

**Managing Bowels and Bladders
for
People with Profound and
Multiple Learning Disabilities**



Introduction

Continence is *'having the ability to store urine in the bladder or faeces in the bowel and to excrete voluntarily when and where it is socially appropriate.'*

People with profound and multiple learning disabilities (PMLD) are extremely likely to have continence issues due to poor neurological development, but there are also additional factors that can impact on an individual's ability to manage their bowels and bladders. These include medical problems, the effects of medication, behavioural, dietary and emotional issues.

Continence is both a health issue and a quality of life issue. It is therefore extremely important that people with PMLD get the right kind of individual support that meets their circumstances, while upholding their dignity and privacy and maintaining good health to manage their bowels and bladders.

All people with continence problems are entitled to a continence assessment. Assessment is vital to identify the underlying causes and contributory factors. The key aspects of a continence assessment include: taking a history; a physical examination; urine testing (urinalysis - screening conditions such as diabetes, urine infections, and assessing the level of hydration in the body) and an understanding of contributory factors. Once a diagnosis is made, a treatment plan can be developed.

A normal bladder on average voids 6 times a day at 4-6 hourly intervals. A normal bowel movement is no more than 3 times a day and no less than 3 times a week. There should be no need to strain more than 25% of the time and the stools should be soft and comfortable to pass.

It is vital that carers of people with PMLD are aware of the additional continence problems they may experience and are provided ways with which to manage them.

Dehydration

People with PMLD often have problems with eating, drinking and swallowing. This is called dysphagia, see *PAMIS* leaflet on *Managing Nutrition* for more information. For people with dysphagia, fluid is surprisingly difficult to manage. It is vitally important that appropriate

training is given to all carers on good dysphagia management to minimise the risks of dehydration.

Maintenance of the correct level of fluid is crucial to good health. Approximately 60% of the total body weight of men and 52% of women is fluid. A reduction of only 5% in the total fluid circulating around the body will result in feelings of thirst. A reduction of 10-15% is classified as severe dehydration and can result in death. Dehydration increases the risk of urinary tract infections and bladder cancers.

There is no recommended daily fluid intake but on average it should be around 1200-1500ml/day which is about 8-10 drinks, however this does depend of the weight of the individual (a heavier person requires more fluid intake).

The digestive system is the primary mechanism for getting fluids into the body. So any digestive disorder such as constipation or diarrhoea will cause an upset in the person's fluid balance and require careful monitoring. Some people with undiagnosed or poorly controlled diabetes experience excessive urination and/or excessive thirst. This can also cause dehydration.

Signs & Symptoms of dehydration

- dark malodorous urine
- dry continence pads or low urine output
- rapid shallow breathing
- frequent urinary infections, elevated temperature
- dry loose skin that is cold & clammy
- dry mouth, thick viscous saliva
- sunken features, particularly the eyes
- headaches, confusion & dizziness
- constipation
- weight loss.

If a person is dehydrated they will need more fluid intake and food that contains water such as fruit, vegetables, cereal with milk, yogurt, ice-cream, custard and soups.

Hyperhydration

This is when there is too much fluid in the body. This may occur with the over administration of tube feeds. Too much fluid can also lead to reduced appetite leading to a poor nutritional status.

Symptoms of hyperhydration include:

- increased urine output
- bloated face, eyelid swelling
- rapid pulse & rapid breathing
- large amounts of frothy saliva, moist tongue
- puffy skin that pits when pressed
- weight gain
- irritability, anxiety, disorientation, possibly seizures.

Constipation

Constipation is when the stools are hard and/or bowel evacuation is less than 3 times a week. This is a very common problem with people with PMLD because of lack of mobility, hypotonia (poor muscle tone), effects of medication and low fluid and fibre intake.

Signs & Symptoms of constipation

- abdominal pain
- bloating
- straining
- soiling
- haemorrhoids/anal fissures
- challenging behaviour
- loss of appetite.

The treatment and management of constipation is very individual and ideally should be addressed by adjusting diet and fluid intake though this is not always successful or possible.

Abdominal massage is an alternative, non invasive technique that can help to improve the movement of the stools through the colon when a person has little mobility. It also has the added benefit of being a pleasant and relaxing experience, and increases communication and social interaction. It is important to check with the person's GP that this procedure is not going to cause any problems and ensure training is given to the carer by a physiotherapist or nurse on the correct techniques of massage.

N.B The hydration status of a person with constipation should be assessed before laxatives are used as they can exacerbate any dehydration.

