

Guideline for the identification and management of swallowing difficulties in adults with learning disability

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Guideline for the identification and management of swallowing difficulties in adults with learning disability

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Introduction

Learning disability is defined as a significantly reduced ability to understand new or complex information, to learn new skills, and to cope independently.¹ The disability is associated with onset before adulthood, and has a lasting effect on development. In *Valuing People*, the Department of Health estimated 210,000 people in England had severe or profound learning disabilities: 65,000 children and young people, 120,000 adults of working age, and 25,000 older people. Approximately 1.2 million adults were thought to have mild or moderate learning disabilities.^{1,2}

Adults with learning disabilities experience a higher incidence of health problems than the general population.^{1,3,4} The National Patient Safety Agency (NPSA) identified dysphagia, characterised by either difficulty initiating a swallow (oropharyngeal dysphagia), or a feeling that foods and/or liquids are hindered in the passage from the mouth to the stomach (oesophageal dysphagia), as a key area of risk.^{5,6} Dysphagia, which might result from either one or a multitude of medical problems including stroke, progressive neurological conditions, and poor oral health,⁷ can lead to malnutrition, dehydration, impaired quality of life, aspiration, choking, and death.⁷

The incidence of dysphagia in acute care has been reported to be 33%, and studies have shown that 30–40% of patients in nursing homes have swallowing disturbances.⁶ Although the prevalence of dysphagia increases with age,^{8–10} no reliable data

exist for adults with learning disabilities, with figures ranging from 36% based on general speech and language therapy caseloads, to 73% based on inpatient populations.¹¹ Swallowing difficulties not only have a detrimental effect on the quality of life of adults with learning disabilities, but are associated with large financial burden on the NHS, and can pose serious risks to the patient if it is not managed appropriately.¹²

Although there is a plethora of information surrounding swallowing difficulties, an overview of the management is currently unavailable, particularly in adults with learning disability. The aim of this guideline is to encourage optimal practice by summarising the best information available on the diagnosis and management of patients with learning disability and swallowing difficulties. An overview of the legal duties and implications of caring for adults with learning disability and swallowing difficulties is also provided.

Swallowing phases and dysphagia

Speech and language therapists (SLTs) specialising in the evaluation and management of dysphagia refer to the normal phases of swallow, i.e. oral preparatory phase, oral phase, pharyngeal phase, and oesophageal phase, in order to define the anatomical location of difficulties with eating and drinking. Some research suggests that dysphagia can be characterised according to the phase of swallow in which the dysfunction occurs.^{13,14}

Dysphagia can disrupt the normal process of feeding, eating and drinking at any or all of the phases of swallow.^{13,15} Pharyngeal phase dysfunction can also increase the risk of aspiration, which can result in serious and potentially fatal respiratory infection.¹⁶ At the very least, failure to recognise dysphagia can result in impaired nutrition and poorer quality of life.

Adults with learning disabilities are at greater risk of feeding, eating, and drinking difficulties than healthy individuals.¹⁷ Identifying which phases of the swallow are affected can help the development of management strategies to maximise safety and minimise risk during feeding.¹⁷

Classification and causes of dysphagia

Dysphagia is classified into two major types: oropharyngeal dysphagia and oesophageal dysphagia. Although both types of dysphagia can occur together, most health professionals find it useful to consider their identification separately. Table 1, p.5 summarises the key characteristics of oropharyngeal and oesophageal dysphagia.

The causes of oropharyngeal dysphagia can be classified as mechanical and obstructive, or neuromuscular. Oropharyngeal dysphagia may also be caused by factors such as xerostomia, oral ulcers, and poor dentition. The causes of oesophageal dysphagia can be divided into mucosal, mediastinal, and neuromuscular. As a guiding principle it is helpful to identify neuromuscular causes separately from mechanical and obstructive causes. It is important to remember that side-effects of medications can contribute to, or be the main cause of, the problems.

