DYSPHAGIA IN PEOPLE WITH LEARNING DISABILITIES

Tom Howseman reviews guidance for carers and professionals on the management of service users who have difficulties swallowing

Abstract

Dysphagia has a detrimental effect on quality of life, particularly among people with learning disabilities. The cause of the condition must be identified to assess risk, plan management and, above all, ensure the safe administration of medicines. Yet, although people with learning disabilities and swallowing difficulties may be at serious risk if their conditions are not diagnosed and managed appropriately, there has been a lack of guidance on the subject in the UK. This article explains how a multidisciplinary group of UK healthcare professionals shared their knowledge about dysphagia in a guideline for best practice. It also describes how to determine its causes and emphasise the importance of the condition. The article covers the administration of medications to people with swallowing difficulties, the importance of regular and comprehensive reviews of medications, and the need to involve the people concerned and their carers in such reviews, and in care planning. It also deals with some of the legal principles underpinning this area of care, where many service users have insufficient mental capacity to make necessary decisions.

Keywords
Dysphagia, best practice, medication, legal issues

Dysphagia is a distressing and dangerous condition that in some people can lead to death. Thacker et al (2008) states that ‘feeding and swallowing impairments are key predictors of increased morbidity and mortality in adults with learning disabilities’, while Chadwick and Jolliffe (2009) show that dysphagia is a significant issue for people with learning disabilities and those who care for them.

The disproportionately high prevalence of dysphagia among service users is due mainly to the effects of hypo- or hypertonia and poor co-ordination. Having reduced IQ, people with learning disabilities may be unaware that some foods, such as tough meat that must be chewed, require specific masticatory preparation before it is swallowed. Communication with people with learning disabilities and dysphagia can be difficult too. Kelly et al (2011) state that administering medicines to people with dysphagia is complex and requires knowledge, understanding and skilful attention to detail. Helpful, effective guidance alerts staff to all of these factors and their consequences.

The number of people with learning disabilities living in community settings has increased over recent years, but there is a scarcity of guidance on the subject in the UK. The general NPSA (2007b) guideline on the subject is excellent but does not cover people with learning disabilities as a specific group. A simple guideline on the subject would therefore help clinicians recognise and manage dysphagia in people with learning disabilities.

To attempt to solve this problem, a multidisciplinary group of UK clinicians comprising,
as well as the author, a professor of pharmacy practice, two chief pharmacists, a senior lecturer in communication disabilities, a lecturer in health law, a consultant gastroenterologist, a specialist nutrition support dietitian, chair of the Royal College of General Practitioners Learning Disabilities Group and two associate directors of medicines management, pooled their clinical knowledge on the subject to draw up such a guideline.

The Guideline for the Identification and Management of Swallowing Difficulties in Adults With Learning Disability (Wright et al 2013) was launched in March 2013 at the headquarters of the Royal College of General Practitioners to an audience of GPs, speech and language therapists (SALTs) and learning disability nurses. Its reception was overwhelmingly positive and its authors subsequently presented the guideline at a series of continuing professional development-accredited events. In June 2013, short and long versions of the guideline were published on an internet microsite, along with videos of the presentations, slideshows and background documentation.

The guideline provides all the information professionals need to recognise, diagnose and manage dysphagia. It encourages reflection on clients and practice, and can assist in decisions about when to recommend further assessments of the condition. There are concise tables to help assimilate the knowledge provided and a flowchart that guides the reader through the whole journey of a person with learning disability and dysphagia (Figure 1). The flowchart also includes a section that explains the particular legalities of prescribing and medicines administration.

Causes and characteristics

Dysphagia can result from one or a multitude of medical problems, including stroke, progressive neurological conditions and poor oral health (NPSA 2007b). Aspiration, choking and death are more likely in people with the condition, which can lead to malnutrition, dehydration and a lower quality of life (NPSA 2007b).

Dysphagia can contribute to a reduced sense of wellbeing and have a negative impact on body image. Eating is a social activity but the presence of dysphagia can alter the dynamic of joint meals with carers, families or friends, and thereby affect all members of people’s social circles.

Consequently, successful dysphagia interventions can improve many social and psychological aspects of people’s lives. Such interventions can also help reduce the risk of aspiration, leading to fewer chest infections. This in turn leads to fewer preventable and costly hospital admissions, which saves the people involved from the constant discomfort and anxiety that is associated with going into hospital. Avoidance of emergency admissions is high on the agenda of all clinical commissioning groups (CCGs) and so the authors of the guideline made it clear that staff who refer to it can better identify and treat people with learning disabilities and dysphagia, and thereby prevent, delay or reduce the occurrence of aspiration, which is a common cause of preventable admissions.

