DYSPHAGIA POLICY FOR ADULT LEARNING DISABILITY SERVICES
QUICK REFERENCE GUIDE

Use this policy to find out about Community Dysphagia Services for Adults with Learning Disability.

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**Why we need this Policy**

This policy describes the management of risk to adults with Learning Disability who have been identified with actual or potential dysphagia.

The policy is needed to provide clear guidance to clinicians, professionals and managers operating within Adult Learning Disability Services. This includes the Community Teams for People with Learning Disability (CTPLDs), the Intensive Support Service (ISS) and the Short Term Care service. It is also relevant to other NHFT staff who are concerned that an adult with Learning Disability may be experiencing dysphagia.

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)

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 admission 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)
What the Policy is trying to do

The aim of the policy is to ensure safe and effective management for people with Learning Disabilities with actual or suspected dysphagia.

Staff will be aware of the need to identify service users who may potentially have dysphagia and to refer to professionals with the relevant skills and training in the diagnosis, assessment and management of dysphagia (NICE guidance, 2006).

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 et 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 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.

(Guthrie et al., 2015)

In the most extreme cases of choking, a piece of food (or non-food item) can obstruct the airway and lead to death. (Hampshire County Council, 2012)
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 at al 2007).

A review of National Reporting and Learning System (NRLS) incidents over a recent two-year period identified seven reports where patients appear to have come to significant harm because of confusion about the meaning of the term ‘soft diet’. These incidents included choking requiring an emergency team response, and aspiration pneumonia. (Patient safety alert June 2018)

As a consequence of this, the International Dysphagia Diet Standardisation Initiative (IDDSI) has been launched (April 2019) to use a standard terminology with a colour and numerical index to describe texture modification for food and drink. IDDSI terminology is now reflected in patient management and referenced by speech and language therapists within Northamptonshire Healthcare Foundation Trust (NHFT) Learning Disabilities Service in reports, care plans and clinical record keeping.

**Which stakeholders have been involved in the creation of this Policy**

Speech and Language Therapists involved in dysphagia management within Learning Disability Services

Learning Disability managers

Willows short term break service

**Any required definitions/explanations**

**Dysphagia** – difficulty with the eating, drinking and swallowing process characterised by difficulty in oral preparation for the swallow or in moving a bolus from the mouth to the stomach.

**Learning Disability (LD)** - The government white paper “Valuing People” defines Learning Disability as a significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence – IQ less than 70) coupled with a reduced ability to cope independently (impaired social functioning) which started before adulthood, with a lasting effect on development

**SALT** - Speech and Language Therapist

**NHFT** - Northamptonshire Healthcare NHS Foundation Trust
CTPLD – Community Team for People with Learning Disability

ISS – Intensive Support Service

**Key duties**

Team managers of CTPLDs, ISS and Short Term Care Services – ensuring their staff are aware of dysphagia and can access training as required.

Dysphagia Lead for Adult Learning Disability – review and update of policy.

Speech and Language Therapists within Learning Disability Services – to provide dysphagia assessments, advice and management; to provide training on signs of dysphagia, referral processes and management as and when required; to provide person centred training around individuals who are referred with dysphagia.

Staff members within CTPLDs, ISS and Short Term Care units – to be aware of the signs and symptoms, the referral process and management of dysphagia; to attend training as necessary; to implement dysphagia care plans.

**Policy detail**

**Referral**

The Speech and Language Therapy Service within the CTPLDs provides dysphagia assessments for adults with Learning Disability in community settings. Dysphagia assessment and management in acute hospitals is provided by the Adult Speech and Language Therapy Service.

Dysphagia services for adults *without* Learning Disability are provided by the Adult Speech and Language Therapy Service. Dysphagia services for children (under 18) are provided by the paediatric Speech and Language Therapy Service. Learning Disability and paediatric services will work jointly where a young adult with Learning Disability is transitioning between child and adult services (aged 16-18).

Access to dysphagia assessment for adults with Learning Disability in the community is via the local CTPLD. To meet the CTPLD referral criteria the person must have a Learning Disability plus a health need which requires specialist intervention.

For individuals not already open to the CTPLD, a CTPLD referral form should be completed. Once received by the team secretaries this will be passed to a member of the Speech and Language Therapy (SALT) team.

If the individual is already open to the CTPLD, a qualified member of staff will complete a task referral to Speech and Language Therapy via SystmOne.
Please see the LD Dysphagia Care Pathway flow chart in Appendix 1 for further details and timescales.

