Public Health England

Protecting and improving the nation's health

Making reasonable adjustments to dysphagia services for people with learning disabilities

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

About Improving Health and Lives

Improving Health and Lives (IHaL) was set up in April 2010 to provide high quality data and information about the health and healthcare of people with learning disabilities. The information helps commissioners and providers of health and social care to understand the needs of people with learning disabilities, their families and carers, and, ultimately, to deliver better healthcare. IHaL is a collaboration between PHE, the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion. Since April 2013, IHaL has been operated by PHE.

Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UR
Tel: 020 7654 8000
www.gov.uk/phe
Twitter: @PHE_uk
Facebook: www.facebook.com/PublicHealthEngland

Prepared by: Anna Marriott and Sue Turner
For queries relating to this document, please contact: anna.marriott@ndti.org.uk

© Crown copyright 2016
You may re-use this information (excluding logos) free of charge in any format or medium, under the terms of the Open Government Licence v3.0. To view this licence, visit OGL or email psi@nationalarchives.gsi.gov.uk. Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

Published March 2016
PHE publications gateway number: 2015776

Contents

About Public Health England 2

About Improving Health and Lives 2

Easy-read summary 4

Introduction 6

People with learning disabilities and dysphagia 7

- Evidence and research 7
- Consent and capacity 12

Resources 13

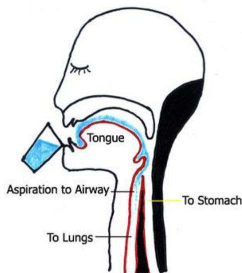
- Table 1: Guidance about the management of dysphagia 13
- Table 2: Resources for professionals/family members and carers 15
- Table 3: Easy-read resources 22
- Table 4: Apps related to dysphagia 24

Examples of reasonable adjustments and case studies 25

References 39

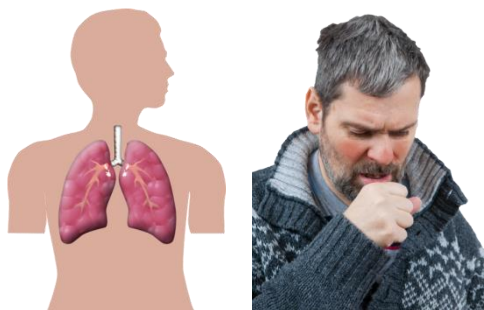
Appendix A 41

Easy-read summary



This report is about dysphagia.

Dysphagia means swallowing difficulties.



Dysphagia can be dangerous.

People can choke if they have difficulty swallowing.

People can get chest infections if they have difficulty swallowing.

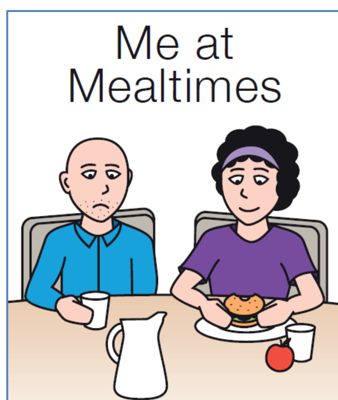
People with learning disabilities are more likely to have dysphagia than other people.

They don't always get the support they need to make sure they are eating and drinking safely.

If people don't get the right support with their swallowing then they may need to go to hospital as an emergency.

Some people may die from chest infections or from choking.

The law says public services should put ‘reasonable adjustments’ in place to help people with learning disabilities use the services. This means they need to change their services so they are easier to use.



This report has information about reasonable adjustments in dysphagia management.

Professionals and carers can use them to get better services for people with learning disabilities who have difficulty swallowing.

The report contains examples of how local services have put reasonable adjustments in place so that people with learning disabilities and dysphagia get better care.

The pictures in this report are from Photosymbols: www.photosymbols.co.uk

Introduction

Under the Equalities Act 2010,[1] public sector organisations have to make changes in their approach or provision to ensure that services are accessible to disabled people as well as everybody else. IHaL has a database of examples of reasonable adjustments made by health services (www.ihal.org.uk/adjustments/).

This report is the tenth in a series of reports looking at reasonable adjustments in a specific service area (see Appendix A). The aim of these reports is to share information, ideas and good practice in relation to the provision of reasonable adjustments.

We searched for policy and guidelines that relate to people with learning disabilities and dysphagia. A summary of this information is below. We looked at websites to find resources that might be of use to people with learning disabilities and dysphagia or to those supporting them. There is a brief description of these and information about how to obtain them in the resource tables.

We put a request out through the UK Health and Learning Disability Network, a major email network for people interested in services and care for people with learning disabilities. We asked people to send us information about what they have done to improve dysphagia management for people with learning disabilities. Examples of what has proved useful are given at the end of the report.

People with learning disabilities and dysphagia

Evidence and research

Prevalence and impact of dysphagia

Dysphagia is the medical term for swallowing problems. There are different causes and types of dysphagia. Some people have difficulty swallowing specific types of food or liquids. Some people cannot swallow at all. Difficulties in any of the main stages of the eating, drinking and swallowing process can be called dysphagia.[2]

There are no reliable data on the prevalence of dysphagia in people with learning disabilities. Historically, estimates have ranged from 36% (based on speech and language therapy caseloads) to over 70% (based on inpatient populations).[3] More recent studies have shown that about 15% of adults with learning disabilities require support with eating and drinking[4] and 8% of those known to learning disability services will have dysphagia.[2] This figure is likely to be an underestimate, as we know the signs of dysphagia (particularly when it is mild) are often missed.[5] Therefore, not everybody with swallowing problems will be referred appropriately.

It is generally accepted that people with learning disabilities are more likely to have dysphagia than other people. In 2004, the National Patient Safety Agency (NPSA) identified it as a significant health risk for people with learning disabilities.[6] Dysphagia can result in choking and may lead to death. A multi-agency review in Hampshire was commissioned following five cases of choking resulting in death.[7] This review noted the difficulty in obtaining national figures for premature deaths of people with learning disabilities caused by choking and concluded that there is a lack of understanding of the issue. Research analysing both locally and nationally reported choking incidents concluded that many choking incidents in people with learning disabilities are being missed, leading to an underestimate of choking episodes.[8]

The recent Mazars report into the deaths of people with learning disabilities in one NHS trust highlighted particular concerns around dysphagia assessments and the management of eating and drinking difficulties.[9] The report made a number of recommendations, including the need to investigate the quality, timing and follow-up of dysphagia assessments.

Swallowing problems can result in people breathing in food or drink, which can then lead to aspiration pneumonia. Figures show that 40% of people with learning disabilities and dysphagia experience recurrent respiratory tract infections.[2] The Confidential Inquiry into premature deaths of people with learning disabilities identified aspiration pneumonia as a significant cause of death.[10] Analysis of information from death certificates has shown that people with learning disabilities are much more likely to die of the consequences of solids or liquids in their lungs or windpipe than those in the general population.[11] The authors concluded that this is a common, possibly preventable cause of death.

Other health problems related to dysphagia include malnutrition and dehydration.[12] Dysphagia has been linked to avoidable hospital admissions such as dehydration and constipation, as well as aspiration pneumonia.[13] In addition to the significant health risks posed by dysphagia, there is also a huge impact on quality of life for individuals. Eating and drinking are fundamental aspects of people's lives. Dysphagia may prevent people from being able to enjoy the taste and textures of food they like, as well as the social aspect of shared meals.[14] Modified meals and eating/drinking apparatus can make people feel different and excluded at mealtimes.[15]

Therefore, successful management of dysphagia has the potential to improve physical health, psychological wellbeing and to reduce hospital admissions. Despite this, there has been a lack of clinical guidance around dysphagia in people with learning disabilities.[16] To address this, a multidisciplinary group of clinicians worked together to draw up *The Guideline for the Identification and Management of Swallowing Difficulties in Adults with Learning Disability*.[17] This resource provides information about the recognition, diagnosis and management of dysphagia in adults with learning disabilities.