Diagnosis and management of swallowing difficulties

As adults with learning disabilities may be unable to communicate effectively, it is essential to discuss their eating and drinking abilities with their carer; in addition, clinicians might observe patients during a meal in order to evaluate the risk of aspiration (see Table 2, p.5). Speech and language therapists should also conduct a thorough review of their patient's clinical history in order to identify risk factors associated with the development of swallowing difficulties (see Box 1, above and Box 2, above).¹⁸ In instances where dysphagia is suspected, a more formal diagnosis should be made.

Treatment and management of swallowing difficulties – oropharyngeal dysphagia

In most cases, pharmacological and surgical interventions are inappropriate for managing the neurological and

Box 1: Factors that increase the risk of aspiration¹⁶

- > Medical disorder
- > Severe sensory feeding disorder
- > Fatigue issues
- > Respiration difficulties
- > Chest condition
- > Lengthy feeds
- > Motor disorders
- > Medical interventions
- > Poor oxygen saturation
- > Medication
- > Postural issues
- > Birth history
- > Environmental factors
- > Compliance issues
- > Blood chemistry
- > Epilepsy
- > Variable feeding status

Box 2: Medical conditions that predispose aspiration¹⁶

- > Asthma
- > Epilepsy
- > Cardiac problems
- > Degenerative conditions
- > Post-traumatic incidents
- > Neurological disorders
- > Craniofacial abnormalities
- > Gastroenterological difficulties

neuromuscular aetiologies of oropharyngeal dysphagia. However, other management strategies have proved invaluable. These include:

i. Modifying food consistency

Food texture is frequently modified in therapy programmes to help compensate for motor difficulties. Modified food texture can aid 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: fork-mashable diet, pre-mashed diet, thick puree, and thin puree.¹⁹ The type of food texture required is dependent upon the oral–motor and swallowing needs of the patient, and which texture best reduces the risk of aspiration.

Thickeners can be used to reduce the risk of aspiration; they help the patient create a cohesive bolus, thus aiding oropharyngeal control and slowing transit time in the pharynx.^{20–22} However, supporting literature is limited and controversial. Thickeners can also alter bolus viscosity and texture, which might affect both food palatability^{23–27} and the bioavailability of medications taken at mealtimes. Further,

Table 1: Key characteristics of oropharyngeal and oesophageal dysphagia⁶

| Oropharyngeal dysphagia | Oesophageal dysphagia |
|---------------------------------|-------------------------------|
| Difficulty initiating a swallow | Poor bolus formation |
| Nasal regurgitation | Absent protective reflexes |
| Coughing | Tongue pumping |
| Nasal speech | Gurgly voice |
| Diminished cough reflex | Wet respiration |
| Choking | Nasal regurgitation |
| Dysarthria and diplopia | Gagging/vomiting |
| Halitosis | Delayed initiation of swallow |

Table 2: Features suggesting risk of aspiration¹⁶

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

thickeners are often mixed incorrectly by carers and the required fluid viscosity may not be achieved.²⁸⁻³³ Generally, patients on thickened fluids rarely meet the hydration targets necessary for good health, and still experience a high incidence of aspiration pneumonia.³²⁻³⁴

ii. Postural change

Limited motor ability affects the initiation of oral–motor skills, the breathing pattern required for eating and drinking, the swallow mechanism, and effective gut motility.³⁵ Providing postural stability during mealtimes might improve oral preparatory and oral phase stability. Further, appropriate head control and whole body stability during mealtimes, particularly in the pelvis and hips, trunk, shoulder girdle, and legs, will help to reduce the risk of aspiration.^{35,36}

Adults with acquired disorders, who have previously experienced normal eating and drinking, may use specific postural techniques that aid bolus transit through the cricopharyngeous muscle, and can reduce the risk of aspiration by improving pharyngeal opening during the

swallow.³⁷⁻⁴⁴ These include the Mendelsohn manoeuvre, chin tuck, super supraglottic swallow, effortful swallow, tongue hold technique, and double swallow. This strategy might not be suitable for patients with poor cognitive or communication abilities, and/or those who do not have a reference point on which to base their compensatory attempts.

iii. Swallowing therapy and re-education

Where possible, patients should be encouraged to be independent. Independence during mealtimes can enable an adult with learning disabilities 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.⁴⁵ Hand-over-hand prompting when using utensils might maximise opportunities for independent eating and drinking.