If the referral is not appropriate to the LD SALT Service due to age or lack of learning disability the referral will be passed to the paediatric or adult services. The referrer and referred individual will be informed of this in writing.

**Assessment**

On receipt of referral the Speech and Language Therapy team member will complete a telephone screening assessment to ascertain the level of risk and priority. Full assessment will then be carried out as necessary.

Please see the LD Dysphagia Care Pathway flow chart in Appendix 1 for further details and timescales.

**Management**

Following assessment, a detailed care plan will be written collaboratively with the individual, other relevant disciplines, carers and relatives.

Consent will be sought from the service user before any intervention is implemented or best interests applied (please refer to the Trust Consent Policy for guidance).

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.

Staff in short term care facilities are responsible for ensuring care plans are adhered to and regularly reviewed. If there are any problems or changes with the service user, the Speech and Language Therapist or other relevant professional should be contacted to discuss a change to the care plan.

Please see LD Dysphagia Care Pathway flow chart in Appendix 1 for further details.

**Training requirements associated with this Policy**

**Mandatory Training**

There is no mandatory training associated with this policy.

**Specific Training not covered by Mandatory Training**

Ad hoc training sessions based on an individual's training needs as defined within their annual appraisal or job description.
How this Policy will be monitored for compliance and effectiveness

The table below outlines the Trust’s monitoring arrangements for this document. The Trust reserves the right to commission additional work or change the monitoring arrangements to meet organisational needs.

<table>
<thead>
<tr>
<th>Aspect of compliance or effectiveness being monitored</th>
<th>Method of monitoring</th>
<th>Individual responsible for the monitoring</th>
<th>Monitoring frequency</th>
<th>Group or committee who receive the findings or report</th>
<th>Group or committee or individual responsible for completing any actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duties</td>
<td>To be addressed by the monitoring activities below.</td>
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<tr>
<td>Referral process and timescale</td>
<td>Audit of 8 cases – 4 from each CTPLD selected at random</td>
<td>SALT Dysphagia Lead for LD</td>
<td>Annually</td>
<td>LDSM (Learning Disability Service Meeting – includes clinical leads, operational managers and heads of LD service)</td>
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<tr>
<td>Completion of telephone screen</td>
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<td>Waiting times</td>
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<tr>
<td>Care plans</td>
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Where a lack of compliance is found, the identified group, committee or individual will identify required actions, allocate responsible leads, target completion dates and ensure an assurance report is represented showing how any gaps have been addressed.

For further information

Please contact the Learning disabilities speech and language service

Equality considerations

The Trust has a duty under the Equality Act and the Public Sector Equality Duty to assess the impact of Policy changes for different groups within the community. In particular, the Trust is required to assess the impact (both positive and negative) for a number of ‘protected characteristics’ including:

- Age;
- Disability;
- Gender reassignment;
- Marriage and civil partnership;
- Race;
- Religion or belief;
- Sexual orientation;
- Sex;
- Pregnancy and maternity; and
- Other excluded groups and/or those with multiple and social deprivation (for example carers, transient communities, ex-offenders, asylum seekers, sex-workers and homeless people).

The author has considered the impact on these groups of the adoption of this Policy as follows:

| **Age** | Eating, drinking and swallowing difficulties can occur at any age and can affect people with learning disability throughout their lifespan. This policy covers services for people aged 18 and over and for those undergoing transition from child to adult services. The service does not exclude people on the basis of their age apart from where there are other specialist services more appropriate to their needs (i.e. paediatric SALT service). |
| **Disability** | The policy is likely to have a positive impact on people with Learning Disability as our service provides a specialist service for people with LD and we work closely with other disciplines to provide an integrated, holistic approach. People with physical or sensory disabilities are not excluded from our services. Eating and drinking needs are considered within a social model of disability. |
| **Gender (male, female and transsexual, incl. Pregnancy and maternity)** | This policy is unlikely to negatively impact on these groups. People who are male, female, transsexual, pregnant or new mothers would not be excluded from the service or treated adversely. |
| **Gender reassignment** | This policy is unlikely to negatively impact on this group. People who are undergoing/ have undergone gender reassignment would not be excluded from our service or treated adversely. |
| **Sexual Orientation (incl. Marriage & civil partnerships)** | People would not be excluded from the service or treated adversely on grounds of sexual orientation or type of relationship they are in. |
| **Race** | The policy is unlikely to negatively impact on people of a particular race or ethnicity. People would not be excluded from the service or treated adversely for reasons of race or ethnicity. Staff are mindful of different beliefs for example around health and disability, food and drink preferences and linguistic differences. |
| **Religion or Belief (including non-belief)** | This policy is unlikely to negatively impact on someone because of their religion or beliefs. A person would not be excluded from the service due to their religion or beliefs. Staff are mindful of different beliefs for example around health and disability, food and drink preferences. |
Throughout the production of this policy due regard has been given to the elimination of unlawful discrimination, harassment and victimisation (as cited in the Equality Act 2010).

