

A large, stylized graphic of the letters 'NO' in a light blue color. The 'N' is a simple vertical bar with a rounded top, and the 'O' is a large circle with a square cutout on its right side. The text 'Problems swallowing?' is overlaid on the 'NO' graphic.

# Problems swallowing?

Resources for **healthcare staff**  
**July 2007**

Ensuring safer practice for adults with learning disabilities who have dysphagia

Difficulty in swallowing ('dysphagia') is a serious problem for some adults with learning disabilities and, in serious instances, has led to death.

Improving the safety of clients with dysphagia is essential, and introducing individual patient management guidelines can reduce the risks associated with this potentially life-threatening condition.



# Introduction

By putting into action some of the best practice activities outlined in this document, the safety of adults with learning disabilities who have dysphagia can be improved, reducing the risks associated with this potentially life-threatening condition.

This document outlines the issues facing adults with learning disabilities who have dysphagia and introduces support materials that can provide practical help for these people. The tools can be adapted for local use and for any adult who has dysphagia.

## Background

Dysphagia refers to difficulty in eating, drinking or swallowing. It can lead to malnutrition, dehydration, reduced quality of life and choking. Asphyxia and respiratory-related mortality are known to be disproportionately high in people with learning disabilities.

Dysphagia can occur as a result of either a single medical problem, e.g. stroke, progressive neurological condition, or as a result of:

- oropharyngeal structural problems;
- motor processing difficulties;
- central nervous system disorders;
- pharyngo-oesophageal problems;
- poor oral health;
- the psychological effects of institutionalisation;
- mental health problems;
- the effects of medication.

Some signs and symptoms of swallowing difficulties or dysphagia include the inability to recognise food, difficulty placing food in the mouth, inability to control food or saliva in the mouth, difficulty initiating a swallow, coughing, choking, frequent chest infections, unexplained weight loss, gurgly or wet voice after swallowing, regurgitation, and client complaint of swallowing difficulty.

Since the publication of the National Patient Safety Agency (NPSA) report, *Understanding the patient safety issues for people with learning disabilities* in 2004, the NPSA has received 605 reports of choking-related incidents involving adults with learning disabilities between 30 April 2004 and 30 April 2007. The majority of these incidents (58 per cent) took place at meal times. Incidents occurring in residential care homes accounted for 41 per cent of incidents and 58 per cent took place within inpatient and assessment services. The remaining one per cent occurred in public places.

# Best practice

This document aims to share resources and examples of best practice, currently used by some healthcare staff at local level, that might be useful nationally.

It is best practice that a local policy on dysphagia care for adults with learning disabilities is in place. This policy ensures that all adults with dysphagia have an individual management plan that is regularly monitored and updated. It will also ensure that all adults with dysphagia are assessed so as to accurately determine the level of dysphagia they have and the associated risks. Ideally this assessment should be carried out by specialist practitioners, often speech and language therapists and those trained to recognise the varying symptoms of dysphagia in adult clients with communication difficulties. The assessment is then shared with the clients and their carers and families.

The safety of adults with learning disabilities who have dysphagia can be improved when accessible information on dysphagia management is made available for people with learning disabilities and their carers and families, including advice on the preparation of suitable food and fluids.

To help continuously improve safety in the future, systems should be put in place for the accurate reporting of patient safety incidents involving all patients with dysphagia.

Carers and staff working with clients with dysphagia need to be aware that a change in a client's medication could produce side effects that may worsen their condition. Any such change should ideally be first checked with a GP, pharmacist or medication information centre. In addition, local liaison and care transfer protocols should be in place between the hospital and community services.

To improve safety for people with learning disabilities who have dysphagia, NHS organisations and carers who provide a service for such clients should consider the benefits of having a lead clinician with overall responsibility for dysphagia services. This lead could be part of the role of a speech and language therapist.

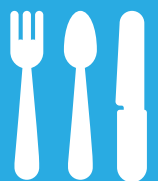
Where possible, care from trained carers/practitioners should be available for adults with learning disabilities who have dysphagia and all staff and carers in direct contact with clients with dysphagia should have knowledge of dealing with choking incidents.

