

Managing swallowing difficulties in patients with learning disabilities

David Wright, Tom Howseman

In 2012 a national working party consisting of experts in the care of patients with learning disabilities and the management of swallowing difficulties (dysphagia) was convened to develop guidelines to assist with the identification of at-risk patients. The aim was to improve the diagnosis and management of dysphagia in this patient population. The guidelines were also designed to improve the protection of such patients by ensuring that they are treated in a fair and equitable manner. This article provides an overview of the guidelines (Wright et al, 2012) for the community nurse.

KEYWORDS:

Learning disabilities ■ Dysphagia ■ Medication ■ Guidelines

Learning disability is defined as a significantly reduced ability to understand new or complex information, to learn new skills, and to cope independently (Department of Health [DH], 2001). It usually appears before adulthood and significantly impairs the individual's development. The DH estimates that 1.2 million people in England have mild or moderate learning disabilities and 210,000 people have severe or profound learning disabilities, which are most commonly caused by Down's syndrome and cerebral palsy (DH, 2001; Emerson and Hatton, 2008).

Consequently, the average GP will have approximately 40 patients with learning disabilities on his or her caseload, a patient group that is known to have a higher incidence of health problems than the general population (DH, 2001). Using data from general speech and language therapy caseloads, it is estimated that approximately 36% of patients

with learning disabilities in primary care have swallowing difficulties (Leslie et al, 2009).

THE IMPACT OF DYSPHAGIA

While the swallowing function is necessary for the ingestion of fluid and food, meals and coffee breaks provide the focus for much of our social interaction. Consequently, any condition that affects the ability to swallow or provides embarrassment when eating and drinking can significantly affect an individual's quality of life.

An inability to sufficiently masticate and lubricate a bolus before swallowing can increase the likelihood of choking, while conditions that impair closure of the epiglottis (which prevents food or liquids from entering the lungs during the act of swallowing) (Figure 1), can increase the likelihood of aspiration pneumonia.

In certain diseases that cause dysphagia, such as Parkinson's disease, aspiration pneumonia is the main cause of death (Wermuth et al, 1995). It is unsurprising, therefore, that the National Patient Safety Agency (NPSA) has identified

dysphagia as a key area of risk for this population group (NPSA, 2007).

Managing swallowing difficulties appropriately can improve patients' wellbeing through appropriate nutrition and hydration, ensuring they receive their prescribed medication and preventing adverse events such as choking and aspiration pneumonia. Consequently, it is important that community nurses assess patients with learning disabilities for risk of swallowing difficulties and, where these are identified, put appropriate interventions in place to improve patient care.

IDENTIFYING THE CAUSE OF DYSPHAGIA IN PATIENTS WITH LEARNING DISABILITIES

Speech and language therapists specialising in the evaluation and management of dysphagia divide the swallowing process into three phases:

- ▶ Oral
- ▶ Pharyngeal
- ▶ Oesophageal.

This enables the location of the anatomical problem to be accurately described (Figure 2) (Wright, 2011).

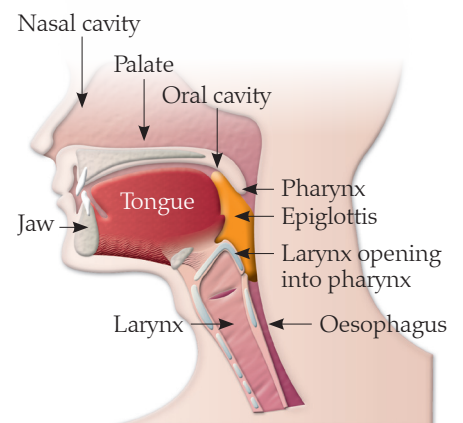


Figure 1. The physiology of swallowing.