Dysphagia is characterised either by problems initiating a swallow, known as oropharyngeal dysphagia, or by a feeling that foods and/or liquids are being hindered in their passage from mouth to stomach, known as oesophageal dysphagia (Malagelada et al 2007, NPSA 2007a).

Although both types of the disorder can occur together, most health professionals prefer to identify them separately. The causes of oropharyngeal dysphagia can be classified as mechanical and obstructive, or neuromuscular, although it can also be caused by factors such as dry mouth, or xerostomia, and by oral ulcers and poor dentition.

The causes of oesophageal dysphagia can be divided into mucosal, mediastinal – that is relating to neighbouring anatomy - or neuromuscular. The side effects of medications can contribute to, or be the main cause of, such problems.

The main characteristics of oesophageal dysphagia (RCSLT 2006) are:

- Choking.
- Coughing.
- Difficulty initiating a swallow.
- Diminished cough reflex.
- Dysarthria and diplopia.
- Halitosis.
- Nasal regurgitation.
- Nasal speech.

The main characteristics of oesophageal dysphagia (RCLST 2006) are:

- Absent protective reflexes.
- Delayed initiation of swallow.
- Gagging and vomiting.
- Gurgling voice.
- Nasal regurgitation.
- Poor bolus formation.
- Tongue pumping.
- Wet respiration.

Clinicians specialising in the evaluation and management of dysphagia refer to four normal phases of swallow that define the anatomical locations of eating and drinking difficulties (Wright et al 2013).
Figure 1  Referral pathway for people with swallowing difficulties

GP regularly reviews patient’s symptoms and medical history

- Does the patient’s medical history and/or symptoms indicate onset or worsening of swallowing difficulties or dysphagia? For example, is there:
  - ‘Bubbly’ voice quality.
  - Cerebral palsy.
  - Coughing during and/or after meals.
  - Dementia.
  - Dysarthria
  - Failure to maintain weight.
  - History of choking episodes.
  - History of frequent chest infections.
  - Regurgitation.
  - Severe and complex disabilities.
  - Shortness of breath when eating or drinking.
  - Slow eating and/or refusing food.
  - Stroke.

Conduct medication review using NO TEARS

Consider further screening and possible water-swallow test

- Does a further screen or water-swallow test indicate swallowing difficulties?

Identify the progression of swallowing difficulties or dysphagia

- Progressive
- Intermittent and chronic

Refer patient for two-week wait and upper gastrointestinal gastroscopy

Refer patient to a speech and language therapist

Refer patient to a gastroenterologist

Consider whether the swallowing difficulty is due to cancer?

- Yes
- No

Can the patient be fed in a way that minimises risk without further medical examination?

- Yes
- No

Create management plan, consulting dietitian if appropriate

Is the swallowing difficulty oesophageal or oropharyngeal? Diagnose by undertaking the following, as appropriate:

- Barium swallow.
- Central nervous system imaging.
- Laboratory tests.
- Nasoendoscopy.
- Videofluoroscopy, possibly with manometry.

Refer patient to an oncologist

Consider:

- Medical therapy.
- Surgery.
- Tracheotomy.

Alternative feeding methods, such as percutaneous endoscopic gastrostomy.

Refer patient to speech and language therapist

Consider legal duties

(Adapted from National Patient Safety Agency 2007)
Research suggests that dysphagia can be classified according to the phase of swallow in which the dysfunction occurs (Logemann 1983, Arvedson et al 1994). The phases are:

- **Oral preparatory**, in which food is prepared into a bolus ready to be swallowed.
- **Oral**, in which the bolus is moved posteriorly to initiate the pharyngeal reflex.
- **Pharyngeal**, in which the bolus triggers the pharyngeal reflex and so moves out of the mouth into the oesophagus with associated closure and protection of the airway.
- **Oesophageal**, in which the bolus is moved through the oesophagus by the propulsive contractions of the oesophageal muscles.

Dysphagia can disrupt the normal processes of eating and drinking at any or all of these phases (Logemann 1983, Arvedson et al 1994). Pharyngeal phase dysfunction can also increase the risk of aspiration, which may result in serious and potentially fatal respiratory infection (Cichero and Murdoch 2006).