Assessment of dysphagia

There are two main types of dysphagia. One is caused by problems with the mouth or throat and occurs when a person has difficulty moving the food/fluid to the back of the mouth and starting the swallowing process (oropharyngeal). The other is related to problems with foods/liquid passing from the top of the oesophagus and into the stomach (oesophageal dysphagia). They can occur together but as they have different causes and different symptoms most clinicians will consider them separately.[16,17] There are four stages of swallowing and any (or all) of these can be affected by dysphagia. It is important to pinpoint which phase of the swallow is impaired in order to assess risk and plan the most suitable intervention.[18]

Since many adults with learning disabilities who have dysphagia will have limited verbal communication it is important that their family carers or paid supporters are asked about their symptoms when eating and drinking. It is also likely that a speech and language therapist or a nurse will observe the person during a meal. A detailed referral pathway

can be found in *The Guideline for the Identification and Management of Swallowing Difficulties in Adults with Learning Disability*.[17]

The *Screening Tool of fEeding Problems* (STEP) was developed to identify eating/drinking problems in people with learning disabilities. It is based on an interview with someone who knows the individual well and includes items such as feeding skill deficits and food refusal.[19] The Dysphagia Disorders Survey (DDS) is another measure of feeding and swallowing disorder in people with learning disabilities. This involves mealtime observation and is administered by a certified professional.[20]

The more formal types of tests that may be used to diagnose dysphagia include:
- bedside swallowing assessment
- videofluoroscopy/modified barium swallow
- fibreoptic endoscopic evaluation of swallowing (FEES)/nasendoscopy
- manometry
- diagnostic gastroscopy

Further information about these assessments can be found at http://www.nhs.uk/Conditions/Dysphagia/Pages/Diagnosis.aspx

It is also important to consider the need for nutritional assessment of someone who has problems with eating and drinking. This might be a formal assessment by a dietitian or it might include weighing someone, taking blood tests or the use of an assessment such as the Malnutrition Universal Screening Tool (MUST).[1]

Management of dysphagia

Appropriate management of dysphagia can improve patient care and has the potential to reduce associated healthcare costs.[18] Supporting people with dysphagia has become a growing proportion of the clinical work of speech and language therapists (SaLTs). A multidisciplinary approach is often taken to the management of dysphagia and may include input from dieticians, physiotherapists and nurses.

The Inter-professional Dysphagia Framework provides guidance around the skills, knowledge and abilities needed in identifying and managing feeding/swallowing difficulties.[21] It stresses a holistic approach to the assessment and management of dysphagia and highlights issues beyond a physical assessment of the swallow such as:
- environment
- levels of alertness
- behavioural issues
- psychological issues
- cultural issues

[1] http://www.bapen.org.uk/screening-and-must/must/must-toolkit/the-must-itself

- posture

This framework also emphasises the importance of the role of the specialist carer who may have considerable knowledge about the individual's swallowing difficulties.

The NPSA produced a guide which identifies the factors that increase the risk of negative health consequences arising from a person's dysphagia.[2] These include intrinsic factors, such as level of learning disability/cognitive function, fatigue and seizure activity. They include external factors, such as behavioural difficulties, unmanaged pain and staffing levels. Each factor can affect the indvdiual's risk of problems such as choking, aspiration, dyhydration and malnutrition and should be considered in a management plan.

The type of treatment will depend on the cause and type of dysphagia. The most common interventions are described below.

Eating and drinking guidance
Speech and language therapists will assess the swallow of an individual in order to ascertain the most suitable food texture for them. Modification of the consistency of food and liquid is one of the most common interventions and can reduce the risk of choking and aspiration. There are nationally recognised descriptors tor texture modification which are used by dieticians and SaLTs.[3] Some people will require a soft textured or a puréed diet. Individuals will have specific requirements dependent upon their swallowing problems. It is essential that expert advice is sought in order to ensure the food is an appropriate texture. Some people with dysphagia struggle to drink liquids safely and they may need these to be thickened. It is important to monitor the intake of food and drink in order to guarantee that the person's nutritional needs are being met and that they are sufficiently hydrated.[17]

Eating and drinking guidance should address the use of specialist equipment. This might include adapted spoons, plates and cups. Such equipment can help people to feed themselves independently. It is paramount that any equipment needed by an individual is available to them in all the environments in which they eat and drink. Guidance may also include advice on appropriate pacing which may be crucial in the prevention of aspiration for an indvdiual. Research suggests that pacing, as a strategy is the most difficult for non-family members to comply with.[15]

Eating and drinking guidance needs to be accompanied by appropriate training for all family carers/support staff. Supporters do not always follow eating and drinking

---

[2] http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=62847&type=full&servicetype=Attachment
[3] http://premierfoodservice.co.uk/wp-content/uploads/2013/03/Dysphagia-Generic-Brochure-MR.pdf

guidelines. Evidence suggests that they are better at adhering to tangible guidance, such as using specialist equipment and altering the food texture. Supporters are less good at remembering guidance about pacing, prompting and social interaction during meals.[22] Guidance should be as short and simple as possible and training should include opportunities to modify food/drink textures. It is essential the training and guidance are clear about the reasons for modifications to the food. There is a better chance of compliance if people understand the reasoning behind the guidance. It has also been shown that it is important that there are regular refresher sessions for supporters.[22,23]

Swallowing therapy and re-education

Guidance emphasises the benefits of encouraging individuals to be as independent as possible when eating and drinking.[17] This can help them to control the speed and the pace at which they eat. Hand-over-hand prompting involves physical guidance with utensils and this can help prepare the individual for the next swallow.

Postural care

Posture is an important factor to consider. Poor posture can negatively affect breathing and swallowing. Careful positioning can help with swallowing and can decrease the risk of aspiration and choking.[18]

Modifying the environment

There should be minimal distractions when someone who has difficulties in swallowing is eating. Modifying the environment will involve consideration of how the individual is positioned in the room in relation to noise, heat and light. Such issues should be addressed in a management plan for eating and drinking.

Medication

Medication (particularly antipsychotic medication) can contribute to, or even be the main cause of, dysphagia and therefore a medication review is an important aspect of dysphagia management.[16] A structured review process can help to ensure the quality of a medication review. Guidance recommends the NO TEARS tool,[24] which considers the need for the medication as well as monitoring and adverse events.

People with dysphagia may struggle to swallow tablets and need some adjustments to ensure they are taking their prescribed medication. This might involve swapping to a liquid or an alternative administration method such as suppositories or patches. Some tablets can simply be crushed but it is necessary to consider the impact of this upon taste. More importantly, this can affect the timing of the release into the body and some medications (such as alendronic acid) are contraindicated for chewing or crushing. It is essential there is clear guidance about medication and this should be written into a care plan.[16] There are guidelines about the best practice in the medication management of adults with swallowing difficulties.[25]

Alternative feeding methods

For some people their swallowing difficulties are so severe that it may be concluded oral feeding is unsafe or not providing sufficient nutrition. In these cases a percutaneous endoscopic gastrostomy (PEG) may be necessary. If someone has to receive medication via a PEG this must be assessed by a suitable clinician. Some people with a PEG will continue to have small amounts of food orally. There is limited evidence around decisions about pleasure feeding and it can be a difficult balance between the risks and benefits.[14]

Consent and capacity

Consent must be sought prior to any investigation or treatment. The Mental Capacity Act 2005 applies to individuals aged 16 and over and sets out the law regarding capacity and consent. It is underpinned by five key principles which must be considered when assessing capacity:

- a person must be assumed to have capacity unless it has been clearly established that they lack capacity regarding the specific decision under consideration at that point in time
- a person is not to be treated as unable to make a decision unless all practicable steps to help him/her to do so have been taken without success
- a person is not to be treated as unable to make a decision merely because he/she makes what is considered to be an unwise decision
- an act done, or decision made, under the Mental Capacity Act for or on behalf of a person who lacks capacity must be done, or made, in his/her best interests
- before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action

It is important to remember that capacity can fluctuate with time and an individual may lack capacity for a decision at one point in time, but be able to make the same decision at a later time. If an individual is judged to lack the capacity to make a decision then the decision should be made for them in their best interests. The Mental Capacity Act Code of Practice contains guidance on this process and emphasises the need to encourage participation. The individual should be supported to be as involved as possible in the decision and their feelings and beliefs should be taken into consideration. There is a video resource listed in Table 2 that addresses the issue of a best interest decision about having a PEG put in place for someone with dysphagia.

The Mental Capacity Act Code of Practice can be downloaded from:
www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act

There is a helpful guide and videos for family carers on the Mental Capacity Act at http://www.hft.org.uk/Supporting-people/Family-carers/Resources/Using-the-Mental-Capacity-Act/

Resources

The four tables that follow list all the information and resources we have found in relation to the management of dysphagia.

- Table 1 lists guidance about the management of dysphagia. This information is likely to be of use to commissioners, service managers and clinicians
- Table 2 lists resources for professionals/family members and carers. This includes leaflets, templates, web-pages and videos. These resources are not easy-read
- Table 3 lists all the easy-read resources we have found. This is where you can find information to use with people with learning disabilities
- Table 4 lists all the relevant free apps we have found

Some resources may be available from more than one site, but we have only given one link. We have only included resources that are free to download, although some of the websites also include resources you can buy.