Some studies have attempted to reduce tongue thrust and have incorporated behavioural methods into mealtime interventions for children with learning disabilities.⁴⁶⁻⁴⁸ Some of the methods have involved massaging the facial and

Table 3: Treatment and management options for oesophageal dysphagia⁶

| Oesophageal dysphagia | Conservative treatment | Invasive treatment |
|--|---|--|
| Diffuse oesophageal spasm | Nitrates, calcium-channel blockers | Serial dilations or longitudinal myotomy |
| Achalasia | Soft food, anticholinergics, calcium channel blockers | Dilation, botulinum toxin injections, Heller’s myotomy |
| Scleroderma | Anti-reflux drugs, systemic medical management of scleroderma | None |
| Peptic stricture | Anti-reflux drugs (H ₂ blockers, proton-pump inhibitors) | Dilation, fundoplication |
| Infectious oesophagitis | Antibiotics (nystatin, acyclovir) | None |
| Pharyngoesophageal (Zenker’s) diverticulum | None | Endoscopic or external repair in addition to cricopharyngeal myotomy |
| Schatzki’s ring | Soft food | Dilation |

oral motor muscles, both outside of and during mealtimes. However, these studies have not been repeated with adult populations and therefore need to be treated with caution.

iv. Alternative feeding methods

Percutaneous endoscopic gastrostomy 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. In these situations, oral hygiene is essential to ensure that oral residue does not build up, cause infection, or contribute to aspiration-related illnesses.⁴⁹

Treatment and management of swallowing difficulties – oesophageal dysphagia

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 (e.g. botulinum toxin injections), surgery, and/or endoscopic therapy. Table 3 summarises the main treatment options for oesophageal dysphagia.

Administering medications to patients with swallowing difficulties

Choosing the best method of drug delivery can improve the willingness of a patient to take their medication. Healthcare professionals need to consider the appropriateness of the selected method of delivery, patient safety, and the legality of any recommendations that are made.

i. Appropriateness

The problem of tablet swallowing may be overcome by simple adjustments; which is important given the need to reassure this patient group. Examples include: changing the tablet from

a circular to a torpedo shape. If a patient is unable to swallow a tablet whole, chewing prior to swallowing could be considered. In some cases chewing, crushing, or dispersing a tablet can cause a previously palatable tablet to become inedible or unpleasant—patients should be asked whether the taste of the tablet is acceptable. Adults with learning disabilities might struggle to communicate this information, and so communication passports prepared by SLTs might be used.

If tablets cannot be swallowed, an alternative liquid medicine or route of administration (such as patches, orodispersibles, or suppositories) should be considered. Licensed liquid medicines are not the same as crushed or dispersed tablets as they are designed to be palatable to the patient and have an even drug distribution, ensuring that the patient receives the full measured dose.⁵⁰ Unlike thin fluids or tablets dispersed in water, liquid medicines are designed to cohere during the swallow and, therefore, minimise the risk of aspiration in patients who have difficulties with coordinating closure of the glottis during the pharyngeal phase. Thickeners should be used with caution as they may alter the effect of the medicine as it is administering it outside the terms of its license. Where licensed liquids are unavailable then unlicensed ‘specials’ might be available; N.B. licensed preparations should be considered in most clinical cases before unlicensed products.