# Supporting documentation and resources

The NPSA has produced a series of materials, many of which are already being successfully used within the NHS, to support safer practice for people with dysphagia. This NPSA resource set provides healthcare professionals with a series of documents and supporting materials, that can be adapted for local use, and may help them to implement the suggestions for best practice outlined above.

The resources are:

- risk assessment and guide to levels of risk;
- dysphagia risk assessment form;
- dysphagia report;
- eating, drinking and swallowing care plan;
- mealtime information forms;
- learning disabilities/dysphagia protocol for general practitioners;
- consent form for assessment of eating and drinking or swallowing problems.



## Risk assessment and guide to levels of risk

The risk assessment and guide to levels of risk aim to:

- increase awareness of the risks of dysphagia;
- provide a framework for identifying and managing these risks;
- provide guidance on the severity of particular intrinsic and extrinsic risks;
- enable decisions to be taken that are likely to lead to safer eating and drinking practice;
- ensure that regular reviews of the client with dysphagia are carried out.

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**Guide to levels of risk of negative health consequences from dysphagia**

This guide identifies the factors that increase the risk of negative health consequences arising from a person's dysphagia. The negative health consequences are asphyxiation and/or choking episode, aspiration incidents, dehydration and poor nutritional status. These factors are not related to the severity of the dysphagia itself but to other intrinsic and extrinsic factors which may exacerbate dysphagia risk. These factors affect the probability of the person's presentation and interact with the dysphagia. High risk and low risk are easier to manage than fluctuating risk i.e. the person's risk varies for any intrinsic or extrinsic factor from meal to meal or day to day. Each factor can increase the risk of all the negative health consequences outlined above.

Intrinsic factors	Indicators associated with low risk	Indicators associated with increasing risk	Indicators associated with high risk
<b>Level of learning disability/cognitive function</b>	<ul style="list-style-type: none"> <li>• Person able to understand risks associated with their dysphagia</li> <li>• Person able to understand and implement their management strategies</li> </ul>	<ul style="list-style-type: none"> <li>• Person reliant on others to implement dysphagia management strategies</li> <li>• Person is cognitively dependent on others to eat and drink</li> </ul>	<ul style="list-style-type: none"> <li>• Person unable to understand risks associated with their dysphagia</li> <li>• Person unable to recognise the health aspects of eating and drinking (e.g. water temperature, rate of intake and presence of medicine)</li> </ul>
<b>Alertness and cooperation</b>	<ul style="list-style-type: none"> <li>• Person maintains alertness during eating and drinking</li> <li>• Person alert throughout the day</li> <li>• Person shows anticipation of food and drink presented</li> <li>• Person opens and closes mouth appropriately</li> <li>• Person does not experience things which may affect level of alertness or cooperation</li> </ul>	<ul style="list-style-type: none"> <li>• Person has reduced ability to think</li> <li>• Person less alert at different times of day (e.g. early morning and after bathing)</li> <li>• Person has reduced response to helper or food and drink</li> <li>• Person does not consistently open and close their mouth in response to food and drink</li> <li>• Person experiencing things that may affect levels of alertness or cooperation (e.g. medication and</li> </ul>	<ul style="list-style-type: none"> <li>• Person is sleepy or drowsy and hence less alertness</li> <li>• Person is unable to maintain sustained attention</li> <li>• Person has no anticipatory response to food and drink</li> <li>• Person does not anticipate arrival of help</li> <li>• Person is experiencing many things which lower levels of alertness or cooperation (e.g. medical and serious ill health)</li> </ul>

This document is available for download in MSWord format and for adaptation for local use from [www.npsa.nhs.uk/resources/dysphagia](http://www.npsa.nhs.uk/resources/dysphagia)

## Dysphagia risk assessment form

The NPSA has produced an assessment form that allows for the assessment and review of the client with dysphagia.