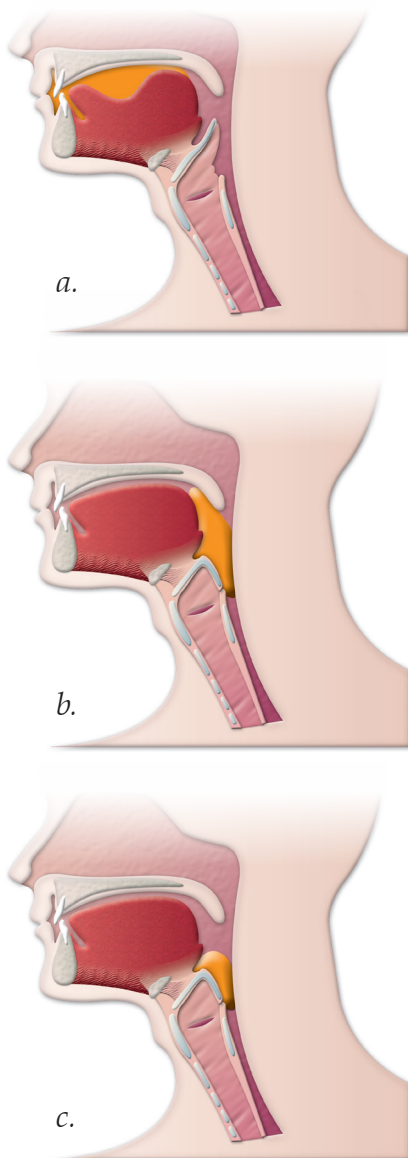


Figure 2.
The phases of swallowing: a.oral, b. pharyngeal and c. oesophageal.

Problems within the oral phase can cause inadequate bolus preparation, while it is in the pharyngeal phase that aspiration occurs (Cichero and Murdoch, 2006).

Identifying which phases of the swallow are impaired can help in the development of management strategies during feeding (Harding and Wright, 2010). Dysphagia is classified into oropharyngeal or oesophageal, and determining the location of the problem can help nurses to identify the most suitable intervention.

While comprehensive lists of symptoms are provided within the guidelines (Wright et al, 2012), those commonly associated with

Table 1: Symptoms commonly associated with dysphagia

Oropharyngeal dysphagia	Oesophageal dysphagia
Difficulty initiating a swallow	Delayed initiation of swallow
Coughing	Gagging/vomiting
Choking	Tongue pumping
Halitosis	'Gurgly' voice

dysphagia and which community nurses are most likely to encounter, are summarised in *Table 1*. Where adults with learning disabilities are unable to communicate effectively, it is strongly recommended that the presence of such symptoms is discussed with his or her carer.

Additionally, the nurse might wish to observe the patient during a meal in order to evaluate the risk of aspiration. *Table 2* provides an outline of the symptoms that may be seen during feeding and which are associated with the risk of aspiration.

In all instances where dysphagia is suspected, a more formal diagnosis should be made and concerns should be raised with the patient's GP, who should determine the most appropriate action. A detailed referral pathway is provided within the guidelines (Wright et al, 2012), which identifies when the patient can be adequately managed within primary care, when a speech and language therapist should be involved and at what point secondary care intervention is required. Subsequent active treatment of dysphagia with drugs, i.e. Botulinum toxin injections, and/or surgery is left to specialists within the field.

The community nurse is, however, ideally located to support the administration of food and medicines in this patient group.

ADMINISTRATION OF FOOD AND LIQUID

Speech and language therapists will assess a patient's swallowing action and identify the most appropriate food texture. Texture can help compensate for motor difficulties by aiding the manipulation of solid food in the oral cavity of patients with oral preparatory or oral phase difficulties.

The British Dietetic Association recommends a hierarchy of textures according to need (Whelan, 2001; British Dietetic Association, 2012):

- ▶ Fork-mashable diet
- ▶ Pre-mashed diet
- ▶ Thick puree
- ▶ Thin puree.

The type of food texture recommended will be individual to the patient and dependent upon the patient's oral motor and swallowing needs, with the aim being to minimise the risk of aspiration.