### Risk factors

Communication difficulties are a common barrier that needs to be overcome when trying to determine if a person has dysphagia. Discussions with the person’s carer about the symptoms are essential, and an additional helpful step is to watch the person during a meal to evaluate the risk of aspiration (Box 1).

Careful review of clinical histories should be carried out, particularly to identify risk factors associated with the development of swallowing difficulties (Van Schrojenstein Lantman-de Valk et al 1997), before more formal diagnoses should be made.

- Risk factors associated with the development of aspiration (Cichero and Murdoch 2006) include:
  - Birth history.
  - Blood chemistry.
  - Chest condition.
  - Concordance issues.
  - Environmental factors.
  - Epilepsy.
  - Fatigue issues.
  - Lengthy feeds.
  - Medical disorder.
  - Medical interventions.
  - Medication.
  - Motor disorders.
  - Poor oxygen saturation.
  - Postural issues.
  - Respiration difficulties.
  - Severe sensory feeding disorder.
  - Variable feeding status.

Medical conditions that predispose to aspiration (Cichero and Murdoch 2006) include:

- Asthma.
- Cardiac problems.
- Craniofacial abnormalities.
- Degenerative conditions.
- Epilepsy.
- Gastroenterological difficulties.
- Neurological disorders.
- Post-traumatic incidents.
In oropharyngeal dysphagia, limited motor ability affects not only oral-motor skills but also the breathing pattern required for eating and drinking, the swallowing mechanism and effective gut motility (Aulton and Taylor 2002). Pharmacological and surgical interventions are largely inappropriate for managing the majority of the neurological and neuromuscular causative mechanisms of oropharyngeal dysphagia. Other management strategies, including altering the texture of the food, which can help with motor difficulties, have proved invaluable.

The British Dietetic Association (2011) recommends a hierarchy of textures according to need. These are:
- Fork-mashable diet.
- Pre-mashed diet.
- Thick puree.
- Thin puree.

The type of food texture required is dependent on the oral-motor and swallowing needs of the person, and which texture best reduces the risk of aspiration. Thickeners can be used to reduce the risk of aspiration; they help the person create a cohesive bolus in the mouth, thus aiding oropharyngeal control and slowing transit time in the pharynx (Sciortino et al 2003, Steel and Van Lieshout 2004). The position of the body can also help when eating, and providing secure postural steadiness during mealtimes can improve oral preparatory and oral phase stability.

Where possible, people should be encouraged to be independent. Independence during mealtimes can enable a person with learning disabilities to control the speed and pace of the meal. By setting the pace, the person can take sufficient time to create a bolus of food and clear the oral cavity before taking the next mouthful (Morton et al 1993). Hand-over-hand prompting, in which nurses places their hands over those of clients to guide them while they use cutlery, can help clients develop coordination and control their speed of eating (Wright et al 2013).

If alternative feeding methods must be adopted, it is important to remember oral hygiene, which is essential to the dignity and comfort of the person concerned. Nurses must ensure that there is no build up of oral residue, which can cause infection or contribute to aspiration-related illnesses (Pinnington and Hegarty 2000). Percutaneous endoscopic gastrostomy (PEG) feeding may be necessary if eating and drinking difficulties are so severe that oral feeding is not safe, or if it is not possible to consume adequate nutrition orally.

The primary goals of treatment for oesophageal dysphagia are to reduce the impact of aspiration and to provide symptom relief. Treatment may include the use of drugs, for example botulinum toxin injections, or surgery, such as fundoplication, and/or endoscopic therapy, such as dilation. Box 2 summarises the main treatment options for oesophageal dysphagia.

Medications
In administering medications safely, clinicians must consider the appropriateness of selected methods.