ii. Safety

Tablets and capsules are frequently designed to optimise how and where the drug is released into the body (e.g. gastro-resistant coatings and modified-release designs) or are coated to mask the flavour (e.g. film and sugar coatings). In addition to altering the taste, crushing, dispersing or chewing tablets/capsules before swallowing can affect how and where the drug is released into the body. The consequences of such actions should always be considered. Modified-release preparations should never be altered as the resultant dose release can increase the chance of side-effects and then provide a period of time when there is not enough in the body for it to be

effective. Many learning disability patients have difficulty in swallowing, and involuntarily grind their teeth, in these circumstances, an MR preparation is best avoided unless absolutely necessary, e.g. an alternative preparation cannot be sourced.

iii. Legality

Oral formulations should be administered in strict accordance with the conditions of their licence, i.e. without prior tampering. The Human Medicines Regulations 2012 allow only 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.⁵¹ If the only option is crushing, dispersing, or compounding medication, then the independent prescriber should assume responsibility by recording their authorisation in the patient's prescription, medical, and care notes. A pharmacist should only dispense this request if satisfied that the form prescribed is suitable to be amended.

Continual patient review

Medication review is increasingly recognised as a cornerstone of medicines management and it is of particular importance for adults with learning disabilities who are specifically protected by law. As there is no standard protocol effectiveness of a medication review can vary widely. However, these 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 (see Box 3, right) has particular utility as it offers a simple approach that brings consistency to the review process in this vulnerable group of patients, and has the potential to optimise treatment.⁵²

Involvement of carers and patients

It is essential to involve patients and their carers in care planning and management; however, non-compliance with management strategies for swallowing difficulties by both patients and their carers is common.^{29,31,53} Patients with a learning disability may find it hard to understand the implications of their swallowing difficulties; it is, therefore, important that their carers recognise the need to follow management guidance in order to reduce the risk of aspiration.^{5,7}

i. Care plans

In order to 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.^{5,7} Written materials

Box 3. The NO TEARS tool⁵²

- › Need and indication
 - Does the patient still need the treatment and is the indication for the medication still relevant?
- › Open questions
 - Whilst difficult in adults 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?

should be used to manage swallowing difficulties in patients with a learning disability; these include eating, drinking, and swallowing care plans, and mealtime information forms.⁷ Management/care plans should be individualised and include advice provided by a SLT and a dietitian. The care plan should outline the patient's needs, identify plans or goals to address those needs, make clear the actions needed to achieve the goals, and evaluate the management process.⁵⁴ Care plans should be reviewed regularly to ensure they continue to meet the patient's needs.

