Cheshire and Wirral Partnership
NHS Foundation Trust

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Good Practice Guidance for the Management of People with Dysphagia in LD Services

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Type of document	Guidance
Target audience	Staff working with people with learning disabilities
Document purpose	This guidance 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.

Approving meeting	LD, NDD & ABI Care Group	Date 24-Aug-12
Implementation date	27-Aug-20	

CWP documents to be read in conjunction with	
HR6	Mandatory Employee Learning (MEL) policy
MH	Mental Health Law Policy Suite

Document change history	
What is different?	references updated information in introduction, definition and risk updated
Appendices / electronic forms	
What is the impact of change?	This document reflects what we do currently and outlines best practice

Training requirements	No - Training requirements for this policy are in accordance with the CWP Training Needs Analysis (TNA) with Education CWP.

Document consultation	
Clinical Services	The CWP LD SLT team
Corporate services	
External agencies	

Financial resource implications	None

External references

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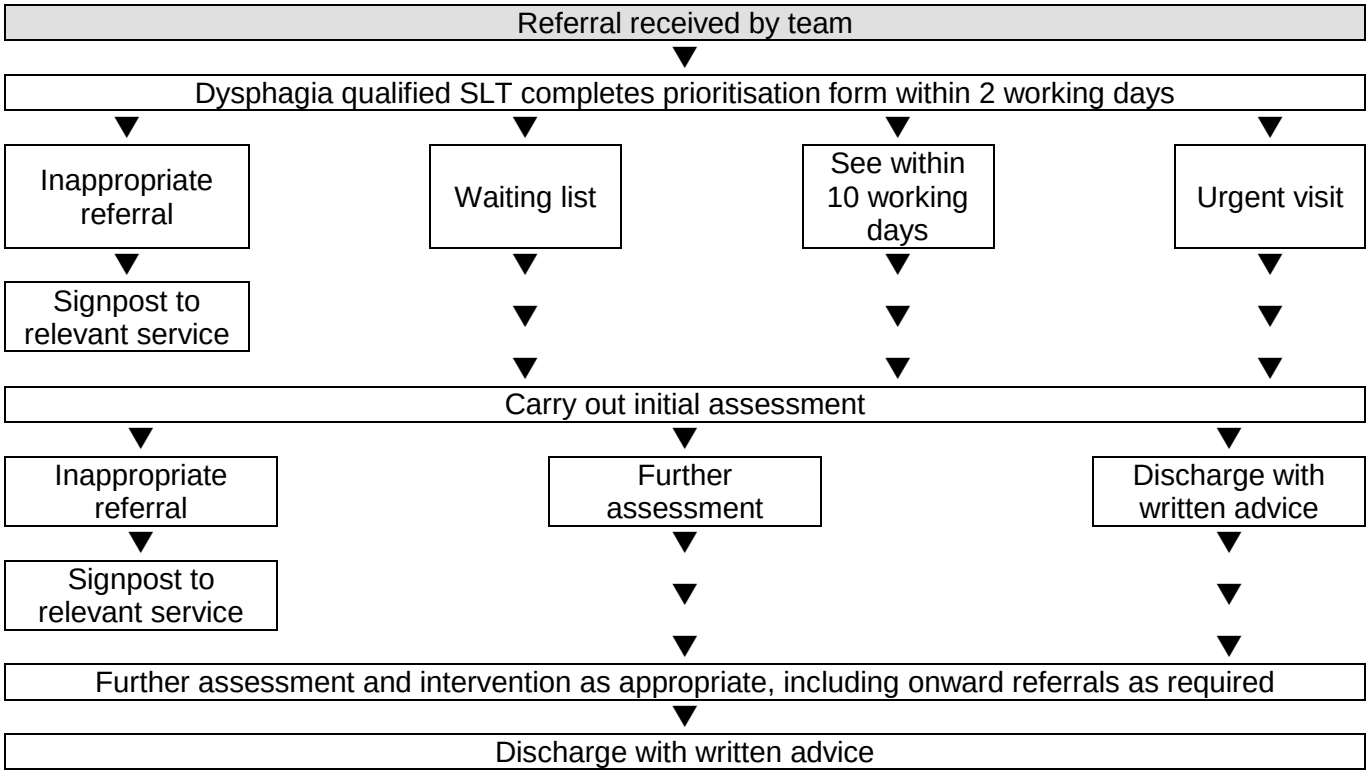
Equality Impact Assessment (EIA) - Initial assessment	Yes/No	Comments
Does this document affect one group less or more favourably than another on the basis of:		
- Race	No	
- Ethnic origins (including gypsies and travellers)	No	
- Nationality	No	
- Gender	No	
- Culture	No	
- Religion or belief	No	

