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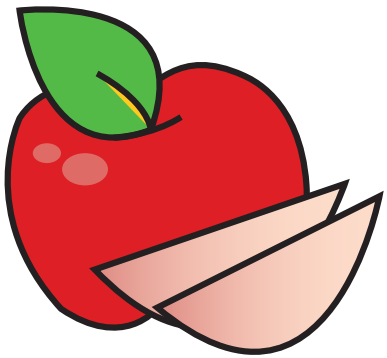
In partnership with people with profound learning disabilities and their carers

Understanding and Managing Nutrition for People with Profound and Multiple Learning Disabilities



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Introduction

People with profound and multiple learning disabilities (PMLD) are more likely to have nutritionally related health problems than the general population. Issues relating to body weight and nutritional status are often caused by health conditions such as swallowing difficulties, gastro-oesophageal reflux, diabetes, constipation and poor oral health. It is important that problems are identified, so positive changes can be implemented, before they become detrimental to the health of the person with PMLD.

There are a number of factors that are likely to impact on the ability of a person with PMLD to eat and drink well and enjoy their meals. These are discussed below.

Swallowing problems – Dysphagia

Over 60% of people with PMLD have been found to have problems with swallowing, either difficulties with dealing with food and drink in the mouth or the process of swallowing. Dysphagia can lead to food or fluid entering the lungs, this is called aspiration – see *PAMIS* leaflet on *Respiration*. Aspiration can cause infections, pneumonia, choking, reduced appetite, weight loss and fear of eating. Lung infections are recognised as a leading cause of death among people with PMLD, so it is very important that an assessment is carried out of the person's eating and drinking technique by a speech and language therapist and/or dietitian.

Techniques that families/carers can use to support people with dysphagia and minimise aspiration include: good positioning, modification of food textures and fluids and the use of adapted equipment.

Positioning

Individual assessment of the best positioning for safe eating and drinking is always necessary for people with PMLD. This should be done by a physiotherapist or an occupational therapist. Although the ideal position is not always possible, the basic principles are to aim for symmetry:

- head in midline, chin tucked towards chest
- trunk as upright as possible
- shoulders relaxed and down

- bottom in mid line and touching the back of the seat
- table or tray to support arms
- feet flat on footrests or floor.

N.B. Correct positioning is also important after eating. An upright position for at least 30 minutes helps with digestion and reduces problems for those people who may have gastro-oesophageal reflux (GOR).

The position of the carer (feeder)

- the person helping someone to eat or drink should be sitting at eye level, so there is face to face contact
- if the person has a visual impairment the carer may need to sit at the side
- food and drink must never be offered whilst standing or sitting behind a person.

Food Textures

Modification of food and fluid is often recommended by a speech and language therapist and/or dietitian to help with swallowing difficulties and minimise gastro-oesophageal reflux (GOR). Below are the terms used to describe different food textures.

- **Soft diet** - foods are well cooked and very little chewing is required. Foods should be diced or sliced and should be able to be mashed easily with a fork
- **Mashed diet** - foods are minced or mashed and do not require chewing. Foods should be moistened with sauce or gravy
- **Pureed diet** - foods which are smooth, free of lumps and not too runny. Texture should not separate into two states, for example, meat particles and fluid gravy.

N.B. Food textures to avoid are; stringy, crunchy, crumbly, small and hard, have husks or skins and have mixed textures such as muesli with milk.

Modifying fluid consistency

There are a number of commercial products available which can thicken food and fluids. The fluids can be prepared to one of three consistencies.

Stage 1 - Syrup consistency, can be drunk through a straw but is thicker than water and leaves a thin coating on the back of a spoon.

Stage 2 – Custard consistency, cannot be drunk through a straw but

can be drunk from a cup, leaves a thick coat on the back of a spoon. **Stage 3** – Pudding consistency, drops rather than flows, cannot be taken from a cup and needs to be taken by a spoon.

Adding liquids to pureed foods may dilute their nutrient content, so it is important to follow the advice of a dietician on ways to fortify foods to increase their nutritional value, for example adding cream, butter, powdered milk or commercial supplements.

It is also very important to make sure the person has enough to drink. Excessive drooling, constipation and diarrhoea can leave people with PMLD dehydrated. On average a person should drink 1200-1500ml a day which is about 8-10 average sized drinks.

Equipment

It is important that the person has the appropriate equipment to eat and drink effectively. Occupational therapists can advise on these aids which may include:

- different shaped cups, with one or two handles, of different weights, materials, and transparencies. A transparent cup is useful to see how much liquid a person has taken
- cutlery of different shapes, sizes, depths and materials, solid plastic cutlery is better for people that have a bite reflex
- plates and bowls which do not slip; and/or have higher sides that prevent spillage
- insulated crockery which keeps food hot if mealtimes are lengthy
- straws (available in different widths) can help those with a weaker suck.

Mealtime management

Socialisation and communication are important for everyone's quality of life, particularly for people with a disability. A noisy dining room with distractions such as a loud TV make it hard to enjoy meals and are often a reason for poor food intake. Allow plenty of time for the person to swallow, giving small mouthfuls at a time and use verbal prompts: talk clearly about the food you are offering, especially if it is pureed.