Table 1: Guidance about the management of dysphagia

Theme	Description	Provider	Link
Guidance about dysphagia services			
Adults with learning disabilities (ALD): Position Paper	This document identifies the role of speech and language therapists (SaLTs) in adult learning disability services across the UK. It presents a tiered model for speech and language therapy service delivery in adult learning disability services with expected outcomes and risks identified for each tier	Royal College of Speech and Language Therapists	http://www.accessibleinfo.co.uk/pdfs/ald_position_paper%5B1%5D.pdf
RCSLT resource manual for commissioning	This report describes the causes and impact of dysphagia as well as a synthesis of the	Royal College of Speech and Language Therapists	http://www.rcslt.org/speech_and_language_therapy/commissioning/dysphagia_manual_072014

and planning services for SLCN: Dysphagia	evidence around assessment and interventions. It is generic guidance rather than specifically related to people with learning disabilities		
Guidelines for the Identification and Management of Swallowing Difficulties in Adults with Learning Disability	The guideline provides information that professionals need to recognise, diagnose and manage dysphagia. It addresses issues such as medication, care planning and capacity to consent	Multidisciplinary Working Party with the support of an unrestricted grant from Rosemont Pharmaceuticals Ltd.	http://www.guidelines.co.uk/gastrointestinal_wp_dysphagia_2012#.Vi9ZarfNzIU
Guideline on the medication management of adults with swallowing difficulties	This provides guidance on the best practice in medication management for those with swallowing difficulties. It is not specific to adults with learning disabilities but it provides a thorough overview of the issues and includes an algorithm for the medication management of adults with swallowing difficulties	Multidisciplinary Working Party with the support of an unrestricted grant from Rosemont Pharmaceuticals Ltd.	http://staticcontent.streamuk.com/sc/rosemont/5_medication_management_adults_swallowing_difficulties.pdf
Reducing the risk of choking for people with a learning disability	This report is aimed at commissioners or providers of services for people with learning disabilities. It suggests simple strategies that providers can use to identify individuals at risk of choking and to ensure their staff are trained to address these risks	Hampshire Safeguarding Adults Board	http://documents.hants.gov.uk/adultservices/safeguarding/Reducingtheriskofchokingforpeoplewithalearningdisability.pdf
Dysphagia in the Social Care & Healthcare Sectors	These descriptors detail the types and textures of foods needed by individuals	National Patient Safety Agency (NPSA) Dysphagia Expert Reference	http://premierfoodservice.co.uk/wp-content/uploads/2013/03/Dysphagia-Generic-Brochure-

	with dysphagia. The descriptors provide standard terminology to be used by all health professionals and food providers when communicating about an individual's requirements for a texture modified diet	Group in association with Cardiff and Vale University Health Board	MR.pdf
Good practice guidance for the management of dysphagia for Learning Disabilities (LD)	This guidance is aimed at SaLTs. It sets out standards to ensure that adults with learning disabilities receive the highest possible level of assessment, care and support to minimise risk whilst striving to maintain quality of life	Cheshire and Wirral Partnership NHS Foundation Trust	http://www.cwp.nhs.uk/policies/1252-ld1-good-practice-guidance-for-the-management-of-dysphagia-for-ld
Eating well: children and adults with learning disabilities. Nutritional and practical guidelines	This is an evidence-based report (164 pages) which summarises available information on the nutritional needs of children, young people and adults with learning disabilities. It looks at issues around food choice and eating well, and provides practical information. This includes recognising and managing swallowing difficulties, modifying food textures and managing the physical environment	The Caroline Walker Trust	http://www.cwt.org.uk/wp-content/uploads/2015/02/EWLDGuidelines.pdf

Table 2: Resources for professionals/family members and carers

Theme	Description	Provider	Link
General information about dysphagia			
Problems Swallowing?	This document outlines the issues	National Patient Safety Agency	http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=6

Resources for healthcare staff	facing adults with learning disabilities who have dysphagia and introduces support materials that can provide practical help for these people (These are listed individually below)		0131&type=full&servicetype=Attachment
Problems Swallowing? Resources for clients and carers	This document describes what swallowing problems are with the use of pictures. It links to some of the resources listed below	National Patient Safety Agency	http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=60130&type=full&servicetype=Attachment
Dysphagia: Mealtime information sheet	A two-page template to provide information about someone's needs/ likes/dislikes in relation to mealtimes	National Patient Safety Agency	http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=62855&type=full&servicetype=Attachment
Dysphagia: Mealtime information sheet with photo	An alternative two-page template to provide information about someone's needs in relation to mealtimes. There is space for a photo of the individual	National Patient Safety Agency	http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=62852&type=full&servicetype=Attachment
Dysphagia: Eating, drinking and swallowing care plan	A template to be used for an eating and drinking care plan for an individual	National Patient Safety Agency	http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=62849&type=full&servicetype=Attachment
Dysphagia: Specific high risk care plan	A short template to be used to describe the problem, intervention /care plan, actions needed and issues to be aware of.	National Patient Safety Agency	http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=62857&type=full&servicetype=Attachment
Learning disabilities dysphagia protocol for general	A brief guide for GPs. It highlights the potential symptoms that could indicate	National Patient Safety Agency	http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=62860&type=full&servicetype=Attachment

practitioners	dysphagia and suggested actions and good practice		
Dysphagia: Interim mealtime information	A single A4 sheet to be completed by a SaLT following an assessment of someone's eating and drinking. It is designed to be used prior to a full report, and eating and drinking care plan being produced	National Patient Safety Agency	http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=62858&type=full&servicetype=Attachment
Dysphagia report	A template to use to write up a referral for dysphagia. This includes recommendations, intervention and criteria for re-referral	National Patient Safety Agency	http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=62848&type=full&servicetype=Attachment
Dysphagia: Negative health consequences	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	National Patient Safety Agency	http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=62847&type=full&servicetype=Attachment
Dysphagia: Consent form	An easy-read consent form for assessment of eating, drinking or swallowing problems. It also includes a template for an eating and drinking plan	National Patient Safety Agency	http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=62841&type=full&servicetype=Attachment
Dysphagia: Risk assessment form	This risk assessment is designed to be used at a formal risk review meeting.	National Patient Safety Agency	http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=62840&type=full&servicetype=Attachment

	Agreed actions should be identified in relation to any risks		
The Purple Star Practice 2015 summer edition: learning disability and dysphagia	This special edition includes articles from various professionals about their work related to dysphagia management as well as relevant Makaton signs and symbols and information about resources	Hertfordshire County Council	http://www.hertsdirect.org/docs/pdf/p/purplestarsummer2015.pdf
Clinical Guidelines and Integrated Care Pathways for the Oral Health Care of People with Learning Disabilities	These guidelines focus on oral health care and how it can be improved through an approach which is focused on integrated care. They explore the barriers to good oral health but the emphasis is on practical recommendations to improve this and they signpost further resources	Royal College of Surgeons	https://www.rcseng.ac.uk/publications/docs/clinical_guidelines_oral_health_care.html
Oral health care advice for carers: Individuals with swallowing problems	This leaflet has been designed for family carers, residential and nursing staff who support individuals with learning disabilities and/or mental health issues who have problems with chewing and swallowing (dysphagia) or who are fed by tube	Greenwich Teaching Primary Care Trust/Oxleas NHS Foundation Trust	http://pathwaysassociates.co.uk/accessinfo/Oral%20Health%20Care%20-%20Dysphagia.pdf
Dysphagia and Oral Health Recommendati	These recommendations have been produced	All Wales Special Interest Group: Special	http://www.sigwales.org/wp-content/uploads/finaldysphagiasept-142015edit1.pdf

ons for the dental team for the management of oral health care of children and adults with dysphagia	to help inform and support the dental team when providing oral health care for children and adults who have dysphagia. It is based on published research and guidance, and on expert advice and best practice	Oral Health Care	
Mouthcare For Children with Swallowing Problems (Dysphagia)	A 16-page booklet about how to safely support mouthcare for children with swallowing problems	All Wales Special Interest Group: Special Oral Health Care	http://www.sigwales.org/wp-content/uploads/dysphagia-child-mouthcare-booklet3.pdf
Advice To Support Mouth Care For Adults With Swallowing Problems	A nine-page booklet about how to safely support mouth care for adults with swallowing problems	All Wales Special Interest Group: Special Oral Health Care	http://www.sigwales.org/wp-content/uploads/dysphagia-adult-mouthcare-booklet3.pdf
Dysphagia (swallowing problems)	These webpages have an overview of dysphagia, including information on causes, diagnosis, treatment and complications	NHS Choices	http://www.nhs.uk/conditions/Dysphagia/Pages/definition.aspx
Dysphagia	Online information about dysphagia including a section about learning disabilities. There is also an online tool to find alternatives to solid dose medications	Keele University	http://www.dysphagia-medicine.com/dysphagia.html
Swallowing difficulties website	This website is designed to provide an easy to use and up-to-date source of information for prescribing and administering medicines to patients with	Swallowing difficulties	http://www.swallowingdifficulties.com/