Speech and language therapy service delivery is committed to the promotion of independence, choice, inclusion and civil rights. Speech and language therapy service delivery considers communication and eating and drinking needs in the context of a social model of disability (Baker et al, 2010).

The social model of disability “sees disability as created by social barriers rather than individual impairment” (Walmsley, 2001) p195.

(a) Line Managers should ensure that staff returning from maternity or paternity leave are given time to update themselves on any changes made to the policy.
(b) Equality Considerations - Should the reader of this policy or any other group believe they are disadvantaged by anything contained in this policy, please contact the Equality & Inclusion Manager, who will then actively respond to the enquiry.

Reference Guide


Cicala et al. (2019) A comprehensive review of swallowing difficulties and dysphagia associated with antipsychotics in adults. Expert review of clinical pharmacology; Mar 2019; vol. 12 (no. 3); p. 219-234


Hampshire County Council Adult Services Department (2012) Reducing the risk of choking for people with a learning disability. *A multi-agency review in Hampshire*


NICE guidelines, (2018) Care and support of people growing older with learning disabilities


NPSA, (2007), Problems Swallowing? *Resources for Healthcare Staff*


**Document control details**

<table>
<thead>
<tr>
<th>Version No.</th>
<th>Date Ratified/Amended</th>
<th>Date of Implementation</th>
<th>Next Review Date</th>
<th>Reason for Change (e.g. full rewrite, amendment to reflect new legislation, updated flowchart, minor amendments, etc.)</th>
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<tr>
<td>V2.1</td>
<td>08/02/2015</td>
<td>09/02/2015</td>
<td>08/12/2018</td>
<td>Minor amendments to flow chart to reflect new S1 processes and updated with current references</td>
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<tr>
<td>V3</td>
<td>13/08/2019</td>
<td>14/08/2019</td>
<td>13/08/2020</td>
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<tr>
<td>V3.1</td>
<td>30/03/20</td>
<td>31/03/20</td>
<td>31/12/2020</td>
<td>Decision made by the Chief Nurse and Chief Executive to extend review date to December 2020 due to Covoid-19.</td>
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</tbody>
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APPENDIX 1 - LD DYSPHAGIA CARE PATHWAY

Referral received by CTPLD team secretaries re: dysphagia

Secretary aims to pass to SaLT within one working day

SaLT will try to establish appropriateness to CTPLD e.g. LD, age. (Refer to transition pathway as appropriate)

Not appropriate – refer to paediatric or adult services if no LD

Appropriate – SaLT will aim to make screening telephone call within two working days. Use SystmOne telephone screen template. Document advice given in contact notes.

Emergency
Advisory to go to hospital

Priority
Will be seen by SaLT within 10 working days

Low Priority
Will be seen within 12 weeks (60 working days)

SaLT Initial Eating and Drinking Assessment
- Discussion with the person/carer about the nature/frequency of the difficulty
- Case history including current medical status – chest infections/UTI
- Initial observations
- Complete paperwork – assessment care plan, 3CC and eating and drinking assessment form
- Update risk assessment if appropriate and complete goal outcome form

Diagnostic Assessment
- Observations
- Instrumental assessment – CA/pulse oximeter
- Request a medical history from the GP
- SaLT will repeat assessment at different meals or in different settings, as appropriate
- May include onward referral to videofluoroscopy, OT, Physio or Dietician
- Interim eating and drinking guidelines will be issued
- Update Risk Assessment and complete goal outcome form, if appropriate

No intervention needed –
- Report to referrer and discharge
- Report to be written with 4 weeks of last contact
- Update Risk Assessment
- 3CC
- IWGC form
- Goal outcome form on S1

Plan of Care
Aim – person to eat and drink safely and pleasurably
Interim eating and drinking guidelines will be issued
Formal report and guidelines/Care Plan will be produced within 4 weeks of last assessment contact. Report may include:
- Advice on food and drink consistencies
- Positioning
- Pacing
- Communication
- Environment
- Therapeutic exercises programme
- Desensitisation programme
- Training of carers and report to referrer and GP, e.g. request for thickener

Update Systm One Risk Assessment and goal outcome form

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