Gastro-oesophageal reflux disease (GOR)

It has been found that up to 70% of people with PMLD have GOR, this is caused by acid from the stomach entering the oesophagus. This is very painful and can permanently damage the oesophagus and can even lead to oesophageal cancer. GOR is highly treatable either by drugs or modification of fluids, see *PAMIS* leaflet on *Respiratory Health* for more information.

Medication

Carers need to be aware of the effect of medications (drugs) on the nutritional status of the person.

- some medications interact with food. The number and types of medication a person is taking may make the interaction with their nutrition more complex
- medications can depress or increase appetite or thirst. Some also affect the taste of food. Others may cause nausea or vomiting, drooling or a dry mouth which can make it difficult to swallow food
- weight increase or decrease, constipation, diarrhoea and difficulty in eating should be assessed with relation to the medications the person is taking.

Check with a doctor if you are concerned, particularly if the medication is taken regularly over a long period and there are different types of drugs taken. Also check that the drugs are being taken at the right time e.g. before or after meal times.

Oral Health (see *PAMIS* leaflet on *Oral Health Care* for more information)

Good oral hygiene is essential to enjoy mealtimes and maintain good health. There is considerable evidence to show that people with PMLD have a higher level of dental decay and infections of the mouth than the general population. Therefore, it is essential that teeth are cleaned twice a day with fluoride toothpaste and regular visits are made to the dentist.

Helicobacter Pylori is an infection often found in people with PMLD –this species of bacteria can cause stomach ulcers, but it can be treated with antibiotics. It is important that carers are aware of this as it may explain changes in behaviour such as irritability, self-injurious and challenging behaviour.

It is frequently reported that some people with PMLD may use behaviour when being fed to communicate their distress. It is important that this is recognised and time is taken to understand the causes of the person's behaviour and address any underlying issues.

Enteral nutrition

The number of people with PMLD who are fed directly by a tube into the gastrointestinal tract is increasing. The tube is usually inserted directly into the stomach (gastrostomy) or occasionally into the small intestine (jejunostomy). A person may need this form of nutrition when they are unable to eat sufficient food to ensure adequate nutrition or if they have swallowing problems which make it dangerous for them to continue to eat and drink by mouth.

It is important that families and carers are given adequate information on the effects of tube feeding for the person they care for, and the consequences for the rest of the family. Although medically it can be very successful, it can also be very stressful emotionally for carers. It is also important that adequate training is given to all the family and carers and that there is continued support.

All the above factors make it very important to continually assess the nutritional status of someone with PMLD. Weight is fundamental to assessing nutritional status, hydration, calculating energy requirements and monitoring intervention and progress. Specialist weighing equipment such as ceiling track hoist with scales or wheelchair beam scales are needed to weigh people who are non ambulant. It is a good idea to record changes of weight in a person with PMLD with maximum and minimum lines (a dietician can do this), so that, if a person's weight changes, appropriate and immediate action can be taken.

References

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

British Dietetic Association (2008) *Home enteral tube feeding for adults with a learning disability.* Birmingham: BDA.

Crawley, H. (2007) *Eating well: children and adults with learning disabilities.* Herts: The Caroline Walker Trust

Department of Ageing, Disability & Home Care (2003) 2nd Edition. *Nutrition in practice manual*. Sydney: DADHC

DiMascio, F, Hamilton, K. and Smith, L. (2008) The nutritional care of adults with a learning disability in care settings. British Diatetic Association. www.bda.uk.com/publications/statements/EnteralTubeFeedingAdultsLD.pdf

Duffin, C. (2010) Raising awareness of dysphagia among healthcare professionals. *Learning Disability Practice* **13**, 4, 21-24

NHS Quality Improvement Scotland (2007) *Caring for children and young people in the community receiving enteral tube feeding: best practice statement.* Edinburgh: NHS QIS. www.nhshealthquality.org/nhsqis/files/TUBEFEEDCHILDREV_BPS_SEP06.pdf

NHS Scotland (2004) *Health needs assessment report: people with learning disabilities in Scotland.* Glasgow: NHS Scotland.

Pawlyn, J. and Carnaby, S. eds. (2009) *Profound intellectual and multiple disabilities: nursing complex needs.* Chichester: Wiley-Blackwell

Roberts, J. (2010) Dysphagia: the challenge of managing eating and drinking difficulties in children and adults who have learning disabilities. *Tizard Learning Disability Review* **15**, 1, 14-16

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 2002***, 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.eatwell.gov.uk
Eatwell is the Food Standards Agency's consumer advice and information site. It is packed with reliable and practical advice about healthy eating, understanding food labels and how what we eat can affect our health.

www.PINNT.com
This site is intended for people who are on intravenous and nasogastric nutrition therapy and their carers as well as healthcare professionals. PINNT provides support and information to carers.

www.bda.uk.com
The British Dietetic Association is for professional dieticians but the website has lots of factsheets on food, diet and health that are useful.

www.bapen.org.uk
The British Association for Parenteral and Enteral Nutrition, largely for professionals but lots of good links to other useful sites and voluntary organisations.

www.publicguardian-scotland.gov.uk
This site provides a single access point for information relating to the welfare and financial provisions contained in the Adults with Incapacity (Scotland) Act 2000.

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