DYSPHAGIA – PROMOTING THE TEAM APPROACH

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INTRODUCTION

Dysphagia affects 55% of people with stroke and 45% of children with cerebral palsy. It is common in many types of complex longterm disability, affecting quality of life and at times life itself. The benefits of adopting a team approach in the management of dysphagia are well recognised in the literature. In this article we describe work being undertaken in the Morecambe Bay area in developing a culture where team management of dysphagia is accepted as best practice.

DEFINITION

Dysphagia is the term used to describe a problem with eating and drinking due to swallowing difficulties caused by congenital anomalies such as tracheo-oesophageal fistula (TOF), neurological disorders including cerebral palsy and motor neurone disease (MND) and tumour or other disease. 'It occurs in all age groups from newborns to the elderly and can be of sudden onset for example after a stroke. Equally it may slowly present becoming more severe over time in the case of progressive disease or tumour.'⁽¹⁾ Often, as the original cause for dysphagia in childhood, such as gastrointestinal reflux (GOR), improves, the child is then left with secondary behavioural difficulties which interfere with feeding in the long term. These can include food refusal and texture sensitivity.

SIGNS AND SYMPTOMS OF DYSPHAGIA

Typical signs and symptoms include coughing before, during or after meals, recurrent chest infections, weight loss and dehydration and individuals reporting swallowing difficulty (though not everyone with dysphagia is aware of the problem). Dysphagia is of concern to many health professionals working in a wide variety of settings; clients' homes, special schools, acute hospitals and nursing homes. As well as the risk of choking if the swallow is not functioning adequately, and aspiration pneumonia if food and fluids swallowed go down into the lungs, there are concerns about malnutrition if people cannot eat enough to support their nutritional needs.

REFERRAL TO SPEECH AND LANGUAGE THERAPY

Communicating Quality 2 (professional standards manual for speech and language therapists)⁽²⁾ recommends the following:

- all referrals should be supported by a medical practitioner. Referrals can be made by anyone in the team working with dysphagia
- inpatients should be seen within two working days. This is not always achievable in Morecambe Bay with current staffing levels
- outpatients should be seen within two weeks. A waiting list currently operates for community paediatric and adult speech and language therapy services.

A study in a rural area similar to Morecambe Bay⁽³⁾ found that speech and language therapists (SLTs) were unable to meet the response time for inpatients for swallow assessment although the location of the patient is no reflection on the severity of the swallowing deficit. Dysphagia affects the patient's quality of life and general health and in severe cases it may be life-threatening. Safety issues are serious enough when the person is in hospital, but it becomes a major problem when the person is living at home with no emergency services readily accessible. Many staff working in the community regularly come across people at grave risk.

ASSESSMENT

Oral phase On receipt of a referral, the SLT would arrange to see the patient on the ward or at home. Initially a detailed feeding and health history would be taken and a clinical assessment carried out. This provides valuable information on the oral phase of swallowing and mealtime dynamics. Aspiration can occur without any observable clinical indications such as coughing or choking especially in patients with neurological deficits, so clinical assessment alone is inadequate. It is important for the team to understand the variety of tests available and the value of the information they provide.

Pharyngeal phase Objective measures are particularly important in evaluating the pharyngeal phase of swallowing and determining the presence of aspiration. Other assessments which are being considered locally to aid clinical assessment, especially in the community, include:

- cervical auscultation: a stethoscope/microphone is used to amplify sounds made during swallowing and breathing. Special sounds indicate the presence or absence of a swallow and the number of infant sucks prior to a swallow
- portable pulse oximetry: this monitors baseline oxygen levels and subsequent changes in oxygen saturation during the swallowing process.

The most commonly used diagnostic tests that should be readily available as recommended by Evans and Dunn⁽⁴⁾ are:

- **videofluoroscopy/videofluoroscopic swallow study/modified barium swallow** indications: to analyse the swallow mechanism, rule out aspiration and determine the point of aspiration
- **fibreoptic endoscopic evaluation of swallowing (FEES):** indications – to analyse laryngopharyngeal movements and anatomy of respiration even during swallowing. It can be used to identify the presence of aspiration before or after a swallow.