It is important that any recommendation made by a speech and language therapist regarding texture is effectively communicated to all individuals responsible for care and that this is taken into account when determining how best to administer medication, e.g. the thickness of any liquid medicines requires consideration as does any recommendation to disperse or

Table 2: Symptoms associated with risk of aspiration

Mild aspiration risk	Moderate aspiration risk	Severe aspiration risk
Poor tongue control	Poor bolus formation	Reduced laryngeal elevation
Pocketing of food	Absent protective reflexes	Coughing associated with feeding
Variable feeding status	Tongue pumping	Changes in voice quality
Immature feeding patterns	'Gurgly' voice	Increased respiration rate
	Wet respiration	Sudden change in colour
	Nasal regurgitation	Change in facial expression
	Gagging/vomiting	Sudden sweating
	Delayed initiation of swallow	

crush tablets and add them to water. The latter usually produces a bolus, which is not as thick as a thin puree — however, if the thickness is not appropriate for the patient then they may be more at risk of aspiration.

Thickeners are designed to reduce the risk of aspiration by helping the patient create a cohesive bolus and altering the bolus' viscosity and texture. However, thickeners can also negatively affect both food palatability and the bio-availability of medications taken at mealtimes. Also, thickeners are often mixed incorrectly by carers and the required fluid viscosity may not be achieved (Crawford et al, 2007).

It has been shown that patients on thickened fluids rarely meet the hydration targets necessary for good health, while still experiencing a high incidence of aspiration pneumonia (Finestone et al, 2001).

Posture is important for patients with limited motor ability. During the feeding process poor posture can affect the initiation of motor skills, the breathing pattern required for eating and drinking, the swallow mechanism, and effective gut motility (Morton et al, 1993). Providing postural stability during mealtimes can improve oral preparatory and oral phase stability. Also, appropriate head control and whole-body stability — particularly in the pelvis and hips, trunk, shoulder girdle, and legs — can help to reduce the risk of aspiration.

Where possible, patients should be encouraged to be independent when eating as this enables them to control the speed and pace of the meal. Importantly, by setting the pace, the patient can create a bolus of food and clear the oral cavity before taking the next mouthful (Pinnington and Hegarty, 2000). When using utensils, hand-over-hand prompting can also maximise opportunities for independent eating and drinking. This method involves the clinician actually 'cupping' the patient's cutlery-holding hand and providing physical guidance. Hand-over-hand prompting can help the patient

prepare themselves as much as possible for the subsequent swallow.

PEG feeding

Percutaneous endoscopic gastrostomy (PEG) may be necessary if eating and drinking difficulties are so severe that oral feeding is not safe or if the patient is not able to consume adequate nutrition orally.

In these situations the guidelines highlight the importance of oral hygiene to prevent the build-up of residues that can cause infection or contribute to aspiration-related illnesses. If a patient is receiving food and liquids via PEG, nurses should assess the administration of medicines as they may be unlicensed through this route — White and Bradnam (2010) provide guidance on safe PEG administration.

Care plans

In their guidelines, Wright et al (2012) state that in order to

'It has been shown that patients on thickened fluids rarely meet the hydration targets necessary for good health.'

adequately care for patients with swallowing difficulties, carers need to understand the implications of the condition, have received training on management strategies, and have a written management plan. Written materials should be used to manage swallowing difficulties in patients with a learning disability and these should include care plans for eating, drinking and swallowing and mealtime information forms.

Management/care plans should:

- ▶ Be individualised
- ▶ Include advice provided by a speech and language therapist and a dietitian
- ▶ Outline the patient's needs
- ▶ Identify plans or goals to address those needs
- ▶ Make clear the actions needed to achieve the goals
- ▶ Evaluate the management process.

A community nurse visiting a patient should be aware of such plans and is ideally placed to monitor their implementation.

ADMINISTRATION OF MEDICATION

The correct administration of medicines is key to patient safety. An appropriate medication review must include investigating the best method of drug delivery, which will improve patients' willingness to take their medication. When selecting the administration method it is necessary to consider delivery, patient safety, and the legality of any recommendations that are made.