Drug therapy to treat constipation

- bulk-forming laxatives e.g. Ispaghula husk speeds up the transit time or foods such as whole grain cereals and porridge
- stimulant laxatives e.g. Senna which encourages peristalsis (muscle movement) by stimulating the nerves of the bowel and reduces water re-absorption to give a soft stool
- osmotic laxatives e.g. Lactulose & Movicol soften the stool by increasing the water content and volume of the stool in the bowel.

N.B. Always check with a doctor before using any over the counter medications.

Diarrhoea

Diarrhoea is when there is frequent bowel evacuation and abnormally soft stools. It is caused by gut infections, food intolerances, constipation and the side effects of medication, especially antibiotics. Constipation is the commonest reason for diarrhoea and it is known as overflow diarrhoea.

Dehydration usually results from periods of diarrhoea so it is important that people are adequately hydrated. It may be necessary to use oral hydration therapy to replace salts and electrolytes (sodium, chloride and potassium) which have been lost.

Cancer of the Gastro-intestinal tract

People with PMLD are particularly at risk from cancer of the gastro-intestinal tract. This is likely to be due to the high incidence of gastro-oesophageal reflux (GOR) – see *PAMIS* leaflet on *Managing & Understanding Nutrition*, and chronic constipation and the delays in treatment of these conditions.

Another factor is a bacterial infection of the stomach called *Helicobacter pylori*. This is a common bacteria and is more prevalent where people live close together because of risk of cross-infection. This infection causes symptoms such as indigestion, bloating and fullness and often leads to ulcers in the stomach and increased risk of stomach cancers. Treatment for *Helicobacter pylori* involves a course of antibiotics.

Self Management

In some cases people with PMLD may be able to have some degree of self management of their toileting. There should be an assessment made of the person by an occupational therapist, physiotherapist or continence specialist. This should include an assessment of the functional ability and postural difficulties. The aim is to achieve optimum positioning for voiding on the toilet with support. Research has found that the best results are from a timed toileting programme. This involves observing the individual, learning about the patterns of urination and evacuation. Plan the toileting programme around the most likely times for these to happen and use plenty of verbal and physical prompts. *PAMIS* has designed a multi-sensory story to develop independence in the toilet routine called *Toilet Time*, which can be borrowed from the *PAMIS* library. Bag Books also have several multi-sensory stories concerning toileting.

For many people with PMLD the most suitable method of management is through containment using pads which are available from the continence nurse. *PAMIS* is aware of several cases where the supply of pads have been highly regulated. This is not acceptable. People with PMLD have the same right of dignity as everyone else and rationing pads puts further stress on family carers.

PAMIS actively campaigns for the provision of fully accessible toilets - Changing Places toilets. These facilities are required to have enough room for a wheelchair and two carers as well as a height adjustable, adult sized, changing bench and a hoist. These toilets allow people to be changed in a suitable and dignified environment by carers. For further information on the location of Changing Places toilets see www.changing-places.org.uk.

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.

References

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

Bradley, A. and Lambe, L. (2006) *Managing continence, helping people with learning disabilities*. Kidderminster: BILD.

Cooke, L.B. (1997) Cancer and learning disability. *Journal of Intellectual Disability Research*, **41**, 312-316.

Hogg, J. (2008) Cancer and intellectual disability: a review of some key contextual issues. *Journal of Applied Research in Intellectual Disabilities*, **21**: 509-518.

Marsh, L. (2010) Management of constipation. *Learning Disability Practice* **13**, 4, 26-28

Pawlyn, J. and S. Carnaby 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.

Smith, M and Moss, L. (2008) Abdominal massage for constipation in children. *Learning Disability Practice*, **11**: 4, 33-36.

Welch, K. (2010) Fluid balance. *Learning Disability Practice*, **13**, 6, 33-38.

Recommended Websites

www.bagbooks.org

Bag Books is a UK-wide charity providing tactile and multi-sensory stories to people with learning disabilities. Some of their stories are specifically designed to encourage toilet training.

www.bladderandbowelfoundation.org

This organisation provides a whole range of literature and information as well as a directory of continence clinics across the UK.

www.eric.org.uk

This website provides information and advice for supporting children with continence problems.

www.fledglings.org.uk

Fledglings is a charity which sources and supplies practical, affordable products for disabled children. These include swimming costumes for children and young adults that are incontinent and radar keys.

www.promocon.co.uk

Promocon is a national service to promote continence and product awareness. Lots of information and products and has a confidential helpline.

www.changing-places.org

Information on design, equipment and location of Changing Places toilets across the UK.

www.ldascotland.org

Map of all the Changing Places toilets in Scotland with some photos.

www.publicguardian-scotland.gov.uk

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

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