Oesophageal phase

- **barium swallow/upper gastrointestinal oesophagram:** indications – to analyse anatomy and motility of oesophagus, stomach and duodenum
- **pH probe:** indications – to quantify the frequency and duration of gastro-oesophageal reflux.

Gastro-intestinal (GI) endoscopy: indications – to provide a direct view of the upper gastrointestinal tract.

Gastro-oesophageal scintigraphy/technetium scan /milk scan: Indications – to evaluate oesophageal function and provide information on stomach emptying.

The only diagnostic assessment readily available across Morecambe Bay is the barium swallow. This assessment is useful for those patients who may have structural anomalies of the GI tract, but it does have many limitations, especially when compared to videofluoroscopy. A barium swallow should not be routinely used in those patients with a known swallowing difficulty. It is an unsafe procedure as the patient is expected to swallow large amounts of liquid barium whilst in the supine position and there is, therefore, an increased risk of aspiration. There is also a greater risk of exposure to x-ray. The study is short in duration and gastro-oesophageal reflux is likely to be missed.

Videofluoroscopy is considered to be the ‘gold standard’ in the assessment of dysphagia worldwide⁽¹⁾ and is routinely used across most trusts in the UK. Unfortunately this assessment is not readily available within Morecambe Bay. Many vulnerable patients are required to travel miles, if well enough, and to wait several months for this assessment. Videofluoroscopy has previously been offered at Furness General Hospital and its reintroduction is being explored at present.

Fluoroscopy is a radiographic technique that permits dynamic imaging. Movement can be observed in real time as images are transmitted directly to videotape for a permanent record. During the study every attempt is made to duplicate the feeding situation (maintaining usual positioning and utensils and offering different textures). The focus of the procedure is on the oral, pharyngeal and oesophageal aspects of swallowing. Quantities of food and fluid given are much less than those used in the standard barium swallow, making it a safer procedure. In summary, therefore, videofluoroscopy answers some important clinical questions which clinical assessment alone cannot:

- **aspiration** What are the risk factors contributing to this? Does aspiration occur and if so when? Any silent aspiration? Is the swallow normal?
- **treatment options** Are changes in positioning beneficial? Is it useful to control the amount and timing of feeds given? What texture is most easily managed? What is the preferred feeding utensil?
- **swallowing characteristics** What is the timing and oral control in the initiation of the swallow, the duration of the

pharyngeal swallow and the ability to clear the bolus safely? Are there changes in the swallow over time?

It is important to note that videofluoroscopy is only one of a battery of tools available to aid in diagnosis and analysis of dysphagia, alongside clinical experience. There will be patients for whom the procedure is contraindicated because of their ill health, the severity of their physical disabilities or the stresses associated with travel and a novel clinical environment. For some of these people the problems may become apparent enough using other techniques, making videofluoroscopy unnecessary.

INTERVENTION

Intervention in dysphagia involves a combination of nutrition modification and therapeutic strategies to rehabilitate, train or maintain optimal safe swallow ability.

1 Nutrition modification

NUTRITION MODIFICATION		
Recommendation	For most children & adults in rehab	For people with end stage disease
Nil by mouth	Short term nasogastric	Sweet puree food tastes
	Long term PEG Puree food taste trials Swallow monitoring	Alternative hydration may be offered Dry mouth iced water swabs
Mixed intake (combination of oral & enteral nutrition)	Modified texture foods and fluids (see below) Hydration, medication and nutrition: option to have via PEG if the client's health status deteriorates	
Modified texture Full oral intake	Dietary supplements Food texture selected from puree; minced; mashed; soft or normal diet Fluid consistency selected from thick custard; custard; syrup or thin fluids No tube feeds	

2 Therapeutic strategies used by speech and language therapists

Desensitization, where the mouth may be overly sensitive, requires short but frequent periods of gentle touch to reduce excessive reactions (or abnormal reactions such as the bite reflex) to presentation of food or fluids to the oral area. Exercises to practise movements intended to extend the rate, strength and range of movement of the muscles of the lips, tongue and soft palate can be useful. Chewing and swallowing practice is used. Looking at alterations to posture and the positioning of the body and head to facilitate safe swallow is useful.

