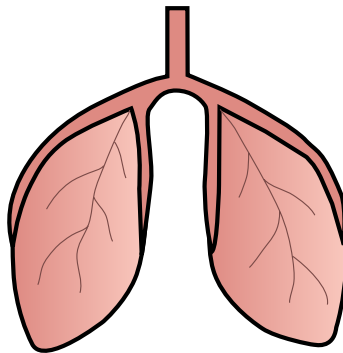


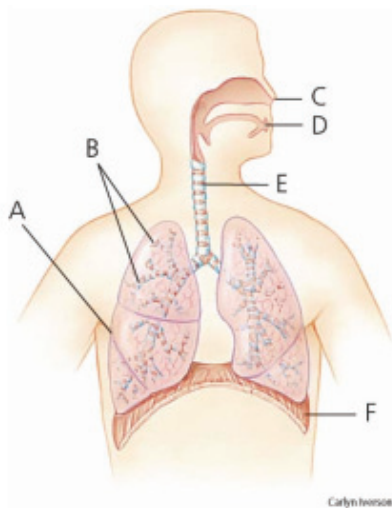
**Respiratory Health  
for  
People with Profound and  
Multiple Learning Disabilities**



## Introduction

Respiratory disease is consistently shown to be the leading cause of death for people with profound and multiple learning disabilities (PMLD), especially pneumonia. This is not the case in the general population and suggests that signs of respiratory disease are not being picked up early enough in this group of people. This may be partly due to difficulties in communication with people with PMLD and partly due to their susceptibility to respiratory infection. It is therefore important that carers are aware of the signs of respiratory distress and the reasons why it occurs.

### A diagram of the lungs and main air passages



- A - Lungs
- B - Bronchi
- C - Nasal Cavity
- D - Oral Cavity
- E - Trachea
- F - Diaphragm

### Classic signs of respiratory distress are:

- **breathing rate** – increased
- **nose flaring** – nostrils spreading open when breathing indicate a person is having to work harder to breathe
- **retraction** – the chest appears to sink in just below the neck and/or under the breastbone
- **sweating** – increased sweat on the head, but the skin does not feel warm to touch, more often the skin feels cool or clammy
- **wheezing** – a whistling or musical sound with each breath may indicate that air passages have straightened and become smaller making it more difficult to breathe.

When any of these changes occur you should immediately contact your local GP.

People with PMLD are very susceptible to respiratory infections for a number of reasons: these include aspiration; asthma; poor positioning; skeletal changes; immobility; and ageing.

## **Aspiration**

Aspiration is when fluid or ingested food enters the lungs. This is normally prevented by a series of protective reflexes such as coughing and swallowing. People with PMLD can find it difficult to swallow; this is called dysphagia. They may also have a weak or ineffective cough. These factors can lead to food and fluid entering the lungs which is called 'over the top aspiration'. The right lower lobe of the lungs is the most common pathway for aspirated material as the angle of the right main bronchus is less acute.

'Over the top' aspiration can go unnoticed or be masked by other medical conditions and may occur for example during a seizure.

### **Possible signs of aspiration**

- coughing and choking during feeds
- difficulty with mealtimes and food refusal
- prolonged feeding times
- gagging with certain consistencies/inability to cope with lumps
- wheezing episodes following a bottle or fluid feed
- repeated chest infections
- repeated episodes of lung or partial lung collapse
- blue episodes.

Fluid and food entering the lungs can have a varied effect on the lungs, in some cases it has little effect, in others rapid damage occurs which is irreversible. The reasons for this are not clear.

If aspiration is suspected, an assessment should take place of the person's eating and drinking. This requires a multidisciplinary approach, including a physiotherapist, occupation therapist and dietitian.

### **The main ways of managing aspiration are:**

- thickening of fluids, careful choices of purees and avoidance of lumpy textures
- optimising seating positions – stable upright body, head upright and midline. Allow plenty of time for the person to take control of the food when in the mouth – this is easier if it is the right consistency and given in small spoonfuls. Avoid lying the person flat straight after meals
- surgery – enteral (tube) feeding; nasogastric, gastrostomy or jejunostomy.

The number of people with PMLD having such surgery has increased considerably during the past decade. It is important that careful consideration is given before such major surgery takes place. There is no doubt of the improvement of the person's nutritional status and weight gain, decreased length of feeding times and, consequently, more flexibility for the family. However, the disadvantages include increased reflux (often requiring additional surgery called fundoplication, which involves wrapping the stomach around the lower oesophagus), changes in mealtime routines and further emotional stress for the family who may feel they have failed with feeding and are guilty of depriving the person of the enjoyment of tasting and eating food. It is important that the practical, social and emotional impacts of enteral feeding are fully explored before the decision is taken to proceed with surgery.

**N.B** see *PAMIS* leaflet on *Understanding & Managing Nutrition* for more information.

### **Aspiration of oral secretions**

With non oral feeding there may be difficulty with normal saliva secretions, these can be thick and lead to choking and aspiration.