The guidelines strongly recommend that patients with learning disabilities who are newly diagnosed with dysphagia should undergo a medication review to ensure they are only receiving medicines that are necessary and effective as well as being the appropriate dosage (Wright et al, 2012). Medication reviews should be conducted regularly and a structured review process should be created in order to improve care, reduce risk, and address compliance issues. The NO TEARS tool is recommended (Lewis, 2004) and summarised below:

- ▶ Need and indication: does the patient still need the treatment and is the indication for the medication still relevant?
- ▶ Open questions: while difficult in patients with learning disabilities, open questions present an opportunity to explore compliance issues
- ▶ Tests and monitoring: should any tests be conducted or monitoring carried out?
- ▶ Evidence and guidelines: has the premise for initiating, maintaining, or stopping treatment changed?
- ▶ Adverse events: has the patient developed any new signs or symptoms that could be drug-related?
- ▶ Risk reduction or prevention: are there any other risks to consider and would current therapy affect these risks?

- ▶ Simplification and switches: have new formulations become available that are more cost-effective?

Formulation

Once the need for each medication has been established it is important to consider the formulation. Most medicines are prescribed as tablets and capsules and sometimes simple adjustments to their shape and size can overcome problems with administration.

Patients generally prefer torpedo-shaped medicines and, therefore, asking the pharmacy to change the shape or size of a tablet may be all that is required. In some instances it may be appropriate for the patient to chew a medicine before swallowing, however, the coating and formulation requires consideration as does the palatability of the resultant mixture. Chewing, crushing, or dispersing a tablet can cause a previously palatable tablet to become inedible or unpleasant and, therefore, patients should always be asked about acceptability.

Unfortunately, patients with a learning disability might struggle to communicate this information. Therefore, a speech and language therapist may involve the patient and the carers in preparing a communication passport. These are small booklets that include the patient's personal likes and dislikes and which use past experiences, history and current information to help the clinician recognise the individual within the situation.

If tablets cannot be swallowed, an alternative liquid medicine or route of administration (such as patches, oro-dispersibles, or suppositories) should be considered. Licensed liquid medicines are not the same as crushed or dispersed tablets as they are designed to be palatable and have an even drug distribution, ensuring that the patient receives the full measured dose.

Unlike thin fluids or tablets dispersed in water, liquid medicines are designed to cohere during swallowing and, therefore, minimise

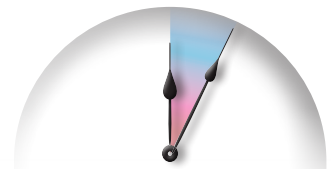
the risk of aspiration. As stated earlier, thickeners should be used with caution as they may alter the effect of the medicine, taking it outside the terms of its license.

Where licensed liquids are unavailable then unlicensed 'specials' might be available. A special is a specific preparation, usually a variation of a licensed medication, made by a specialist manufacturer or pharmacist and which has not undergone the same testing procedures as a medicine. However, in most clinical cases, licensed preparations should be considered before unlicensed products or unlicensed activities, such as tablet crushing or dispersing.

Tablets and capsules are frequently designed to optimise how and where a drug is released into the body (e.g. gastro-resistant coatings and modified-release preparations), or are coated to mask the medicine's flavour (e.g. film and sugar coatings). Crushing, dispersing or chewing tablets/capsules to make them easier to swallow can significantly affect how and where the drug is released into the body and, therefore, the consequences of such actions should always be considered. Simple products such as ibuprofen are sugar- or film-coated to disguise their flavour and any tampering before administration can make them very unpleasant for patients, who may simply refuse them if they are unable to effectively communicate their distaste.

Enteric or 'gastro-resistant' coatings are designed to either protect the drug from stomach acid, i.e. omeprazole; protect the stomach lining from the drug itself, i.e. diclofenac; or to release the drug where it needs to work, i.e. sulfasalazine. Therefore, it is not appropriate to tamper with the coating before it is taken.

Modified-release preparations should never be crushed, dispersed or chewed as the resultant release of the full dose increases the chance of side-effects. Also, as the body will subsequently excrete the full dose more quickly, there will be a period



Five-minute test

Answer the following questions about this article, either to test the new knowledge you have gained or to form part of your ongoing practice development portfolio.