	dysphagia, the availability of alternative formulations and guidance on the appropriateness of tablet crushing and dispersion		
Dysphagia: Swallowing Difficulties and Medicines	This is a free online course designed to enhance the knowledge of any person involved in the administration of medicines to patients with dysphagia		https://www.futurelearn.com/courses/dysphagia
Steps to Understanding Dysphagia in Adults with Learning Disability	This is an RCGP accredited educational webcast	RCGP	http://microsites.streamuk.com/rosemont/login/
Looking after the Mouth – A training guide for Carers	These three videos provide practical advice and information for health and care professionals who perform mouth care. They can be used on a personal basis or for staff training	The British Society of Gerodontology and British Society for Disability and Oral Health (BSG and BSDH).	http://www.1000livesplus.wales.nhs.uk/looking-after-the-mouth
In my best interests - Michael's story	A film (approximately 30 minutes) which illustrates a situation when the MCA was used to take a best interest decision about whether or not Michael should have a PEG	Michael, St. Anne's Community Services, Calderdale and Huddersfield NHS Trust and The University of Huddersfield	http://www.hud.ac.uk/hhs/michaels-story/
Eating and drinking risk assessment recommendations	A single page risk assessment tool with space for recommendations pertaining to each identified risk	Leicestershire Partnership NHS Trust	www.improvinghealthandlives.org.uk/adjustments/?adjustment=375
Communicating	This short,	Leicestershire	www.improvinghealthandlives.org.

at meals	accessible booklet has top tips about supporting someone at mealtimes and drink times. This includes advice on involving the person and giving them choices	Partnership NHS Trust	uk/adjustments/?adjustment=376
Supporting people who eat and drink too fast	A leaflet with advice on supporting people who eat or drink too fast. This can make it more difficult for them to swallow safely and more likely that they will cough or choke	Leicestershire Partnership NHS Trust	www.improvinghealthandlives.org.uk/adjustments/?adjustment=377
Supporting people with enteral tube feeding	This leaflet has some top tips to consider when supporting a person who is being tube fed	Leicestershire Partnership NHS Trust	www.improvinghealthandlives.org.uk/adjustments/?adjustment=378
Foods with Higher Risk of choking	This is a simple list of foods with a higher risk of choking. These should be avoided for people with swallowing difficulties	Leicestershire Partnership NHS Trust	www.improvinghealthandlives.org.uk/adjustments/?adjustment=379
Tips to help eating and drinking for someone with dementia	This leaflet gives advice about eating and drinking problems people with dementia may have	Leicestershire Partnership NHS Trust	www.improvinghealthandlives.org.uk/adjustments/?adjustment=380
Working together on pacing when eating	This tool is to help the person or family/carers and the health worker to write an effective plan to manage rushing	Leicestershire Partnership NHS Trust	www.improvinghealthandlives.org.uk/adjustments/?adjustment=381
Help Stop Choking video clips	This is a series of 11 clips from an award-winning DVD to help increase awareness of	Belfast Health and Social Care Trust	What is choking? https://youtu.be/wXyCo5sjxvk Change what you eat - make safe food choices https://youtu.be/Z2HMvYlh2aQ

	choking, promote safe eating strategies and reduce avoidable mortality and adverse harm effects from choking. Some of these clips may be useful to use directly with people with learning disabilities		Change the way you eat - encouraging safe eating strategies https://youtu.be/5sSQtpgvlM4 Change where you eat – promote safe eating environments, https://youtu.be/_SeghdNkt7Y Role of the carer https://youtu.be/KF9SlLrgxv0 Capacity and choice making – social worker https://youtu.be/F43nWkzUBqQ First aid https://youtu.be/k2eT8X4UrXA Oral care https://youtu.be/1WI1e4v8m-U Talking Mats - How to support communication https://youtu.be/DbSZJvY-zGk Personal Place Mats https://youtu.be/1FOcJGE4m5I Good ideas to help stop choking https://youtu.be/q-czyj5IuZE

Table 3: Easy-read resources

Theme	Description	Provider	Link
Easy-read resources about dysphagia			
Dysphagia	An 11-page easy-read leaflet describing what dysphagia is. It also covers the warning signs and what to do about it	NHS North Somerset	http://www.easyhealth.org.uk/sites/default/files/dysphagia.pdf
Me at Mealtimes	Me at Mealtimes is an easy-read booklet designed to help make eating more enjoyable and fun for those who find mealtimes difficult. The book encourages people to score their mealtimes using the Me at Mealtimes scorecard and provides advice on who to contact for help with eating,	Calderstones and Lancashire Care NHS Trusts	http://www.bild.org.uk/EasySiteWeb/GatewayLink.aspx?alId=6246 http://www.calderstones.nhs.uk/media/files/Misc/me_at_mealtimes_booklet.pdf

	drinking or swallowing problems		
Me at Mealtimes scorecard	This scorecard is designed to accompany the booklet. It has 14 questions about how someone feels when eating and drinking	Calderstones and Lancashire Care NHS Trusts	http://www.calderstones.nhs.uk/media/files/Misc/me%20at%20mealtimes%20score%20card.pdf
Dysphagia	Easy-read web pages with information about the causes and signs of dysphagia. There is also information about what you should and should not do	NHS inform	http://www.nhsinform.co.uk/easy-info/healthconditions/dysphagia/
About tube feeding	An easy-read leaflet answering common questions about tube feeding	Hertfordshire Partnership University Foundation Trust	www.improvinghealthandlives.org.uk/adjustments/?adjustment=383
Why does Connor cough?	A picture-based, easy-read story board about dysphagia. It aims to highlight dysphagia issues and prompt carers to seek timely investigation of symptoms which might otherwise be missed	Hertfordshire County Council	http://www.hertsdirect.org/docs/pdf/c/connorwhycough.pdf
Food Choices Booklet	This food choice booklet was developed for an individual who needed some additional support to understand foods that are/are not safe to eat	Southern Health NHS Foundation Trust	www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=370
Help Stop Choking song	This song is part of a choking awareness campaign	Belfast Health and Social Care Trust	https://www.youtube.com/watch?v=SBAehzR_AN0
Video Fluoroscopy	An easy-read leaflet explaining what a video fluoroscopy is. There is also a consent form as part of this	Leicestershire Partnership NHS Trust	www.improvinghealthandlives.org.uk/adjustments/?adjustment=382

Table 4: Apps related to dysphagia

Theme	Description	Provider	Link
Apps giving information about dysphagia			
SmallTalk Dysphagia	SmallTalk Dysphagia provides a vocabulary of pictures and icons that talk in a natural human voice	Lingraphica	Available in Apple i-store: https://itunes.apple.com/us/app/smalltalk-dysphagia/id337184701?mt=8
SmallTalk Oral Motor Exercises	This app is designed for people with weak mouth, tongue, and lip muscles and/or poor oral coordination. It contains videos illustrating cheek, tongue, palate, lip, and jaw exercises that help strengthen the oral musculature	Lingraphica	Available in Apple i-store: https://itunes.apple.com/us/app/smalltalk-oral-motor-exercises/id337145605?mt=8
St John Ambulance First Aid	This app includes the latest first aid advice and protocols for dealing with emergency situations. It is simple to follow with illustrated guides and voiced instructions. Choking and resuscitation are two of the emergency situations covered	St John Ambulance	Available in Apple i-store: https://itunes.apple.com/gb/app/st-john-ambulance-first-aid/id347574230?mt=8 Android: https://play.google.com/store/apps/details?id=an.sc.sja

Examples of reasonable adjustments and case studies

Community Learning Disability Team, North East Lincolnshire

In North East Lincolnshire the Community Learning Disability Team (CLDT) has run specialist dysphagia training for over nine years. They developed a one-day dysphagia course which is delivered to staff who work with people with learning disabilities in either supported living settings, residential/nursing homes or in day services. The training is delivered by a speech and language therapist (SaLT) from the CLDT and co-facilitated by the deputy manager of a day service for adults with learning disabilities.