### **Management of secretions can be either by:**

- drying agents e.g. Glycopyrrolate or Hysoscine patches which can reduce the volume of saliva
- antibiotics to treat or decrease chest infections
- surgery – removal of saliva ducts or diversion of ducts or tracheostomy.

**N.B.** Hysoscine patches can have adverse effects on a person's eyesight as they cause the pupils to dilate and reduce the ability to focus (see references).

## Gastro-oesophageal reflux – GOR

The symptoms of GOR can sometimes be mistaken for asthma. GOR is the backward flow of acidic stomach contents up the oesophagus, which may then be aspirated. It is usually caused by loss of tone of the muscle at the top of the stomach. Other contributory factors include scoliosis, seizures, sedative medications and maintenance of the lying position. GOR occurs in 70% of people with PMLD and it is important that it is diagnosed as it is extremely uncomfortable for the person and can increase the risk of oesophageal cancer.

### Management includes:

- medical therapies that increase gut movement and gastric emptying together with anti-acid therapy
- thickeners added to drinks
- good positioning e.g sitting at an angle of 40 degrees or more, lying on the right side to promote gastric emptying
- surgery – fundoplication (stomach wrapped around the lower oesophagus, tightening the opening and stopping the gastric contents to reflux). This is often combined with insertion of a gastrostomy, or undertaken later.

Good oral hygiene is very important in people that are susceptible to any type of aspiration. Teeth that are not regularly cleaned can harbour dangerous pathogens that, when entering the lungs, may cause the development of aspiration pneumonia.

**N.B.** GOR can lead to dental problems, e.g. erosion of enamel - see *PAMIS* leaflet on *Oral Health Care* for more information.

## Thoracic cage abnormalities

Respiratory health is heavily dependent on a symmetrical rib cage of adequate volume and good musculature for both inspiration and expiration. These two qualities are also important to generate enough power to produce an effective cough. Changes in shape of the rib cage in people with PMLD are very common due to scoliosis and neuromuscular weakness, these can have significant effects on the functioning and expansion of the lungs.

### **These changes in body shape can be minimised by:**

- postural management – it has been found that distortion of body shape can be prevented by following a personalised programme of postural management
- surgery to correct scoliosis
- chest physiotherapy – postural drainage, percussion and vibration.

## **Airway obstruction**

When people with PMLD are sleeping, loss of tone of the muscles around the nasal passageways can lead to potential airway obstructions. This can lead to low levels of oxygen in the body and consequent damage to the heart.

Damage to the lungs after repeated chest infections can affect the efficient gas exchange of oxygen from the lungs to the blood supply. Treatment to prevent this includes nasal or facial masks to maintain pressure on the air passageways and oxygen therapy to increase the amount of oxygen delivered to the lungs.

## **Asthma**

Asthma is a condition in which there is widespread narrowing of the bronchial airways which changes in severity over short periods of time. People with PMLD may already have compromised breathing systems, so the addition of asthma attacks puts further pressure on the system. It is important to avoid any known external triggers such as highly scented candles or oils that are sometimes used in multi-sensory environments.

### **Practical ways to maintain respiratory health:**

- increase activity e.g. rebound therapy, hydrotherapy
- frequent changes of position and good positioning at mealtimes
- minimise postural deterioration e.g. sleep systems, correct support of head and neck whilst in wheelchairs
- reduce adverse external influences e.g. smoke free environments, highly scented rooms and toiletries.

## References

All the references listed below are available at the PAMIS library – contact [j.t.taylor@dundee.ac.uk](mailto:j.t.taylor@dundee.ac.uk) or tel: 01382 385 154

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## Medical Consent

In Scotland if you are over the age of 16 you are legally an adult. The law assumes you can then make decisions about your medical treatment. People with profound a multiple learning disabilities may not be capable of giving informed consent. Under the **Adults with Incapacity Act (Scotland) Act 2000**, parents (and others) are able to apply to become **welfare guardians**. This involves an assessment of the ability of the adult concerned to make informed decisions and an application to the Sheriff's Court for a **guardianship order** to authorise a particular person to make decisions on her/his behalf.

## Recommended Websites

### **[www.asthma.org.uk](http://www.asthma.org.uk)**

This charity provides a wealth of information on asthma including factfiles on how to reduce the triggers that induce asthma episodes both inside and outside the home.

### **[www.dysphagia.com](http://www.dysphagia.com)**

An American site for professionals, quite technical but does have has a forum where you can post queries.

### **[www.posturalcareskills.com](http://www.posturalcareskills.com)**

Postural Care CIC works to Protect Body Shape for people with movement difficulties. They provide accredited training in therapeutic positioning and non-invasive measurement of body symmetry.

### **[www.publicguardian-scotland.gov.uk](http://www.publicguardian-scotland.gov.uk)**

This site provides a single access point for information relating to welfare guardianship contained in the *Adults with Incapacity (Scotland) Act 2000*.

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