<table>
<thead>
<tr>
<th>Cause</th>
<th>Conservative management</th>
<th>Invasive treatment</th>
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<tbody>
<tr>
<td>Diffuse oesophageal spasm</td>
<td>Nitrates, calcium-channel blockers</td>
<td>Serial dilations or longitudinal myotomy</td>
</tr>
<tr>
<td>Achalasia</td>
<td>Soft food, anticholinergics, calcium channel blockers</td>
<td>Dilation, botulinum toxin injections, Heller's myotomy</td>
</tr>
<tr>
<td>Scleroderma</td>
<td>Anti-reflux drugs, medical management of scleroderma</td>
<td>None</td>
</tr>
<tr>
<td>Peptic stricture</td>
<td>Anti-reflux drugs (H2 blockers, proton-pump inhibitors)</td>
<td>Dilation, fundoplication</td>
</tr>
<tr>
<td>Infectious oesophagitis</td>
<td>Antibiotics (nystatin, acyclovir)</td>
<td>None</td>
</tr>
<tr>
<td>Pharyngoesophageal (Zenker's) diverticulum</td>
<td>None</td>
<td>Endoscopic or external repair and cricopharyngeal myotomy</td>
</tr>
<tr>
<td>Schatzki's ring</td>
<td>Soft food</td>
<td>Dilation</td>
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of delivery, patient safety and the legality of their recommendations. Nurses have the most important professional roles in drug administration, however, and have specific training in the area, including knowledge of the relevant NPSA (2007c) guidance. Nurses who refer to Wright et al’s (2013) guideline will be aware of the implications for service users and professionals of failing to follow instructions for medication administration.

People are usually more willing to take medications if the best method of drug delivery is chosen. If tablet swallowing is a problem, it can be mitigated by simple adjustments. Chewing, or crushing and dispersing previously palatable tablets can make taking them unpleasant, so the people concerned should be asked whether the taste of the tablet is acceptable (Wright et al 2013). People with learning disabilities may struggle to communicate this information, so it is important to remember to use the communication passports prepared by SALTs.

If tablets cannot be swallowed, alternative liquid medicines or routes of administration, such as patches, orodispersibles or suppositories, should be considered. Unlike most crushed or dispersed tablets, licensed liquid medicines are formulated to be palatable and to ensure distribution of a full measured dose is even (Aulton and Taylor 2002). Also unlike thin fluids or tablets dispersed in water, liquid medicines are formulated to cohere when swallowed, which reduces the risk of aspiration in people who have difficulties co-ordinating closure of the glottis during the pharyngeal phase (Wright et al 2013). In all clinical cases, licensed preparations should be tried before unlicensed products are considered. If licensed liquids are unavailable, however, unlicensed ‘specials’ may be used (Wright et al 2013). In such cases, thickeners should be used with caution because they may alter the effect of the medicine and, as such, are administered outside the terms of their license.

Many tablets and capsules are designed, for example with gastro-resistant coatings, to ensure that the drug they contain is released into the body at the optimum time. Such coatings may include sugar or flavourings that mask the taste of the drug. If tablets or capsules are chewed, crushed and/or dispersed before being swallowed, therefore, their taste may become unpleasant, and their time and method of release into the body may be affected. The consequences of crushing, chewing and dispersing tablets should always be considered, especially if the people taking them grind their teeth involuntarily. In such circumstances, a modified-release preparation is best avoided unless absolutely necessary and when an alternative preparation cannot be sourced (Wright et al 2008).

Oral formulations should be administered in strict accordance with the conditions of their licences, without previous tampering. The Medicines and Healthcare Products Regulatory Agency (2013) states that only independent prescribers are authorised to administer unlicensed medicines. However, crushing, dispersing and mixing can be undertaken by people acting under the written instructions of independent prescribers (Home Office 2012).

Medication reviews are a cornerstone of medicines management and are especially important in the care of people with learning disabilities,

<table>
<thead>
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<th>Box 3 The NO TEARS tool</th>
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<tr>
<td><strong>Need and indication</strong></td>
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<td><strong>Open questions</strong></td>
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<td><strong>Tests and monitoring</strong></td>
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<td><strong>Evidence and guidelines</strong></td>
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<td><strong>Adverse events</strong></td>
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<td><strong>Risk reduction or prevention</strong></td>
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<td><strong>Simplification and switches</strong></td>
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(Lewis 2004)
who are specifically protected in law (Wright et al 2013). The quality and effectiveness of medication reviews can vary widely, however. Reviews should be conducted regularly and a structured review process should be created to improve care, reduce risk and address concordance issues. The NO TEARS tool (Lewis 2004) is particularly straightforward and can ensure consistency for this vulnerable group of people. It is described in Box 3.

**Person and carer involvement**

If nurses do not administer medications, carers probably do and should be involved in care planning and management processes. When nurses make risk assessments, create safe care plans, ensure correct medication administration and participate in best-interest meetings for clients who lack capacity to make decisions, they should differentiate between paid care providers and informal carers, such as friends or family members. This is because paid carers’ level of attachment to patients differs from that of informal carers, who may act in ways that are clinically incorrect in the belief that they are doing what is right for the patients concerned.