Supervised guided practice with small safe quantities of the recommended texture of foods and fluids helps to gain control of the chewing and swallowing mechanism, moving through from the safest texture to the more difficult to manage foods and drinks.

PROFESSIONAL, ETHICAL AND MORAL ISSUES

Individual professionals in all work settings face difficult decisions in dysphagia management. Conflicts can arise between our duty of care to offer the safest eating regime and the person's desire to eat a normal diet. In the case of adults,

they are entitled to take risks, while in paediatrics clinicians and parents may disagree about the management of a child's dysphagia. Our duty, in both cases, is to provide all the necessary information for an informed choice. This needs to be formally documented to protect the professionals from litigation if problems arise, and such a situation may need to be handled with great tact to enable relationships to be maintained between clinicians and families.

Equally we may work with a person found to be unsafe for oral intake. Here alternatives to provide adequate nutrition need to be explored. Tube feeding may be unacceptable to client and family, confused clients pull tubes out, nasogastric tubes interfere with swallow rehabilitation. In the case of advanced dementia, recent research indicates that tube feeding may not prevent aspiration or weight loss, or prolong life^(5,7).

As professionals we may find it upsetting and worrying when our advice is not taken. We need strong support systems to help us to deal with such challenges. A dysphagia team provides the range of skills needed to enable shared decision-making, mutual support and objectivity.

THE DYSPHAGIA TEAM

Speech and language therapists, dietitians, nurses and medical officers are all crucially involved in the management of dysphagia, with differing skills and roles to play.

A model showing the interaction between members of the dysphagia team

The speech and language therapist evaluates the individual's oral and facial muscle function including rate and range of movement of lips, tongue and soft palate. They assess the swallow, its effectiveness, rate and coordination and the risk or presence of aspiration. They coordinate the management of the dysphagia, recommending the safest textures of food and fluids, advising on strategies to minimise risk and aid recovery of function, liaising with their colleagues, the client and family, training, rehabilitating or maintaining function and monitoring changes in swallow effectiveness and safety over time. The standard document for speech and language therapists, Communicating Quality⁽²⁾, requires that they 'should function as members of a multidisciplinary team' and that 'close liaison and joint assessment intervention will further understanding and benefit the client'.

The nurse's role is to detect potential swallow risk and refer to speech and language therapy for assessment, to maintain and monitor health status, to ensure adequate nutrition and hydration, to implement and monitor enteral nutrition, to advise and support family members and to participate in all aspects of the team decision-making. In paediatrics the increasingly complex and fragile problems children with disabilities and diseases can face requires highly specialist nursing care, often from infancy. The nurses are an essential support to education staff in the integration process. In adult services other crucial nursing skills are called for as adults with serious longterm or acute medical conditions are managed in the community or in the hospital setting. The nurses advise on the person's health status and their ability to tolerate assessment and therapy.

Medical staff manage the client's health, and advise family and colleagues on disease states, health management, medications and prognoses. They decide alternative means of nutrition if eating is deemed unsafe or inadequate to maintain health. They are central to the management of the whole person, putting the dysphagia in the context of all other aspects of their health status. Specialists such as gastroenterologists may well be consulted when alternative feeding is considered.

Dietitians assess nutritional status and estimate nutritional requirements. They help carers and clients to understand and interpret the recommendations of the speech and language therapist for food texture modification. They produce eating plans and guidelines to maintain optimum nutrition within the constraints of the person's eating difficulties, advising on food enrichment, the use of prescribable nutritional supplements and thickening agents. Where necessary they facilitate achievement of adequate nutrition via artificial (enteral) feeding, usually gastrostomy or a nasogastric tube.