Equality Impact Assessment (EIA) - Initial assessment	Yes/No	Comments
- Sexual orientation including lesbian, gay and bisexual people	No	
- Age	No	
- Disability - learning disabilities, physical disability, sensory impairment and mental health problems	No	
Is there any evidence that some groups are affected differently?	No	
If you have identified potential discrimination, are there any exceptions valid, legal and/or justifiable?		
N/A		
Is the impact of the document likely to be negative? - If so can the impact be avoided? - What alternatives are there to achieving the document without the impact? - Can we reduce the impact by taking different action?	No N/A N/A N/A	
Where an adverse or negative impact on equality group(s) has been identified during the initial screening process a full EIA assessment should be conducted. If you have identified a potential discriminatory impact of this procedural document, please refer it to the human resource department together with any suggestions as to the action required to avoid / reduce this impact. For advice in respect of answering the above questions, please contact the human resource department.		
Was a full impact assessment required?	No	
What is the level of impact?	Low	

Contents

Quick reference flowchart – Dysphagia pathway

For quick reference the guide below is a summary of actions required.



1. Introduction

This guidance describes the management of risk to adults with Learning Disability who have been identified with actual or potential dysphagia. It aims to ensure that adults with learning disabilities who have dysphagia or who are suspected of having dysphagia receive the highest possible level of assessment, care and support to minimise risk whilst to maintain quality of life

The guidance is needed to provide clear direction to all clinical and non-clinical staff and managers operating within Learning Disability Services.

It is recognised that the assessment and treatment of dysphagia benefits from a multi-disciplinary approach to ensure that all aspects of client care are identified and addressed. This could include the following people: GPs nurses, physiotherapists, social workers, dieticians, families, carers, etc.

2. Definition

The term dysphagia is used here to describe “eating, drinking and swallowing disorders” which are characterised by difficulty in oral preparation for the swallow or in moving a bolus from the mouth to the stomach. Dysphagia may therefore include difficulties in positioning the food in the mouth, difficulties with chewing, sucking or swallowing (RSCLT, 2006).

“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.”
(NPSA, 2007)

3. Risk

Eating, drinking and swallowing difficulties have potentially life-threatening consequences. They can result in choking, pneumonia, chest infections, dehydration, malnutrition and weight loss. They can also make taking medication more difficult. Swallowing difficulties can result in avoidable hospital admissions and in some cases death. They can also lead to a poorer quality of life for the individual and their family. This may be due to embarrassment and lack of enjoyment of food, which can have profound social consequences. (RCSLT, 2019)

People with Learning Disabilities experience a higher incidence of health problems than the general population (NICE 2018) and dysphagia is an important area of risk for people with Learning Disabilities, with increased likelihood of dysphagia occurring with increasing severity of cognitive

impairment (Robertson et al, 2017,Chadwick and Joliffe, 2009). The management of dysphagia is therefore an important public health intervention for people with learning disabilities (Glover, 2010). Swallowing difficulties have been found to be more common in people with Learning Disabilities and are often under recognised (Robertson at al 2017.) Silent aspiration, in particular, is common among people with Learning Disabilities and may go unnoticed (Chadwick et al, 2017, Robertson et al, 2017). If not managed safely, swallowing difficulties can lead to aspiration pneumonia, which is a leading cause of death for people with Learning Disabilities (NICE, 2018, Heslop et al 2014).

Hollins' 1998 study suggests that respiratory disease was the leading cause of death in 52% of adults with Learning Disabilities compared to 15% of males and 17% of females in the general population. People with a diagnosis of Learning Disability are known to be at higher risk of choking than other people but again this is something which is under –recognised (Chadwick et al, 2017, Robertson et al, 2017).

A thematic analysis of choking incident report narratives in England and Wales (Guthrie et al., 2015) identified the following factors influencing the risks of choking:

- Time of day (40% of local incidents were at the evening meal);
- Food types;
- Medication (including antipsychotic side effects);
- Behaviours (e.g. cramming or rushing food);
- Familiarity of staff.

In addition, the issue of dysphagia in people with intellectual disabilities may be complicated by medical co-morbidities, psychiatric, communicative, cognitive and behavioural issues. For example, there is a link between the side-effects of neuroleptic medications and dysphagia and people with intellectual disabilities are more likely than others to be prescribed these (Cicala et al, 2019, Dzievas et al 2007).

In summary adults with learning disabilities who have dysphagia who are not appropriately assessed and managed are at high risk of the following:

- Aspiration;
- Dehydration;
- Choking, including death from choking;
- Poor nutrition and weight loss;
- Poor health;
- Anxiety and distress within the family;
- Hospital admissions or extended hospital stay;
- Reduced quality of life;
- Poor oral health.