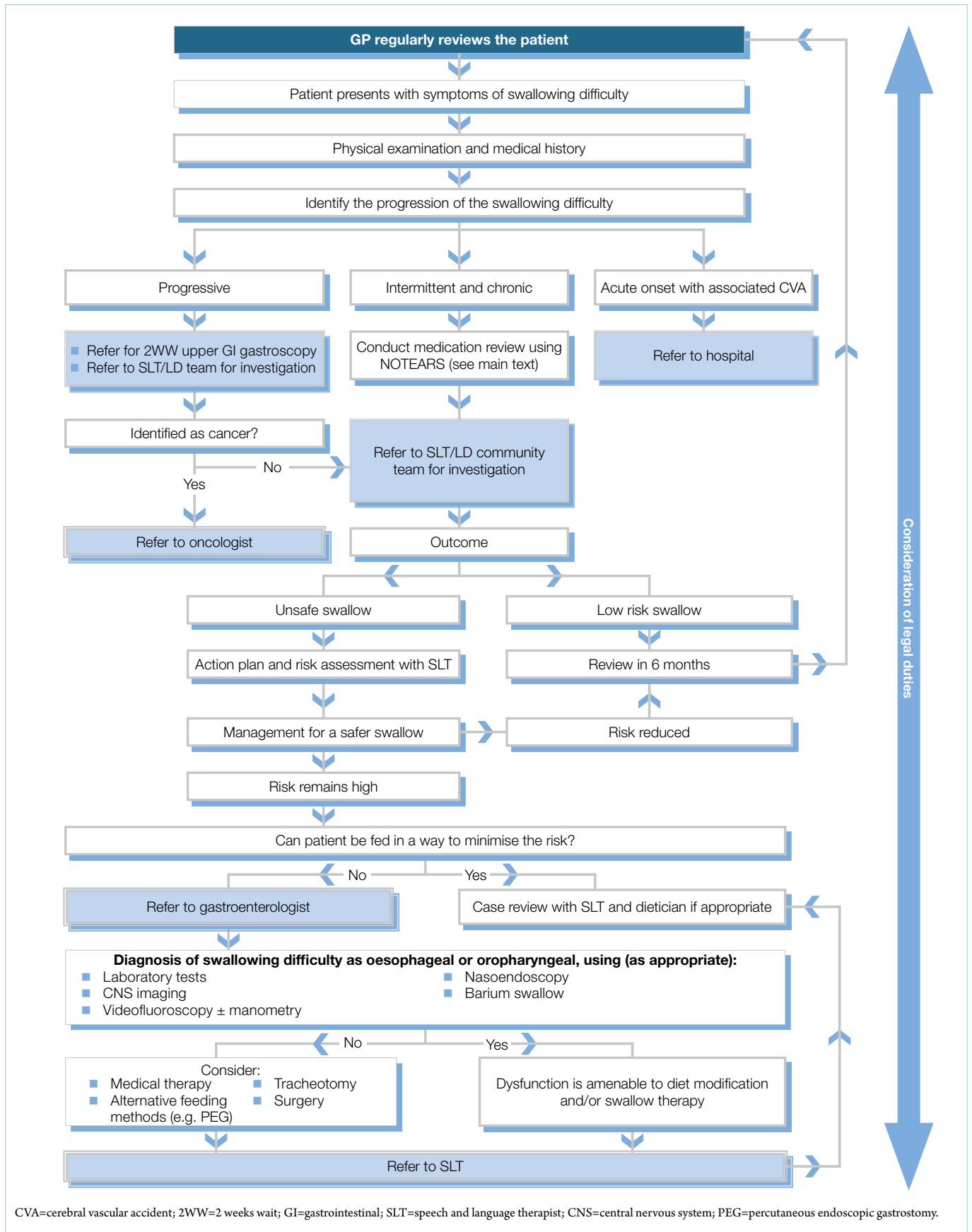
ii. Monitoring feeding

Patients who require pureed food and/or thickened fluids are likely to be at high risk of developing malnutrition and/or dehydration,^{15,33,55,56} which can negatively affect swallowing—malnutrition causes fatigue, muscle weakness, and impaired cough, while dehydration reduces the fluid content of saliva. Carers of patients 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.

Referral pathway

Management of adults with learning disability and swallowing difficulties often requires referral to various specialists, including SLTs, dietitians, and gastroenterologists. Figure 1 (p.8) provides an overview of the referral process and how patients might be managed at each stage.

Figure 1: Referral pathway



CVA=cerebral vascular accident; 2WW=2 weeks wait; GI=gastrointestinal; SLT=speech and language therapist; CNS=central nervous system; PEG=percutaneous endoscopic gastrostomy.

Legal considerations

In their follow-up to *Death by Indifference*, Mencap concluded that many health professionals still fail to provide adequate care and treatment to adults with learning disabilities.⁴ Some of the main legal considerations when treating adults with learning disabilities may include:

i. Duty

A duty situation arises when a health or social care professional (HSCP) undertakes the care of a person with a learning disability; the HSCP is legally obliged to provide evidence-based care and treatment tailored to the individual. The duty continues until treatment is no longer clinically required, the service user refuses further treatment, or care is transferred to another HSCP. Discontinuing the medication of a person with a learning disability because of their inability to swallow tablets prescribed to meet a clinical need would be a breach of this duty of care. An HSCP who fails in their duty is accountable, and has to answer for that failure. Where such a reckless breach contributes to the death of the patient then liability in gross negligence manslaughter will arise.