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**Dysphagia risk assessment**

For use at a formal risk review meeting

Risk assessments carefully examine systems to identify factors that could cause or contribute to harm to an individual. They investigate whether adequate precautions are in place to prevent injury, or if further measures are required. The NPSA dysphagia risk assessment needs to answer the following questions:

1. What is the current situation?
2. What could go wrong?
3. How serious is the harm to the person?
4. How likely is the harm to occur?
5. What actions are needed to prevent harm?
6. How and when will the situation be reviewed?

**Assessment Group Members**  
(Using check boxes to indicate presence. Family members, the person with learning disabilities if appropriate, social worker, health manager and others from day and residential provision. Tick box for those invited)

<b>Person with learning disabilities</b>	Name:.....
	Date of birth:.....
	Address:.....
	.....
<b>Family member/caregiver</b>	Name:.....
<b>Residential staff</b>	Name:.....
<b>Day centre staff</b>	Name:.....
<b>Speech and language therapist</b>	Name:.....
<b>Dietician</b>	Name:.....
<b>Physiotherapist</b>	Name:.....
<b>Occupational therapist</b>	Name:.....
<b>GP</b>	Name:.....
<b>Other (give details)</b>	Name:.....
<b>Notes</b> (including any additional members of the group):	

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## Dysphagia report

This form can be completed for each dysphagia client, and includes such details as patient's background, relevant medical history, food and drink assistance requirements and behavioural patterns.

The form is titled 'National Patient Safety Agency Dysphagia report'. It includes fields for 'Date of report', 'Client's name', 'NHS number', and 'Date of birth'. Below these are sections for 'Reason for referral', 'Background information (include medication, current health status)', 'Summary of assessment', 'Areas of risk', and 'Recommendations'. The 'Recommendations' section lists categories: Environment, Positioning, Food texture, Drinks, Assistance required, Oral hygiene, Sensory issues, Behaviour issues, Intervention plan, Actions required, and Criteria for re-referral. At the bottom, there are lines for 'Name' and 'Signature'.

This document is available for download in MSWord format and for adaptation for local use from [www.npsa.nhs.uk/resources/dysphagia](http://www.npsa.nhs.uk/resources/dysphagia)

## Eating, drinking and swallowing care plan

This form can be used in addition to the dysphagia report. It looks at clients' positioning, methods of feeding and communicating, and equipment use, as well as the individual's food and drink requirements (flavours, temperatures and textures). The form is available as a general care plan or for specific high risk areas of care.

The form is titled 'National Patient Safety Agency Specific high risk care plan'. It includes fields for 'Date', 'Client's name', and 'Date of birth'. The main body contains sections for 'Description of problem', 'Aims of intervention and care plan', 'Actions needed', and 'Things to look out for'. At the bottom, there are two signature lines: one for 'Speech and Language Therapist' and one for 'Manager/key worker', each with a date field.

The form is titled 'National Patient Safety Agency Eating, drinking and swallowing care plan'. It includes fields for 'Date', 'Client's name', and 'Date of birth'. The main body contains sections for 'Description of eating, drinking or swallowing difficulties', 'Aims of intervention and care plan', 'Actions needed' (listing Environment, Positioning, Equipment, Food texture, Drinks, Assistance required, Communication, Likes and dislikes), and 'Things to look out for'. At the bottom, there are two signature lines: one for 'Speech and Language Therapist' and one for 'Manager/key worker', each with a date field.

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## Mealtime information forms

The interim mealtime information sheet outlines the recommendations for individual client requirements at mealtimes, and should be completed by a specialist practitioner or speech and language therapist who has undertaken the assessment. The mealtime information form is a simplified version, which presents the speech therapist's findings in simple, easy-to-follow steps. A version of the mealtime information form with client contact details and photograph is also available, allowing staff and carers the opportunity to familiarise themselves with each client's appearance, needs and requirements. This may be laminated for use as a placemat. The NPSA has also produced an example of a completed mealtime information form based on the needs of a typical adult with learning disabilities who has dysphagia.

These documents are available for download in MSWord format and for adaptation for local use from [www.npsa.nhs.uk/resources/dysphagia](http://www.npsa.nhs.uk/resources/dysphagia)



## Learning disabilities/dysphagia protocol for general practitioners

This provides guidance and considerations, complete with a step-by-step flowchart and further reading recommendations, for the care of patients presenting with dysphagia.

