strategies to increase confidence and reduce fear of choking.
- Support and education for carers in supporting a person to eat and drink.

Aspiration Pneumonia

Aspiration pneumonia occurs when food, saliva, liquids or vomit is breathed into the lungs or airways leading to the lungs, instead of being swallowed into the oesophagus and stomach. This can cause irritation of the lungs, which may progress to bacterial infection, damage to the lungs and respiratory failure.

Aspiration pneumonia can occur with swallowing disorders, during periods of impaired consciousness (e.g. during a seizure), or with other conditions such as gastro-oesophageal reflux or chronic obstructive pulmonary disease (COPD). People receiving nasogastric feeds or with a tracheostomy are at particular risk, as are those with poor mobility or posture problems, frailty, oral health problems, or using certain medications.

Key indicators of aspiration pneumonia are:

- Cough and/or coughing up purulent sputum.
- Difficulty breathing and increased respiratory rate.
- Chest pain.
- Fever.
- Headache.
- Nausea and vomiting.
- Reduced appetite and weight loss.
- Change in voice quality.
- Change in facial expression/colour.

Management of aspiration pneumonia

Management of aspiration pneumonia should be treated promptly with antibiotics. The choice of antibiotics will be influenced by any recent previous antibiotic treatment, microbiology culture results and the person's condition. In severe cases, intubation and mechanical ventilation may be required. A referral to a Speech and Language Therapist should be made to ascertain the cause of the aspiration and to advise on treatment.

All patients with learning disabilities should have a one-off pneumococcal vaccination and an annual flu vaccination. In the 247 deaths of people with learning disabilities reviewed by CIPOLD (2013), respiratory disease was the cause of death in a third of these individuals, despite this group experiencing levels of respiratory illness no higher than the general population. Based on this finding, the report recommended that people with learning disability (irrespective of their place of residence) should be identified as a high risk group in seasonal influenza vaccination programmes.

Following discussions between Public Heath England and NHS England earlier this year it was agreed that the flu plan would specifically emphasise that people with learning disability were in a clinically at risk group by merit of their learning disability alone and should be a priority group to be targeted for flu immunisation.

Summary of key points

Respiratory disease is one of the leading causes of death in people with learning disabilities. Dysphagia increases the risk of aspiration, and aspiration pneumonia. Educating support workers and carers by a speech and language therapist how to modify diet and the provision of support with feeding can help to reduce the risk of aspiration.

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Additional sources of information

Guidelines for identification and management of swallowing difficulties in adults with learning disabilities
www.guidelines.co.uk/wpg/dysphagia-with-learning-disability

Pamis leaflet on respiratory health for people with learning disabilities
pamis.org.uk/cms/files/leaflets/respiratory_leaflet.pdf

Glover, G., & Ayub, M. (2010). How people with learning disabilities die. *Durham: Improving Health & Lives: Learning Disabilities Observatory*. www.improvinghealthandlives.org.uk/uploads/doc/vid_9033_IHAL2010-06%20Mortality.pdf

Guideline for the identification and management of swallowing difficulties in adults with learning disability Working Party—Wright, Beavon, Branford, Griffith, Harding, Howseman, Rasmussen, Sandhu, Shmueli, Smith & Whit
www.guidelines.co.uk/wpg/dysphagia-with-learning-disability

Flu plan 2014/15
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/500928/FluPlan2014_accessiblesuperseded.pdf