ii. Equality Act

Discriminating against a person with a learning disability because of their 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.

iii. Management of medicines

The Health and Social Care Act 2008 created the Care Quality Commission (CQC), which now regulates health providers and adult social care providers in England. The CQC has imposed essential standards for quality, safety, and management of medicines (see Box 4, above). Failure to comply with these guidelines can result in an HSCP receiving a warning or a fine, and may also lead to closure of a service. Additionally, the CQC will also pass on evidence of poor practice to a professional's regulator; this could lead to the investigation of an individual's fitness to practice.⁵⁷

iv. Mental Capacity Act

Where a person with a learning disability lacks decision-making capacity, the Mental Capacity Act 2005 and its code of practice ensures that their rights and interests are at the centre of the decision-making process. The Mental Capacity Act 2005 assumes that an adult has the capacity to make their own decision to accept or refuse treatment. Only once a person has been judged unable to make a decision themselves under the Mental Capacity Act 2005 can another person make a decision for them in their best interests.⁵⁸

Box 4: Examples of CQC-imposed standards for the management of medicines

Medicines prescribed or administered must be appropriate and person-centred

- › Disabilities of a person when prescribing and administering medicines must be considered

Prescriptions must be up-to-date, reviewed and changed as the person's needs change

- › If a person develops swallowing difficulties, the route of drug administration should be reviewed

Risks should be managed through effective medicines handling, including dispensing, preparation, administration, monitoring and disposal of medicines

Procedures should be in place for giving medicines covertly in accordance with the Mental Capacity Act 2005

Where a decision-maker has been appointed (usually under a Health and Welfare Lasting Power of Attorney), HSCPs must obtain consent from that person before treatment can proceed, but can challenge a decision if they feel it is not in the best interest of the patient. Where a designated decision-maker is not appointed, the HSCP determines the best interests of the patient who lacks decision-making capacity, and must decide whether to consult an Independent Mental Capacity Advocate (IMCA) before proceeding with care and treatment. The Mental Capacity Act 2005 (Sections 37, 38, and 39) places a duty on a decision-maker to consult with an IMCA where serious treatment is to be provided by an NHS body, and/or accommodation is to be provided by an NHS body for 28 days or more, or by a local authority body for 8 weeks or more.

HSCPs who fail to meet their duty under the Mental Capacity Act 2005 will lose the protection of the Act and could face prosecution for ill-treating or wilfully neglecting a person who lacks decision-making capacity (Section 44).⁵⁸

v. Professional liability

Undertaking the care and treatment of a person with a learning disability gives rise to duties under the common law, the statutes that govern the practitioner/service user relationship, and the professional regulator. These duties provide maximum protection for the service users; they are not mutually exclusive and can individually or collectively hold an HSCP to account.

Conclusions

The authors hope that this guideline will facilitate the identification of at-risk patients and encourage optimal practice for the diagnosis and management of swallowing difficulties in adults with learning disability. Optimising the diagnosis and management of dysphagia has the potential to reduce the number of acute admissions of adults with learning disability,

thereby providing cost-savings for the NHS. The authors also hope that this guideline will help clinicians to protect adults with learning disability and swallowing difficulties, and their own professional registrations.

Learning action points

- Adults with learning disabilities are more likely to experience dysphagia problems than the general population and are also more likely to experience an adverse outcome
- Risks to patients and to personal professional registration are minimised by following this guidance
- Understanding the phases and classification of swallowing difficulties allows clinicians to refer and diagnose optimally
- A systematic approach to the dietary, therapeutic, medical management, and review of learning disability patients with swallowing difficulties will improve patient outcomes
- Understand the legal duties and implications of caring for adults with learning disability and swallowing difficulties

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