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Learning disabilities dysphagia protocol for general practitioners

**Prevalence and associated health risk**

Feeding, swallowing and nutritional problems have a high prevalence among people with learning disabilities.<sup>1</sup> They can have serious repercussions including poor nutritional status, dehydration, aspiration and aspiration.<sup>2</sup> They can be life threatening or lead to life threatening problems.<sup>3</sup> Adults with cerebral palsy and those with severe intellectual and physical disabilities have a high incidence of dysphagia<sup>4</sup> and patients with spastic quadriplegia are at particular risk of aspiration.<sup>5</sup> Although there is limited research into people with learning disabilities who have dysphagia, there is evidence that successful management decreases risk.<sup>6</sup>

**History and potential symptoms that could indicate dysphagia**

<b>Does your patient exhibit any of the following:</b>	
History of choking episodes	
Coughing during and/or after meals	
History of frequent chest infections	
Increased shortness of breath when eating or drinking	
Dysphagia	
Bubbling voice quality	
Failed to maintain weight	
Slow eating and/or refusing food	
Regurgitation	
<b>Risk Factors</b>	
Cerebral palsy	
Severe and complex disabilities	
Previous history of CVA	
History of dementia	

**Suggested actions**

In all cases:

- request a speech and language therapy dysphagia assessment;
- conduct a simple physical examination of oropharyngeal cavity;
- review medication for drugs with sedative or cholinergic side effects;
- look for evidence of weight loss and malnutrition;
- consider haematological/biochemical/radiological assessment including videofluoroscopy (this may be requested by the speech and language therapist);
- always consider co-existent or other pathologies;
- consider other causes including oesophageal stricture with or without regurgitation;
- consider referral to colleagues in learning disability services including a dietitian for advice about diet and food consistency;
- consider advice from a physiotherapist.

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## Consent form for assessment of eating and drinking or swallowing problems

This is a user-friendly document for the adult client with learning disabilities and the healthcare professional undertaking an assessment of eating and drinking or swallowing problems to work through. It provides a record of consent.


**CONSENT FORM FOR ASSESSMENT OF EATING, DRINKING OR SWALLOWING PROBLEMS**

Client's name \_\_\_\_\_


Sometimes it is hard to eat and drink.




Eating some things can make you cough or choke.




Food or drink may go down the wrong way and harm you.



Some people eat very slowly because it is difficult to chew or swallow.



Some people eat too fast.



This document is available for download in MSWord format and for adaptation for local use from [www.npsa.nhs.uk/resources/dysphagia](http://www.npsa.nhs.uk/resources/dysphagia)

## Acknowledgments

The dysphagia risk assessment was developed by Dr Darren D Chadwick, Manchester Metropolitan University (MMU), Alex Kelly, Manchester Primary Care Trust and Frances Watson, NPSA.

The risk guide was developed by Jane Jolliffe and Dr Darren D Chadwick of MMU.

Ms Gill Arnett (Manchester Primary Care Trust) was also a contributor to the risk guidance

Information sheets for care staff were devised by Alex Kelly, Lead Speech and Language Therapist, Hampshire Partnership Trust.

The general practitioner's dysphagia protocol for people with learning disabilities was devised by Dr Derek Conaty and Dr Peter Baddeley.

Accessible information and consent documents for people with learning disabilities and dysphagia were developed by 'Speaking Up', a self advocacy charity based in Cambridge.

We would also like to thank the many people who contributed to this work, including representatives from:

- The Royal College of Speech and Language Therapists
- The Royal College of General Practitioners
- The British Dietetic Association
- National Forum for People with a Learning Disability
- Valuing People Support Team
- Ayrshire and Arran PCT Learning Disability Services
- 5 Boroughs Partnership NHS Trust
- Coventry Primary Care Trust
- Gloucestershire NHS Partnership Trust
- Hampshire Partnership Trust
- Manchester Learning Disability Partnership
- South Tyneside Primary Care Trust
- Surrey and Borders Partnership NHS Trust
- Wirral and West Cheshire Learning Disability Services