The aims of the training are:
- to increase understanding of the processes of normal and abnormal swallow
- to increase understanding of the acute and chronic signs of dysphagia
- to increase understanding of the roles of all members of multidisciplinary teams in relation to dysphagia
- for staff to learn how to increase dignity and respect and create a positive
- mealtime experience for a client
- to increase understanding of professionals' recommendations in terms of diet and fluid modifications
- to teach staff how to apply their learning in the workplace

The training day includes presentations, workshops activities and discussion groups. These cover topics such as the anatomy of swallowing and signs of dysphagia. The activities include preparation of thickened fluids and an opportunity for reflective practice through staff being supported to eat by someone else.
The training is mandatory for support workers who work in learning disability day centres and is currently delivered on a three-year cycle. In the first year, all staff attend the full day's training as described above. The second year consists of a theory-based refresher quiz and in the third year people attend a practical refresher. At the refresher, there is an opportunity to prepare food to different consistencies and use drink thickeners to achieve different viscosities. Staff attend another full day's training in their fourth year.

The one-day training programme has been evaluated using a control group design. The results showed that those who had attended the training gained knowledge and confidence. This gain was maintained when they were reassessed one month later.[22]
It is hoped that the proactive approach of delivering this training will result in
- a reduction of the amount of chest infections
- a reduction in the amount of antibiotics prescribed
- a reduction of admissions to hospitals

The process of delivering the training has increased the awareness of the SaLT role and responsibilities and improved working relationships with support staff. The SaLT team now gets very few inappropriate referrals. However, members of the team are concerned that a decrease in referrals could be interpreted as less need for their service.

For further information, contact Gerlind Tredinnick at gerlind.tredinnick1@nhs.net

Hertfordshire County Council, Health and Community Services
Community Learning Disability Service

Following an audit of the community nursing staff's knowledge and confidence around dysphagia issues, the Dysphagia and Nutrition group was established in Hertfordshire. The group's aim is to improve dysphagia services for people with learning disabilities. Members of the group are working to do this by increasing early recognition and raising awareness of the condition with service users and carers. They encourage prompt presentation to GP or SaLT services to reduce the risks of complications due to dysphagia.

The multidisciplinary group is attended by members of the community learning disability teams as well as speech and language therapists (from specialist learning disability services and the acute trust), dietitians and allied health professionals. The group meets every six weeks and has a clear annual action plan. This has various strategies to raise awareness and share good practice, including training in dysphagia awareness for the community teams.

The group wrote articles for the summer 2015 edition of the Purple Star Practice magazine, which focused on dysphagia and learning disabilities. There were contributions from various professionals about their work related to dysphagia management. These included case study examples, information about the signs and symptoms of dysphagia and what to do about it. The newsletter includes a resource pack for health professionals and carers. This contains a symptom checklist, easy-read eating and drinking safely pictures, the most useful Makaton signs and symbols, and relevant links and websites.
The newsletter can be found at
http://www.hertsdirect.org/docs/pdf/p/purplestarsummer2015.pdf

One resource included in the newsletter is a picture-based, easy-read storyboard about dysphagia. It highlights dysphagia issues and prompts carers to seek timely investigation of symptoms that might otherwise be missed. This was developed with the Waterside Purple All Stars, which is one of four groups of people with learning disabilities established by the Health Liaison Team, who provide health promotion

messages through the use of creative arts. It has been used at a health promotion event for service-users and carers. This can be downloaded at http://www.hertsdirect.org/docs/pdf/c/connorwhycough.pdf

For further information, contact Natasha Collins at natasha.collins@hertfordshire.gov.uk

Community Learning Disability Team, Brighton and Hove

The Community Learning Disability Team (CLDT) has piloted a multidisciplinary clinic model of service provision for people with learning disabilities who have difficulties with eating, drinking and swallowing. This service replaced the previous approach where each discipline made separate assessments and recommendations. The disciplines included in this multidisciplinary model are:

- speech and language therapy (from both the learning disability team
- and the local adult mainstream service)
- physiotherapy
- occupational therapy
- community nursing
- dietetics

The clinics are held on a monthly basis at the CLDT base and follow a set format. Medical notes are made available to ensure clinicians are fully informed of up-to-date relevant medical history. Each referral is assessed by the SaLT at the initial appointment to determine if the clinic care pathway is appropriate for that individual (see Figure 1).

The team conducted an assessment of the multidisciplinary service model by reviewing SaLT case files from both types of service provision. This showed that there was 100% attendance rate at the multidisciplinary clinic. Additionally, on average, clients attended two clinic appointments per episode of care compared with six appointments in the old model. Joint assessments and reviews allowed the team to make any necessary changes to recommendations within the clinic, rather than the need to review each time another discipline had made their assessment and recommendations. There has been no reduction in the time clinicians give to clients but it is has been given in a more timely, joined-up way and clients received shorter episodes of care in which their health needs were met.

Benefits for clients, carers and clinicians include:

- a second SaLT opinion for all clients
- not having to repeat the same information to a range of different professionals
- improved working relationship with mainstream SaLT colleagues
- establishment of a pathway to access a routine videofluoroscopy clinic and pathways for hospital admissions and discharges

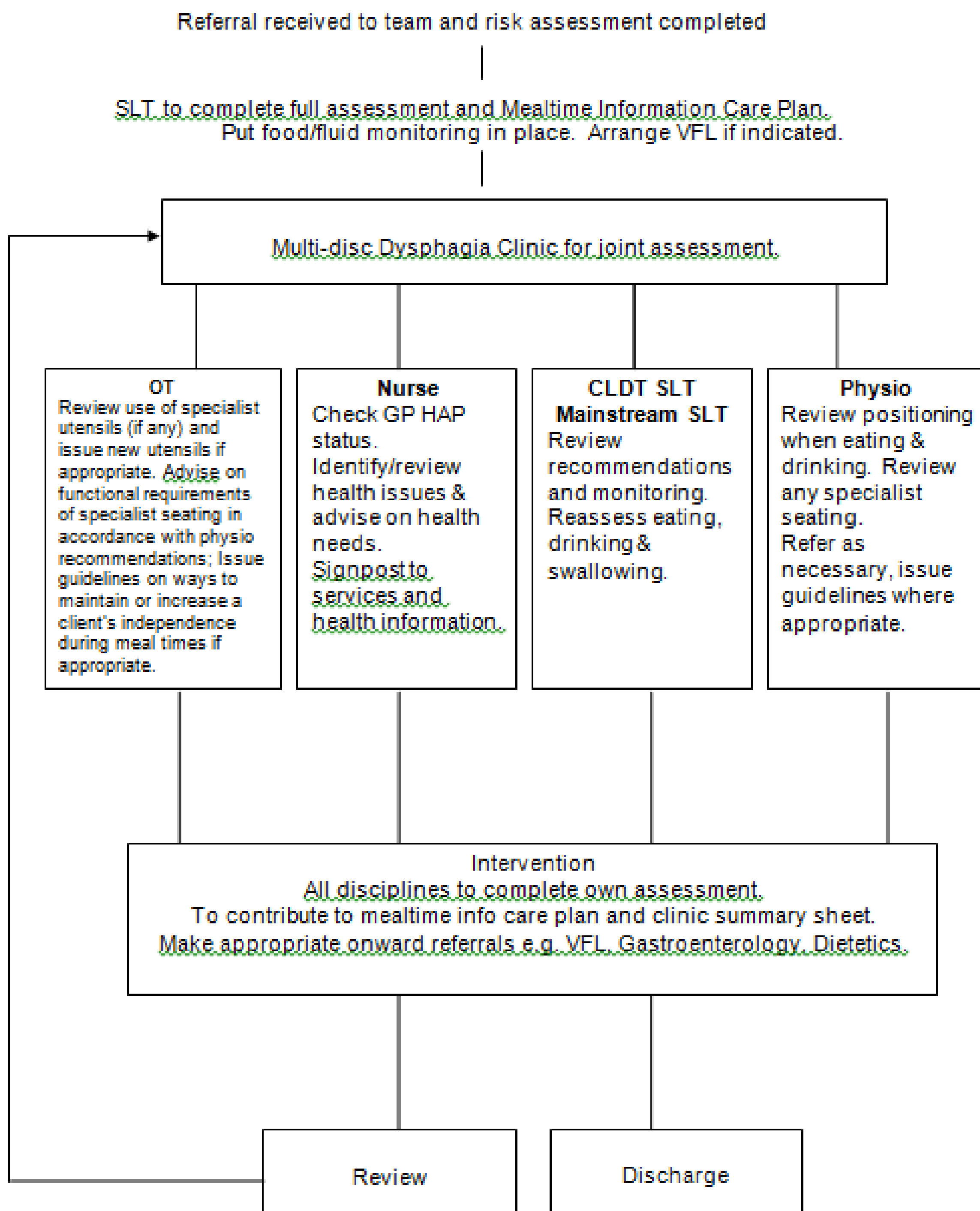
It has proved to be an efficient model for the professionals because all discussion, case notes, reports and outcomes are completed during the clinic day, whereas previously each discipline would do their own assessment and paperwork at different times.

