

Appendix 2

Sunderland and Newcastle Speech and Language Therapy Services

The Management of Dysphagia in Adults
With Learning Disabilities

The Management of Dysphagia of in Adults with Learning Disabilities (LD)

1. INTRODUCTION:

- 1.1 The Sunderland and Newcastle Dysphagia Teams provide an inpatient and outpatient service to adults with learning disabilities with dysphagia (developmental, and/or acquired or progressive).
- 1.2 The term **dysphagia** is used to describe swallowing difficulties characterised by difficulty in oral preparation, oral, pharyngeal and oesophageal phases of the swallow, that is, the transportation of a bolus from the mouth to the stomach. Subsumed in this definition are developmental, neurological, psychological and structural conditions.
- 1.3 Adults with learning disabilities and dysphagia who are admitted to an acute hospital will normally primarily be seen by the Speech and Language Therapy team based at the hospital. However, liaison and support will be facilitated between the hospital and community teams.

2. TEAM MEMBERS

- 2.1 The Sunderland team comprises of four Speech and Language Therapists and two nurses, who have all completed recognised post qualification dysphagia courses (Langmore 1999).
- 2.2 The Newcastle team comprises of five Speech and Language Therapists who have all completed recognised post qualification dysphagia courses (Langmore 1999).
- 2.3 For the purpose of this document, all team members will be referred to as 'Dysphagia Qualified Practitioners'.

3. THE AIMS OF A DYSPHAGIA SERVICE ARE:

- To provide a comprehensive, evidence based and responsive service to Adults with Learning Disabilities presenting with swallowing disorders, including taking a central role in the promotion of health and well-being
- To assess, diagnose, request and interpret diagnostic tests, to refer to other agencies as appropriate, provide a management plan and to discharge
- To be a first point of contact for patient care, including single assessment (where indicated.)
- To facilitate intervention by the multi disciplinary team extending and improving collaboration with other professions and services

- To take an active role in strategic planning and policy development for services to service users presenting with swallowing and communication disorders
- To provide training and education for Speech and Language Therapists, professionals and carers involved in the care of service users with dysphagia
- To develop and apply the best available research evidence and evaluative thinking in all areas of practice

4. REFERRALS

4.1 New referrals:

- An open referral system is available for service users with dysphagia
- All referrals are made through the Single Point of Access system between 9am and 5pm, Monday to Friday
- It is the responsibility of the referrer to ensure consent is given for the referral
- If the service user is unable to consent, a multi-disciplinary discussion should occur to assess the client in their best interests
- 4.2 It is good practice to inform / involve other members of a multi-professional team at the point of referral:
 - To discuss with the other professionals the current issues that may relate to dysphagia assessment and management
 - To facilitate appropriate multi-disciplinary involvement to consider the multifaceted nature of complex swallowing disorders
 - To seek relevant current medical information
 - To facilitate any action of a medical nature and shared responsibility for risk management when drawing up management plans

4.3 Prioritisation

4.3.1 All referrals are passed to an allocated Dysphagia Qualified Practitioner who then contacts the referrer/carer for more information about the referral. This may include administering the 'Dysphagia Referral Checklist over the telephone. This initial contact happens within 2 working days of receipt of the referral.

- 4.3.2. The Dysphagia Qualified Practitioner makes a clinical decision on the urgency of the referral. If the referral is deemed to be 'urgent', provision is made for an initial assessment within 5 working days of referral. The referrer is also advised at this point to access primary healthcare services should they require more immediate support.
- 4.3.3 Routine/non urgent referrals are seen within 10 working days of referral, within service resources.
- 4.3.4 There is no service at weekends or on Bank Holidays.

4.5 Locations

- The service may be carried out in different locations and settings e.g.
 - Community Settings
 - o Home
 - Nursing Homes
 - Social Services Premises
 - LD Inpatient Services

5. ASSESSMENT

5.1 General:

- (a) Some service users may receive a uni-disciplinary Dysphagia Team assessment. However, in cases where more complex interacting factors are involved, an essential part of the assessment process is close liaison with the relevant multi-disciplinary team in order to gain the necessary information regarding the service user and presenting disorder.
- (b) Effective assessment, treatment and management of service users with dysphagia requires expertise from a number of different professions. Dysphagia Qualified Practitioners working with dysphagic service users should function as part of a multi-disciplinary team and this should include service users / carers/ parents.
- (c) Dysphagia Qualified Practitioners should have a clear understanding of the roles of other professions involved and should respect skill boundaries whilst having shared working practices and tools.
- **(d)** Dysphagia Qualified Practitioners will examine the nature of the client's difficulty using a variety of methods.

- Case history including:
 - the service users / carer's view of the problem/s
 - medical background including diagnosis/aetiology
 - neurology
 - weight history
 - medication and possible implications
 - nutritional intake: current method / quantity
 - previous interventions and outcomes
 - respiratory history
 - gastroenterology history
- Examination: for example;-
 - Through observation and discussion of the usual situation surrounding eating drinking or feeding (including physical, behavioural, sensory, environmental, interactions, cognitive and communication)
 - Through observation of simultaneous indicators, for example, response to feeding situation, state, respiration, oral motor skills, reflexes, swallowing coordination, stress signs, indicators of gastroesophageal reflux.
 - Of the oromotor structure and function / laryngeal function
 - Examination may include the use of cervical auscultation, pulse oximetry, FEES (see below)
- (e) The Dysphagia Qualified Practitioner will identify the need for involvement of other professionals as appropriate and will refer on to these agencies.