- 1 – What is dysphagia?
- 2 – Name some of the symptoms of dysphagia.
- 3 – Outline some of the problems with eating and drinking for people with a learning disability and dysphagia.
- 4 – Name some of the primary issues in administering medicine to this patient group.
- 5 – Can you explain the principles behind the concept of 'duty of care'?

when there is not enough of the medication remaining in the body for it to work.

Learning disability patients may have difficulty in swallowing and involuntarily grind their teeth. In this case, a modified-release preparation is best avoided unless absolutely necessary, i.e. if an alternative preparation cannot be sourced.

Community pharmacists

If a community nurse is faced with a patient with a learning disability and dysphagia, he or she should contact the patient's community pharmacist to determine what formulations are available and the safe options for administering any medication.

All medicines should be administered in strict accordance with the conditions of their licence, i.e. without prior tampering. The Human Medicines Regulations 2012 only allow independent prescribers to authorise unlicensed administration of medicines to patients. However, crushing, dispersing, and mixing can be undertaken by a person acting under the written instructions of an independent prescriber.

When a medicine is recommended for administration outside of licence, it is important that this recommendation comes from a reliable source and that it is recorded. This demonstrates that the patient has been treated and considered fairly.

LEGAL RESPONSIBILITIES

In their follow-up to *Death by Indifference*, Mencap (2012) concluded that many clinicians still fail to provide adequate treatment to patients with learning disabilities. The guidelines highlight the clinician's duty to the patient, the need to demonstrate equality in their subsequent actions and the need to be aware of the regulator's perspective (Wright et al, 2012).

A duty of care arises when a health or social care professional undertakes the management of a person with a learning disability — the clinician is legally obliged to provide evidence-based care and treatment tailored to the individual.

This duty continues until treatment is no longer clinically required, the service user refuses further treatment or care is transferred. Deciding to discontinue the medication of a person with a learning disability because of their inability to swallow would be an example of a breach of this duty of care. The law clearly states that any health or social care professional who fails in this duty is accountable, and has to answer for that failure.

Discriminating against a person with a learning disability because of that disability is unlawful and is an offence under the Equality Act, 2010. Where an inability to swallow is a feature of a person's learning disability, the proper assessment, identification and management of that person's swallowing difficulty should be carried out. Consequently, a minimum requirement from the point of view of the community nurse is that anyone with a learning disability suspected of dysphagia should be referred to a GP.

The Health and Social Care Act 2008 created the Care Quality Commission (CQC), which has imposed essential standards for quality, safety, and

management of medicines as summarised below:

- ▶ Medicines prescribed or administered must be appropriate and person-centred
- ▶ A person's disabilities must be considered when prescribing and administering medicines
- ▶ Prescriptions must be up to date, regularly reviewed and changed following the individual's needs
- ▶ If a person develops swallowing difficulties, the route of drug administration should be reviewed
- ▶ Risks should be managed through effective medicines handling, including correctly dispensing, preparing, administering, monitoring and disposing of medicines
- ▶ Procedures should be in place for providing medicines covertly in accordance with the Mental Capacity Act, 2005.

Unsurprisingly, failure to comply with these guidelines can result in a clinician receiving a warning or a fine, and may also lead to closure of a service. Additionally, following a 2010 amendment to the 2008 Health

'A duty of care arises when a health or social care professional undertakes the management of a person with learning disabilities.'

and Social Care Act, the CQC will also pass on evidence of poor practice to a professional's regulator, which could lead to the investigation of an individual's fitness to practice.

CONCLUSION

Community nurses frequently provide care for patients with learning disabilities. Dysphagia is found in more than one-third of these patients and in addition to affecting quality of life, it increases the risk of choking and aspiration. Appropriate management can improve patient care and minimise NHS costs.