It is essential that carers understand the importance of medicines administration and why they should not, for example, crush or mix medications with other food if this is inappropriate. People with learning disabilities do not always understand the implications of their swallowing difficulties so their carers must fully recognise the need to follow management guidance to reduce the risk of aspiration. They should also receive training on management strategies (NPSA 2007a), even though non-concordance with such strategies among service users and their carers is common (Chadwick et al 2003, Crawford et al 2007, King and Ligman 2011).

Carers should also be given written, accessible care plans (NPSA 2007a) to ensure that they adhere to the recommendations of specialists, such as the speech and language specialists and dieticians. Such care plans should be individualised and should outline the needs and strengths of the individuals concerned. They should also set out how service users’ needs will be met and how the management process will be evaluated (Lloyd 2010), and should be reviewed regularly to ensure that they continue to fulfil these purposes. Failure to adhere to care plans raises the risk of harm to the people concerned.

Care packages for people with learning disabilities are often delivered 24-hours a day in the clients’ homes. This means that large numbers of different carers, often working to differing shift patterns, are involved in the care of individuals, and care can become inconsistent. If all carers work to written care plans, however, such consistency of care can be achieved.

People who require pureed food and/or thickened fluids are likely to be at high risk of becoming malnourished and/or dehydrated (Kennedy et al 1997, Whelan 2001, Ekberg et al 2002, Wright et al 2005). Both conditions make swallowing more difficult: malnutrition causes fatigue, muscle weakness and impaired coughing, while dehydration reduces the fluid content of saliva. Carers of people who require pureed food and thickened fluids need to encourage them to eat and drink small amounts of high-energy food and fluids throughout the day.

Management of people with learning disabilities and swallowing difficulties often requires referral to various specialists, including SALTs, dieticians, and gastroenterologists. A referral pathway for people with swallowing difficulties, and how they can be managed at each stage, is provided in Figure 1.

**Legal issues**

Mencap (2007, 2012) has demonstrated that the UK’s healthcare services are failing many people with learning disabilities and, in this context, the Equality Act 2010 and the Mental Capacity Act 2005 are essential reading for all health professionals.

One important part of the law relates to the definition and implications of duty of care, which states that health and social care professionals who care for people with learning disabilities are 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 has been transferred to another professional. Discontinuing medications for people with learning disabilities because they cannot swallow tablets prescribed to meet their clinical needs is therefore a breach of the duty of care. Professionals who fail in this duty are accountable and must answer to their professional regulator. If such a reckless breach of the duty were to contribute to a service user’s death, then the issue of liability in gross negligence manslaughter would arise (Wright et al 2013).

The Care Quality Commission (CQC) has drawn up a series of essential standards, including one for the quality, safety and management of medicines (CQC 2010). If healthcare professionals fail to meet these standards, they can receive warnings or fines, and the services in which they work may be closed. The CQC also passes on evidence of poor practice to the relevant regulators, which could prompt investigations into professionals’ fitness for practice.
Thus, care of, and treatment for, people with learning disabilities involves specific duties under common law, the statutes that govern the practitioner-client relationship and the professional regulator. These duties provide maximum protection for service users. They are not mutually exclusive and can individually or collectively hold a health professional to account (Wright et al 2013).

Conclusion

The authors hope that their guideline will help professionals and carers to identify service users who are at risk of dysphagia, and encourage optimal practice in the management of swallowing difficulties, to improve the lives of a vulnerable group of people. Professionals who follow best practice and have a sound knowledge of the legal implications of caring for people with learning disabilities can protect their professional registrations. Meanwhile, high quality diagnosis and management of dysphagia may reduce the number of acute hospital admissions of people with learning disabilities, thereby saving money for the NHS (Wright et al 2013).

Implications for practice

- One in three people with learning disabilities has dysphagia problems, a figure far higher than that for the general population, and are more likely to experience adverse outcomes of the condition.
- Failure to manage dysphagia appropriately can lead to choking, aspiration, pneumonia and death.
- When dysphagia is suspected, the person concerned should be referred to specialists so that a definitive diagnosis can be made.
- A systematic approach to the dietary, therapeutic, medical and review of people with learning disabilities with swallowing difficulties will improve their outcomes.
- Risks to people and to personal professional registration are minimised by following the guidance described in this article.

Find out more

A single comprehensive guideline on dysphagia with referral pathway is available at tinyurl.com/qz3u487

References