- (f) The Dysphagia Qualified Practitioner will provide justified recommendations and refer for further investigations of dysphagia, for example:-
 - Videofluoroscopic swallow study (VFSS) under a Radiology Group Direction (RGD), or,
 - fibreoptic endoscopic evaluation of swallowing (FEES) as part of the assessment process
 - The planning of intervention may be limited without such investigations. Dysphagia Qualified Practitioners should not undertake a programme of intervention where there is insufficient information about the underlying swallowing disorder. Liaison with medical staff will take place
- (g) The Dysphagia Qualified Practitioner's assessment of a client with dysphagia must be fully documented in the case notes. A report will be sent to the referrer and GP responsible for the care of the service user.
- (h) Results of investigations, assessment findings and planned management should be discussed fully with the service user and carer and with the multidisciplinary team (MDT) as appropriate.

5.2 **Diagnosis**

- (a) The Dysphagia Qualified Practitioner will analyse the assessment findings within a problem-solving model in order to make a diagnosis of the service users eating and swallowing difficulty.
- **(b)** This should be considered within a 'holistic view' in order consider the prognosis and to predict likely outcomes.
 - Diagnosis may indicate:
 - Level of breakdown in swallowing process and nature and severity of dysfunction
 - Prediction of aspiration/qualification of aspiration
 - Psychological aetiology
 - Nature and consequences of deterioration in function, for example, due to progressive condition or secondary disability
 - Indicators of other potential problems/ diagnostic indicators (early identification)
 - Ability to achieve desired nutritional status

6. INTERVENTION

6.1 Action Planning: Treatment and Intervention

- (a) The assessment results, diagnosis, prognosis and action plan should be discussed with the team and used as a basis for treatment planning in conjunction with other team members' findings. For example, other medical issues such as gastroesophageal reflux and nutritional status should be considered together with swallowing dysfunction in order to identify the relative risks and facilitate the development of a treatment plan.
- (b) All forms of intervention will be fully discussed with the client, carer and team at the outset and a written care plan formulated. Some options will need a carefully planned approach as some information is of a highly sensitive and emotive nature.
- (c) Where disagreement exists between the service user or carer and the team, every effort should be made to resolve it through discussion (Communicating Quality 3, 2006). It is important to have full understanding and co-operation for management to be carried out effectively.
- (d) The Dysphagia Qualified Practitioner should explain and demonstrate treatment and or management methods to the service user /carer and assess their learning in relation to these methods. Written instructions relating to feeding programmes and other related interventions should be given to the service user / carer /family where appropriate.
- (e) The Dysphagia Qualified Practitioner may delegate therapy tasks to other team members, the service user or carer. These may include feeding and supervision of oral intake. Training will be given to ensure that tasks are carried out appropriately.
- (g) The Dysphagia Qualified Practitioners will review the programme goals in conjunction with the multidisciplinary team as appropriate;
 - to ensure progress has been maintained or achieved
 - to evaluate readiness for intervention or to change intervention
 - to evaluate any change in status
- (h) The frequency of review should be considered carefully. Service users presenting with degenerative disorders may need regular review over many months (Communicating Quality 3, 2006)

- (i) The intervention programme will:
 - be sensitive to the changing and individual needs and skills of the service user / family / carers, including socially and emotionally and with respect to cultural and religious beliefs
 - take into account the desires of the service user where these can be ascertained
 - take place with regard to consent to treatment
 - ensure that the service user, family and/or carers are actively involved in any treatment plan
- (j) Management of dysphagia may involve
 - Advice on the potential risk of aspiration and the safety of oral feeding, taking into account the limitations of the assessment process. Advice will usually include approaches to minimise risk: the potential for compensatory and / or alternative feeding methods where the risk is significant
 - Indirect or compensatory techniques including changing texture, compensatory postures to facilitate a safe swallow, changing feeding procedures, thickening fluids, sensory considerations such as taste, prosthetic devices, feeding aids, utensils and environmental considerations
 - Training carers in dysphagia management techniques (Hickman & Jenner, 1997)
 - Direct therapy techniques which include specific exercises, for example, Oral Facial Tract Therapy (OFTT), thermo-tactile stimulation, biofeedback, placement and timing of the bolus
 - Risk management may specify non-oral feeding as an option and discussion with the service user/family/carers where appropriate
 - Appropriate ways to take medications
- (k) All intervention should be clearly and precisely recorded and dated on RIO. Updates on outcomes of intervention should be provided to referrers and for service users on a regular basis.

- (I) At any stage during intervention onward referral may be made with service user agreement to, for example:
 - Gastroentrology
 - Radiology
 - Videofluoroscopy Clinic
 - Neurology
 - Clinical Psychology
 - ENT
 - Dietetics
 - Respiratory Medicine
 - Physiotherapy
 - Other agencies as appropriate

7. DISCHARGE

- (a) The Dysphagia Qualified Practitioner should make the decision to discharge including the reason for discharge. All decision-making in this area should involve the service users, carers and the team as appropriate in making the decision to discharge from the caseload.
- **(b)** A written discharge summary will be provided to appropriate personnel including GP. A written report sent to the referrer with a copy to the GP (for community service users).
- (c) The procedure for re-referral to the Dysphagia Team should be made clear.