Following the review it was agreed that the multidisciplinary clinic model of provision provided value for money whilst ensuring a holistic, effective service for this client group. Therefore, it has been continued and is currently being extended to other localities across Sussex Partnership Foundation Trust. In addition, the team now has a GP trainee attending the clinic as part of their training.

More details about this model of working and the review the team undertook are available at www.ihal.org.uk/adjustments/?adjustment=369 along with an easy-read appointment letter and a leaflet about the service.

For further information, contact Claire Bartlett at Claire.Bartlett@sussexpartnership.nhs.uk

Figure 1: Multidisciplinary dysphagia care pathway



Calderstones Partnership Foundation Trust and Lancashire Care Foundation Trust

Susan Guthrie is a specialist speech and language therapist and clinical lead dysphagia working for Lancashire Care NHS Foundation Trust based at Calderstones Partnership NHS Foundation Trust. She has overseen a programme of clinical work and continues to research dysphagia in adults with learning disabilities and mental illness.

Working with care staff:
Following a death by choking in 2007, the trust implemented staff training in dysphagia and risk of choking, enhanced reporting of suspected choking incidents (see below for more details) and screening for signs of dysphagia/risk of choking. Through their staff workshops they identified a problem with standard Basic Life Support training. Care staff reported difficulties in attempting to use the recommended procedures with people who are in wheelchairs or who have severe physical disabilities. Subsequently, they worked with trainers to ensure they offer appropriate, individualised guidelines for choking first aid.

Working with people with learning disabilities:
In addition to the training workshops, Susan has worked with people with learning disabilities and care givers to write a booklet, called *Me at Mealtimes,* to help people with learning disabilities and their supporters think about any difficulties they have at mealtimes. The booklet aims to support and inform conversations about how people feel about eating, drinking and swallowing and is accompanied by an easy-read scorecard. (Both resources are listed in Table 3). The language and pictures are carefully designed so that people with learning disabilities and/or mental illness can reflect on their mealtime experience and talk about any areas of concern.
For people living in low/medium secure settings, their annual health checks are undertaken on site and electronic records are shared. This means that information from annual health checks is incorporated into treatment and care plans. People living in the community ask the care teams to complete an annual check using the training information and the *Me at Mealtimes* booklet. This helps to inform the annual health check, which is undertaken by a GP.
This work has led to improvements. The number and severity of suspected choking incidents has decreased. The number of referrals to Susan’s team has increased for SaLT assessment of mealtime skills. Each referral is more informed and relevant. This helps to explore ways to reduce the risk of choking. People with learning disabilities are more involved by using the booklet and selfie videos to help them understand mealtime difficulties.

Work around choking reporting
At Calderstones Trust, it is mandatory to report all choking incidents as part of the national reporting and learning system. The reports are passed to the dysphagia service lead for monitoring. The service lead led research that explored the differences between

the local and national systems for reporting choking incidents. It was hoped that better reporting could improve support for the individual and subsequently mitigate the risk of further occurrences.

The study found a higher than expected proportion of local reports, which may suggest that nationally there is underreporting of choking incidents. It could also reflect the work the SaLT team has been doing to raise awareness of the issue and the need to report incidents. Many of the local reports related to incidents described as low/no harm. These reports may help in the early diagnosis of swallowing problems and appropriate interventions. Rating the incidents in terms of the first aid administered gives an idea of severity. Since the training in this trust, severe choking incidents requiring the use of abdominal thrust have reduced to zero whereas previously this level of first aid was used in 30% of choking incidents.

Susan’s team has added prompt questions to the electronic reporting system used in Calderstones, which have provided more detail about these incidents and facilitated greater learning. This extra detail has enabled key information to be shared with frontline staff. Analysis of the reported incidents showed that the early evening meal is the most likely time for choking incidents. Meat and bread products are the foods most commonly involved. Another service user may be the first person to respond to a choking incident. Because staff turnover is high, the most consistent contact at mealtimes is likely to be someone’s peers.

The research highlighted the need for familiar staff to support service users at mealtimes because the choking incident can be subtle, quiet and easy to miss for some people. It was concluded that ongoing training is crucial to develop and support the reporting skills of staff. Further consideration is also needed to improve the levels of inclusion of people with learning disabilities into the training of staff.

Further details about this research can be found in Guthrie et al (2015)[8] and Guthrie and Stansfield (2015).[26]

Case study about the management of dysphagia in a young man with learning disabilities:

As well as dysphagia, ‘Joe’ had mental health issues, a degenerative neurological condition and exhibited self-harming and impulsivity. He was supported by a multidisciplinary team, including a psychiatrist, speech and language therapist, and nursing and care staff. His capacity to consent fluctuated with his mental health.

Joe was referred to the SaLT team when it was noted he had increasing difficulty at mealtimes, occasional choking episodes and more frequent chest infections. Mealtimes were an important source of pleasure for Joe and he had strong views on what he would and would not eat. The team worked together to find strategies to keep him safe while maintaining his quality of life.

The first step was to observe him at mealtimes and to start discussions with the nursing team, psychiatry, occupational therapy and Joe himself. SaLT assessed the functionality of his swallow and found he had problems with this. The use of thickened

drinks led to a decrease in his coughing initially, but over time his increasing chest infections were indicative of aspiration of fluids. The SaLT team also advised that he needed to avoid food which was chewy/dry and that he should be offered softer, moister food.
Joe was resistant to changes being made to his meals – he liked food of a chewy texture; he did not like his food to be cut up; he refused to use the thickener, adapted crockery and utensils. He was able to express his fear of not being able to eat his favourite foods and at times he could become aggressive. Therefore, the SaLT team provided individual sessions for Joe where they used accessible, visual resources to help him understand the changes being made.
An important aspect of the work was training for the staff so they were fully aware of the risks and understood the need to follow the guidance for Joe's mealtimes.
Joe had postural problems and these exacerbated the difficulties he had with swallowing. When he was eventually given a made-to-measure wheelchair this improved his sitting position for eating.
The team continued to consider Joe's best interests and his capacity to make decisions; this meant consideration of many factors, including Joe's views, his level of understanding, and the various risks around his dysphagia, aggression and self-injury. Following this, the decision was taken by the team to offer him unthickened fluids to ensure he was staying hydrated and guidelines were drawn up that took account of his favourite tastes as well his need for softer consistencies in foods.
This case study illustrates some of the ethical challenges faced by professionals when they are trying to manage risk issues while ensuring quality of life for an individual who lacks capacity. The provision of education and training was crucial. In order to mitigate the risks for Joe, it was necessary to take a person-centred approach and there was a need for specialist clinicians to work closely with frontline staff.

A full description of this case study can be found in Guthrie et al (2012).[27]

For further information about this work, contact Susan Guthrie at susan.guthrie1@nhs.net

Tameside and Glossop Learning Disabilities Team, Stockport NHS Foundation Trust

The SaLT team was supporting a man with learning disabilities who lived semi-independently. Following a stroke, he had difficulties in swallowing and consequently had to make adjustments to his diet. He found some of the restrictions difficult. The SaLT worked to identify alternative foods that he enjoyed and could eat safely. She then created simple visual reminders to make it clear to him what he could not eat and what the alternative was.

Figure 2: Personalised visual reminders about food that is safe to eat

For further information, contact Eilis Sheridan at eilis.sheridan@nhs.net

Belfast Health and Social Care Trust

Help Stop Choking project

John has learning disabilities, epilepsy, cerebral palsy and swallowing difficulties and experienced a number of choking events. He was referred to speech and language therapy and, following a swallowing assessment, received direct therapy to help him reduce his risk of choking. John felt that his positive experience of the speech and language therapy service saved his life. He was inspired to share his successful story to help other people reduce their risk of choking.

The public health agency funded a patient and public involvement project to develop John's story into an educational DVD. Clips from the DVD are listed in Table 3. This is an accessible learning resource for people with learning disabilities, their staff and carers. The DVD helps people to understand choking and know how to reduce the risk of choking. Professionals who share their perspective on reducing the risk of choking include a SaLT, a community nurse, a day care worker, a health improvement officer for oral health and a social worker.

Along with the DVD, an easy-read information book, activities, posters and a choking awareness campaign song and music video were produced.

The 'Help Stop Choking' song is available on YouTube (http://youtu.be/AEwDb3ZNkAc)

The DVD and other resources were piloted through a series of workshops with carers, people with learning disabilities and support staff. These workshops proved effective in

that all participants increased their understanding of choking and the ways to reduce risk.
John was awarded a top prize at the 2014 Patient Safety and Care Awards under the Preventing Avoidable Harm category. Presenting the award, the judges commended the DVD to all Learning Disability services in the UK, saying it should be used in core training and awareness raising for staff and people with learning disabilities.