Other disciplines are called in at times for special purposes, such as physiotherapy to assist in optimal positioning for eating, and to assess chest status, and psychology to provide advice regarding adjustment to and cooperation with recommendations, and counselling about the loss of eating ability. Occupational therapy can help with aids and appliances, and assessment of upper limb function to facilitate independence in eating, while carers and family members are essential team members who help generalise skills throughout the day, monitor compliance, mood and motivation and provide ongoing support to the client.

All these people have a role to play in educating carers, colleagues and the public about the difficulties and strategies involved in minimising the problems associated with dysphagia.

THE MULTIDISCIPLINARY DYSPHAGIA SPECIAL INTEREST GROUP

This group was formed in early 2002 to increase understanding of each other's roles, views and priorities and to facilitate access to each other's skills. It is a forum open to clinicians working with adults or in paediatrics from all disciplines involved in dysphagia management. We aim to promote best practice, develop and support local initiatives, solve issues, present cases, contribute to local and national policy and provide a consensus of the local professional view.

The group meets three times a year and has an average attendance of eighteen with a diverse range of professionals

representing adult and paediatric services. Medical staff, nurses, dietitians and speech and language therapists come from settings such as the acute hospitals, special schools, community and domiciliary services.

Initiatives under way

- development of bay-wide dysphagia management protocols
- development of care pathways
- support for the development of the dysphagia nurse specialist role (one staff nurse has undertaken the five-day theory component of the postgraduate dysphagia course offered at Manchester University and is undergoing the supervised experience component supervised by members of the speech and language therapy adult service)
- preparation of pamphlets based on the national descriptors developed by the British Dietetic Association (BDA) and Royal College of Speech and Language therapy (RCSLT)⁽⁶⁾
- establishment of a paediatric dysphagia team.

Other projects under consideration

- a grant application for a research project looking at longterm Percutaneous Endoscopic Gastrostomy (PEG) feeding and monitoring changes in swallow status over time
- development of a fluid viscosity measurement tool to aid the reliability of thickened fluid preparation.

Presentations to date

- enteral feeding equipment, its placement and management
- the evidence base for clinical assessment of swallow and objective evaluations of swallow such as pulse oximetry and videofluoroscopy
- clinical cases which highlighted ethical dilemmas for staff.

There is strong support for this Special Interest Group (SIG) among members and meetings are proving stimulating and relevant to local and national initiatives in the areas of multiskilling and multidisciplinary working, while respecting each other's unique expertise and diversity. The next meeting is on Tuesday, 14th October 2003 at 1.15-4.00 pm in the education centre at Westmorland General Hospital in Kendal.

Acknowledgements

Thanks to the following colleagues for their contribution of ideas to this paper: Debbie Sutherland (adults) and Paul Dunstan (paediatrics), Senior Dietitians; Helen Dixon (paediatrics) and Sian Carlton (adults) Senior Speech and Language Therapists; Jill Rollins Senior Paediatric Nurse; Alex Edgell Community Paediatrician.

REFERENCES

1. Logemann, JA. Evaluation and Treatment of Swallowing Disorders 2nd Edition 1998, pro-ed
2. Communicating Quality. Royal College of Speech & Language Therapists 1996
3. Armstrong, L & Pendrowski, A. Twenty Miles between Clients. Bulletin Royal College of Speech and Language Therapists 2002
4. Evans Morris S, Dum Klein M. Pre-Feeding Skills. 2nd Edition Therapy Skill Builders 2000
5. Gillick, MR. Rethinking the role of tube feeding in patients with advanced dementia New Engl J Med 2000;342(3):206-209
6. National Descriptors for Texture Modification in Adults. Royal College of Speech and Language Therapists and The British Dietetic Association, 2000
7. Rosenberg K, Brown Alzheimer's Disease and Nutrition In Complete Nutrition 2002 pp 16-18