It is, therefore, important that dysphagia is identified and any risk of choking and aspiration assessed. This can be undertaken by speaking to the

KEY POINTS

- Over one-third of patients with learning disabilities will have some form of dysphagia.
- Dysphagia increases the risk of choking and aspiration pneumonia.
- Discussion with carers and observation of feeding may be required to identify the possibility of dysphagia.
- Where dysphagia is suspected then referral to the patient's GP is necessary.
- Medication review is essential to ensure that the patient only receives medicines that are necessary.
- Medication formulation requires careful consideration to ease administration and patient acceptability.

patient and carers and by observing the administration of food, liquids and medicines.

Any patient with dysphagia should be referred to their GP to enable them to decide the most appropriate actions and the recent guidelines provide detailed and considered guidance in this respect (Wright et al, 2012).

Simple interventions to improve food and liquid consistency and review medicines and their formulation can reduce the risk of choking and aspiration. The community nurse is ideally located to monitor adherence to swallowing care plans and to instigate medication reviews. Where medicines are being tampered with before swallowing, this practice should be carefully considered for appropriateness, safety and legality. Medicines are central to the decision-making process and are focussed upon by external regulators.

Patients with learning disabilities should be treated in the same way as patients without learning disabilities and all actions and decisions should be accurately documented to demonstrate this. **JCN**

REFERENCES

- British Dietetic Association (2012) Dysphagia Diet Food Texture Descriptors. British Dietetic Association, Birmingham
- Cichero J, Murdoch B (2006) *Dysphagia: Foundation, Theory and Practice*. Wiley and Sons, Chichester
- Crawford H, Leslie P, Drinnan M (2007) Compliance with dysphagia recommendations by carers of adults with intellectual impairment. *Dysphagia* 22(4): 326–34
- DH (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century—A White Paper*. DH, London
- Emerson E, Hatton C (2008) *People with Learning Disabilities in England*. Available at: http://eprints.lancs.ac.uk/9515/1/CeDR_2008-1_People_with_Learning_Disabilities_in_England.pdf (accessed 14 August, 2013)
- Finestone H, Foley N, Woodbury M et al (2001) Quantifying fluid intake in dysphagic stroke patients: A preliminary comparison of oral and non-oral strategies. *Arch Phys Med Rehabil* 82(12): 1744–46
- Harding C, Wright 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): 4–13
- Leslie P, Crawford H, Wilkinson H (2009) People with a learning disability and dysphagia: A Cinderella population? *Dysphagia* 24(1): 103–04
- Lewis T (2004) Using the NO TEARS tool for medication review. *Br Med J* 329: 434
- Mencap (2012) *Death by Indifference: 74 Deaths and Counting. A Progress Report 5 years on*. Mencap, London. Available at: www.mencap.org.uk/74deaths (accessed 14 July, 2013)
- Morton R, Bonas R, Fourie B, et al (1993) Videofluoroscopy in the assessment of feeding disorders of children with neurological problems. *Dev Med Child Neurol* 35(5): 388–95
- NPSA (2007) *Problems Swallowing?* NPSA, London
- Pinnington L, Hegarty J (2000) Effects of consistent food presentation on oral–motor skill acquisition in children with severe neurological impairment. *Dysphagia* 15(4): 213–23
- Wermuth L, Stenager EN, Stenager E, Boldsen J (1995) Mortality in patients with Parkinson's disease. *Acta Neurologica Scandinavica* 92(1): 55–58
- Whelan K (2001) Inadequate fluid intakes in dysphagic acute stroke. *Clin Nutr* 20(5): 423–28
- Wright D (2011) *Prescribing Medicines for Patients with Dysphagia*. Grovesnor House Publishing, Guilford
- Wright D, Beavon N, Branford D, et al (2012) *Guideline for the Identification and Management of Swallowing Difficulties in Adults with Learning Disability*. Available at: www.eguidelines.co.uk/eguidelinesmain/guidelines/summaries/gastrointestinal/wp_dysphagia_2012.php (accessed 14 August, 2013)
- White R, Bradnam V (2010) *Handbook of Drug Administration via Enteral Feeding Tubes*. 2nd Edition. Pharmaceutical Press, London