Personal place mats

Personal place mats (PPM) have key information that others need to know to make mealtimes safe and enjoyable. PPM might tell people about the type of food they eat, how they choose food, highlight risks and if they need help at mealtimes. Many people need some help and support at mealtimes. Having this information on a PPM allows staff to read it when they need to.

"My personal place mat helps me to tell staff about my choking risk"
A person with learning disabilities

The PPMs help present complex information in a simple format and the statements are written in the first person. All information is presented in the order in which it will be needed during a mealtime. PPMs are A4 size and laminated so they are durable and easily wiped clean.
A day care worker said: "At meal times we might have large groups of people that we are supporting and they all have different needs and sometimes it's hard to remember what everybody's needs are. Also there are lots of new staff coming in and out of the department and people from other departments are filling in. It's good to have advice on hand so that everybody is following the same guidelines. The PPM means the information is there if staff need to look anything up or check anything. If you can't speak for yourself, a personal place mat can help keep you safe."

Ideally, an individual is involved in the development of their PPM. If this is not possible, it is important to observe the person at mealtimes and gather information from those who know them best. If the individual has been assessed by a SaLT team, the team's advice should be highlighted on the PPM. It is essential that information on the PPM is regularly reviewed and kept up to date.
Angela Crocker is a SaLT who developed the idea of PPM. The RCSLT five good communication standards[4] highlighted PPM as an example of good practice to help individuals to understand and express their needs in relation to their health and wellbeing.
A template for a personal place mat with instructions for personalisation can be downloaded at www.communicationpassports.org.uk/Common-Assets/spaw2/uploads/files/Placemat_Template.ppt

---

[4] http://www.rcslt.org/news/good_comm_standards

The ‘Help Stop Choking’ website will be available soon. This will have clips of the DVD and other resources including leaflets, posters and forms.

For further information, contact Angela Crocker at angela.crocker@belfasttrust.hscni.net

Sutton and Merton Community Services and Royal Marsden Foundation Trust

Dysphagia Team for Adults with Learning Disabilities:
Following the closure of a long-stay NHS institution for people with learning disabilities in Sutton, there was a large population of adults in the community who had profound and multiple learning disabilities, complex needs and known eating and drinking difficulties. None of these individuals had a record of ever receiving a swallow assessment. It was recognised that they were at risk of malnutrition and choking within their new services, as they would have a team of carers that were new to them. The local learning disability team and the primary care trust (PCT) did not have the knowledge or the capacity to carry out the swallow assessments, or provide information and training that was required to meet their needs. Therefore, with support from the local learning disability teams and the PCT, funding was provided for a local, specialist multidisciplinary dysphagia team for people with learning disabilities.

A crucial role within the team is the specialist dysphagia nurse who is currently employed by Royal Marsden NHS Foundation Trust. The team also includes a SaLT and a dietitian, along with support from occupational therapy and physiotherapy clinicians based at the local learning disability teams.
The aims of the multidisciplinary dysphagia team are:

- to carry out comprehensive/holistic assessments, including assessment on the appropriateness of current diet, determining any contributing health/medical factors, medication requirements and side effects, and considering syndrome specific factors that affect the swallow
- to analyse the emerging information and generate a working hypothesis of need, and refer on to appropriate health professionals or social services, as required
- to provide a point of contact/health keyworker for the client, family carer and professionals
- to co-ordinate and collaboratively develop a comprehensive multi-agency, individualised management plan of dysphagia support needs. An Eating and Drinking Plan is provided in an accessible format, designed as a placemat and/or wallet/handbag guide. An example of an eating and drinking plan can be found at www.improvinghealthandlives.org.uk/adjustments/?adjustment=372

Initially, there was a low referral rate to the team. This was partially due to a lack of awareness of the team’s existence, but there was also evidence that supporters often accept that an individual has eating and drinking difficulties and do not think that something can be done to help. A crucial part of the role of the dysphagia nurse is

therefore education. Training individuals in a range of settings is a requirement of the role. In addition to training for residential home staff, training is provided to day centre staff, other allied health professionals, social workers and GPs.
Noncompliance in following eating and drinking guidelines increases when there is a lack of understanding of the rationale for the recommendations. Therefore, informal training for families/carers is also provided in order to improve the understanding and, subsequently, the implementation of individualised dysphagia plans.

Good practice story:
A young woman with learning disabilities, who had repeated chest infections and was refusing foods, was referred to the team. Subsequently, her physical and mental health deteriorated, which resulted in a hospital admission. She predominately used non-verbal communication limited to facial expressions, and some sounds, and had a physical disability for which she required specialist seating and positioning. Additionally, she had epilepsy, gastro-oesophageal reflux disease and was incontinent.
The Dysphagia Team for Adults with Learning Disabilities involved the following in service delivery:

- the individual and her family
- home carers
- GP
- local learning disability team
- social worker
- acute hospital service
- continence service
- school
- college

Appointments were made at a convenient time for the client so they did not impact on her normal activities/routine. Mealtime assessments were carried out at her usual, preferred time of eating and drinking, including early morning and late evening appointments. The team undertook assessments in all the environments in which she had food and drink, including her school and college. It was necessary to undertake multiple appointments in order to get to know her and gain her trust, as she did not eat during initial visits. This approach eventually led to the team being able to perform a swallowing x-ray (videofluoroscopy) with minimal anxiety for the client.
The assessments revealed a moderate mouth and throat stage (oro-pharyngeal) swallowing impairment (dysphagia) and a perception of anxiety-related food refusal following a previous choking event.
A holistic, person-centred intervention plan was developed. All agencies involved with supporting her were made aware of the relevant health risks associated with her dysphagia. These included chest infections, malnutrition, an increase in seizures (due to difficulty consuming her medication) severe constipation and potential for risk of choking if recommendations were not followed. She was reviewed weekly and her oral-

nutritional supplements, nutritional status and her weight, as well as her general physical and mental health were monitored.
A desensitisation plan was developed to help manage her fear of food and anxiety related to eating. The plan stated that she was not to be put under any pressure to taste food and aimed to help her regain a positive attitude to food, by encouraging her to explore and touch her food. Education and training was provided to her family and carers and the desensitisation plan was carried out at both home and college.
Following this coordinated, comprehensive multidisciplinary team approach and the intervention plan being put in place, she began to eat and enjoy mealtimes with her family and college friends.

Training local Dysphagia Champions:
The dysphagia team are working to train senior care staff to 'foundation dysphagia practitioner' level. This role describes practitioners who are not specialists in dysphagia, but who have a responsibility for providing care for individuals who may present with difficulties swallowing liquids and solids.
These practitioners will demonstrate skills in the recognition and identification of dysphagia, initial protocol-guided assessment and implementation of the protocol-guided actions. They will implement a review process for the clients they are supporting. They should consult more experienced practitioners in order to ensure that their competence is commensurate with best practice. Foundation dysphagia practitioners will recognise the potential health risks presented by the signs of dysphagia and the urgency of the referral and, if appropriate, they will refer to a more experienced/ qualified dysphagia practitioner.
The dysphagia team worked with 12 provider organisations who responded to a letter of invitation. Discussions were held with the provider service managers to agree the responsibilities/expectations of the role of the dysphagia champion within their service.
A resource folder was provided to the dysphagia champions and their training included:

- dysphagia awareness – to understand stages, nature, urgency and implications
- modifying diets and fluids – the different stages and how to achieve them
- use of choking risk assessment tool
- MUST screening tool and practice
- postural care and equipment for people with swallowing difficulties
- oral care and hygiene
- bowel management – use of the Bristol stool chart
- hydration and dehydration – use of the urine colour chart
- medication and how to reduce risk of choking

The competency exam is checked by a highly specialist SALT from NHS community services.

For further information, contact Maureen Hounslow at
Maureen.Hounslow@smcs.nhs.uk

Leicestershire Partnership NHS Trust

In Leicestershire, a CQUIN service improvement has been put in place around the management of people with learning disabilities and dysphagia. The CQUIN is a contract made with GP commissioners to improve the service in a tangible way. Protected Learning time is training time, of which GPs have to attend a certain amount each year. This protected learning time was used to contact GPs to talk about the service and the CQUIN. They found that knowledge of the SaLT service was variable but feedback about the resources they had was positive.

The CQUIN aims to improve support to patients with learning disabilities, who are at risk of choking, through the development of risk management plans.

The target is for at least 90% of patients who are at risk of choking to have benefited from the following three things:

- an Eating and Drinking Risk Assessment (EDRA) has been carried out
- an individualised care plan has been created
- any choking risk has been effectively communicated to multidisciplinary teams and GPs

A quarterly audit of the EDRA process is carried out to monitor the progress being made. At the end of each cycle, areas for improvement are identified by looking at the results, and actions are implemented to improve practice.