Aspiration is known to cause or contribute to:

- An increased risk of respiratory tract infections;
- Chest infections and aspiration pneumonia;
- Long term lung damage;
- Other lung conditions.

4. Consent

Consent will always be considered and assessed as described in the Mental Capacity Act (2005) and in accordance with Trust guidance.

5. Duty of care

All people referred to the community teams who are at risk of dysphagia will be identified, screened and then signposted or prioritised according to need and risk.

Where a risk of dysphagia has been identified or is suspected a dysphagia assessment will be completed.

Treatment/ interventions will be delivered in a person centred context, in ways that support equality and value diversity. Intervention strategies will be tailored to meet the individual's needs, taking into account, for example, their culture and ethnicity, religion, gender, age and disability.

The person will be involved in the assessment of their dysphagia and involved in the development of a management plan for the safe management of their dysphagia or best interest decisions will be applied. Where appropriate any plans will be written collaboratively with the individual, other relevant disciplines, carers and relatives.

Further assessment and intervention will be carried out as required.

The person will be discharged appropriately once assessment and intervention has been completed.

Please see dysphagia pathway in appendix 1 and dysphagia benchmarks in appendix 2 for more detail.

6. Training and education

Training is an important part of minimising the risk related to dysphagia. Speech and Language Therapists recommend training for all staff working with people at risk of dysphagia and will provide this as appropriate.

Team Managers will ensure that staff within their areas are aware of dysphagia and how to access training at a level appropriate to them.

Speech and Language Therapists working with people with dysphagia need to keep up to date with national policy developments, clinical practice, new approaches, etc. This will be implemented via the Trust's appraisal and personal development plans.

Appendix 1 - Dysphagia benchmarks

All people referred at risk of dysphagia are screened and prioritised:

- The SLT is made aware of the dysphagia referral as soon as possible after they are received by the team;
- The dysphagia screening and prioritisation form is completed by a dysphagia trained SLT within two working days of them receiving the referral;
- Appropriate visits are arranged depending on the outcome of the screening and prioritisation; this may also include no further action or signposting if the referral is assessed as inappropriate;
- The screening tool will be reviewed every three years at Trust wide SLT meetings.

An initial assessment is completed:

- There is evidence that a case history has been taken;
- Questions have been asked about the person's oral hygiene;
- Where appropriate the assessment process is discussed with the person with learning disabilities and their carers (see benchmark for consent);
- The person has been observed eating and drinking;
- Where appropriate there is evidence that the risk and outcome document has been completed;
- Interim guidelines have been completed and left as appropriate, or advice given;
- Monitoring forms are left as appropriate;
- Modifications to consistency and texture of food and drink are made if required;
- Actions for future interventions have identified.

The person with learning disabilities has been involved in the assessment of their dysphagia and involved in the development of a plan for the safe management of their dysphagia or best interest has been applied (using the Mental Capacity Act 2005 and Trust guidance)

- The individual is assessed as to their capacity to give consent; the outcome of this is recorded in their clinical notes;
- Where a person has capacity, reasonable adjustments will be made where necessary for example providing information in a format accessible to the person about their assessment, treatment and any advice given;
- Practioners will adhere to CWP guidance regarding the Mental Capacity Act.

The person with learning disabilities has had the appropriate further assessment and intervention.

- As appropriate the following has been considered / actioned:
  - The person has been observed in a range of settings and at different times;
  - Laryngeal palpation;
  - Cervical auscultation;
  - Pulse oximetry;
  - FEES;
  - Videofluoroscopy.

- Where appropriate a request for medical information letter will be sent to the person's GP, or evidence of contact being made with the GP for medical information;
- Liaise with other professionals as appropriate and make onward referrals if necessary;

- Evidence of multi-disciplinary/ multi-agency liaison and involvement where appropriate, including attendance at best interest meetings;
- Trial different consistencies and/or equipment and observe whether this was a success or not;
- Ensure that there is an alert created on Care Notes saying “this client has dysphagia”;
- Relevant CWP documentation completed within timescales;
- Evidence that information is accessible to the individual where appropriate;
- Evidence that, where appropriate, training has been offered to carers.

The person with learning disabilities is discharged appropriately once assessment and interventions are complete.

- Guidelines are provided for the carers and where appropriate these will be made accessible, these will include recommendations regarding:
  - Allergies;
  - Safe swallowing of medication;
  - Equipment;
  - Environment;
  - Positioning;
  - Consistencies;
  - Support and feeding techniques;
  - Communication;
  - Reasons for re-referral.

- Discharge report sent to GP including information about:
  - Referral details;
  - Background information;
  - Summary of assessments;
  - Copy of guidelines;
  - Risks and how they have been reduced;
  - Reason for discharge;
  - Advice about re-referral.

- All relevant CWP documentation has been completed.