In practice, this means that the multidisciplinary team foundation workers carry out the initial protocol guided screening assessment of the person. This involves a holistic approach where they take a case history and observe the person in their natural environment. They undertake the EDRA and write a risk and care plan (adapted from NPSA).
The risk and care plan flags up any possible risks in relation to:

- food
- drinks
- equipment
- position
- nutrition
- support needed

An action/recommendation is identified in relation to every noted risk. Following the assessment, the foundation worker's risk and care plan is written on carbon paper to enable immediate sharing of the information. It has to be signed off by the relevant carer/supporter of the individual. This summary report includes information about the outcome of the assessment such as further referrals to physiotherapy or occupational therapy. A copy is sent immediately to the GP for information.

One of the benefits of this approach is that everyone involved instantly receives a full report about the person's risks when eating and drinking. The plan tells the person how to eat more safely and advises the paid supporters/carers how to support the person to make eating and drinking safe, nutritious and enjoyable.

For further information, contact Jenny Worsfold at Jennifer.Worsfold@leicspart.nhs.uk

References

1. UK Parliament (2010) Equality Act 2010. Available on-line at www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf (accessed 29th March 2016)
2. Chadwick DD and Jolliffe J. (2009) A descriptive investigation of dysphagia in adults with intellectual disabilities. Journal of Intellectual Disability Research; 53: 29-43
3. Leslie P, Crawford H and Wilkinson H. (2009) People with a Learning Disability and Dysphagia: A Cinderella Population? Dysphagia; 24: 103-104
4. Ball SL, Panter SG, Redley M, Proctor CA, Byrne K, Clare ICH and Holland AJ. (2012) The extent and nature of need for mealtime support among adults with intellectual disabilities. Journal of Intellectual Disability Research; 56: 382-401
5. Calis EAC, Veugelers R, Sheppard JJ, Tibboel D, Evenhuis HM and Penning C. (2008) Dysphagia in children with severe generalized cerebral palsy and intellectual disability. Developmental Medicine & Child Neurology; 50: 625-630
6. National Patient Safety Agency (2004) Understanding the patient safety issues for people with learning disabilities. Available online at http://www.npsa.nhs.uk/EasySiteWeb/GatewayLink.aspx?alId=839 (accessed 29th March 2016)
7. Hampshire Safeguarding Adults Board (2012) Reducing the risk of choking for people with a learning disability: A multi-agency review in Hampshire. Available online at http://documents.hants.gov.uk/adultservices/safeguarding/Reducingtheriskofchokingforpeoplewithalearningdisability.pdf (accessed 29th March 2016)
8. Guthrie S, Lecko C and Roddam H. (2015) Care staff perceptions of choking incidents: What details are reported? Journal of Applied Research in Intellectual Disabilities; 28: 121-132
9. Mazars (2015) Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust. Available online at https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/12/mazars-rep.pdf (accessed 29th March 2016)
10. Heslop P, Blair P, Fleming P, Hoghton M, Marriott A and Russ L. (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report. Bristol: Norah Fry Research Centre, University of Bristol. Available online at http://bristol.ac.uk/cipold/reports/ (accessed 29th March 2016)
11. Glover G. & Ayub M. (2010) How People with Learning Disabilities Die. Improving Health & Lives: Learning Disabilities Observatory,

http://www.improvinghealthandlives.org.uk/gsf.php5?f=8586 (accessed 29th March 2016)

12. Emerson E, Baines S, Allerton L and Welch V. (2012) Health Inequalities & People with Learning Disabilities in the UK: 2012. Improving Health & Lives: Learning Disabilities Observatory. Available online at http://www.improvinghealthandlives.org.uk/gsf.php5?f=16453 (accessed 29th March 2016)
13. Glover G and Evison F. (2013) Hospital Admissions That Should Not Happen: Admissions for Ambulatory Care Sensitive Conditions for People with Learning Disabilities in England. Improving Health & Lives: Learning Disabilities Observatory. Available online at http://www.improvinghealthandlives.org.uk/gsf.php5?f=16714 (accessed 29th March 2016)
14. Chadwick DD. (2014) Balancing safety and enjoyment. Current practice when recommending tastes for people with intellectual disabilities who are non-orally fed. Appetite; 81: 152-161
15. Chadwick DD, Jolliffe J, Goldbart J and Burton MH. (2006) Barriers to Caregiver Compliance with Eating and Drinking Recommendations for Adults with Intellectual Disabilities and Dysphagia. Journal of Applied Research in Intellectual Disabilities; 19: 153-162
16. Howseman T. (2013) Dysphagia in people with learning disabilities. Learning Disability Practice; 16(9): 14-22
17. Wright D et al. (2012) Guideline for the identification and management of swallowing difficulties in adults with learning disability. Available online at http://www.guidelines.co.uk/wpg/dysphagia-with-learning-disability#.Vi9ZarfNzIU (accessed 29th March 2016)
18. Wright D and Howseman T. (2013) Managing swallowing difficulties in patients with learning disabilities. Journal of Community Nursing; 27(4): 79-87
19. Matson JL, Fodstad JC and Boisjoli JA. (2008) Cutoff scores, norms and patterns of feeding problems for the Screening Tool of fEeding Problems (STEP) for adults with intellectual disabilities. Research in Developmental Disabilities; 29: 363-372
20. Sheppard JJ, Hochman R and Baer C. (2014) The Dysphagia Disorder Survey: Validation of an assessment for swallowing and feeding function in developmental disability. Research in Developmental Disabilities; 35: 929-942
21. Boaden L, Davies S, Storey L and Watkins C. (2006) Inter-professional Dysphagia Framework (IDF). Available online at http://www.rcslt.org/members/publications/publications2/Framework_pdf (accessed 29th March 2016)
22. Chadwick DD, Jolliffe J and Goldbart J. (2002) Carer knowledge of dysphagia management strategies. International Journal of Language & Communication Disorders; 37: 345-357
23. Tredinnick G and Cocks N. (2013) Effectiveness of dysphagia training for adult learning disabilities support workers. British Journal of Learning Disabilities; 42: 125-132
24. Lewis T. (2004) Using the NO TEARS tool for medication review. BMJ; 329: 434

25. Wright D et al. (2013) Guideline on the medication management of adults with swallowing difficulties. Available online at http://staticcontent.streamuk.com/sc/rosemont/5_medication_management_adults_swallowing_difficulties.pdf (accessed 29th March 2016)

26. Guthrie S and Stansfield J. (2015) Teatime Threats. Choking Incidents at the Evening Meal. Journal of Applied Research in Intellectual Disabilities, Online Early doi: 10.1111/jar.12218

27. Guthrie S, Roddam H, Panna S and Fairburn G. (2012) Capacity to choose and refuse? A case study. Advances in Mental Health and Intellectual Disabilities; 6(6): 293-300

Appendix A

Making reasonable adjustments to cancer screening. November 2015. Learning Disabilities Public Health Observatory. www.improvinghealthandlives.org.uk/gsf.php5?f=313998

Making reasonable adjustments to epilepsy services for people with learning disabilities. November 2014. Learning Disabilities Public Health Observatory. www.improvinghealthandlives.org.uk/gsf.php5?f=313318

Making reasonable adjustments to end of life care for people with learning disabilities. July 2014. Learning Disabilities Public Health Observatory. www.improvinghealthandlives.org.uk/gsf.php5?f=312967

Making reasonable adjustments to primary care services – supporting the implementation of annual health checks for people with learning disabilities. April 2014. Learning Disabilities Public Health Observatory. www.improvinghealthandlives.org.uk/gsf.php5?f=312703

Making Reasonable Adjustments to Dementia Services for People with Learning Disabilities. September 2013. Learning Disabilities Public Health Observatory. www.improvinghealthandlives.org.uk/gsf.php5?f=17985

Making Reasonable Adjustments to Diabetes services for People with Learning Disabilities. March 2013. Learning Disabilities Public Health Observatory. www.improvinghealthandlives.org.uk/gsf.php5?f=16981

Making Reasonable Adjustments to Eye Care Services for People with Learning Disabilities. January 2013. Learning Disabilities Public Health Observatory. www.improvinghealthandlives.org.uk/gsf.php5?f=16591

Making Reasonable Adjustments to Dentistry Services for People with Learning Disabilities. October 2012. Learning Disabilities Public Health Observatory. www.improvinghealthandlives.org.uk/gsf.php5?f=16083

Making reasonable adjustments to cancer screening. August 2012. Learning Disabilities Public Health Observatory. www.improvinghealthandlives.org.uk/gsf.php5?f=15424