PERSONAL PRACTICE

# Assessment of feeding problems in neurodevelopmental handicap: a team approach

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Many children with cerebral palsy and other neurodevelopmental disorders are unable to swallow and eat normally.[1 2] As a result they do not receive adequate nutrition[1–4] and they suffer from recurrent respiratory illness.[1 5 6] Instead of being an enjoyable family event, meals are stressful and time consuming for the child and those caring for them. Feeding may take the parents four to six hours day, and it is punctuated by repeated spillage of food, coughing, choking, or regurgitation. For many parents of handicapped children feeding represents the major difficulty in the daily management of their child.[1 2]

Because of our increasing awareness of these problems, in 1989 we established a specialist clinic to assess and to give advice on severe feeding and swallowing problems in children with neurological or developmental handicap. Given the complexity of such problems it was clear that a team drawn from several paediatric disciplines was needed. The original core team consisted of a neurologist, a specialist speech therapist, a respiratory paediatrician, and a radiologist. A gastroenterologist has since joined the team. Other specialists, including clinical psychologists, surgeons, and dietitians are also involved, depending on the individual child's needs.

The clinic is held in the hospital's assessment unit. Children are referred by paediatricians from throughout the region. Referral letters are reviewed by the neurologist and speech therapist, and parents are sent a letter explaining what the assessment entails. Because of the duration of the assessment we see only two or three children in each session. Each child sees all members of the team, and at the end of the session the results of the assessments, and suggestions on future management, are discussed with the family and accompanying carers (figure). We send a report of our findings and recommendations to all the professionals involved in the child's care, and a letter summarising our views is sent to the parents.

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## Physiology of normal and abnormal swallowing

To assess and manage swallowing disorders we need to understand normal and abnormal patterns of swallowing. Safe, efficient swallowing is a complex act requiring the coordination of six cranial nerves, the brain stem and cerebral cortex, and 26 muscles of the mouth, pharynx, and oesophagus.[7–9] The purposes of swallowing are to propel food from the mouth to the stomach and to protect the respiratory tract against aspiration.

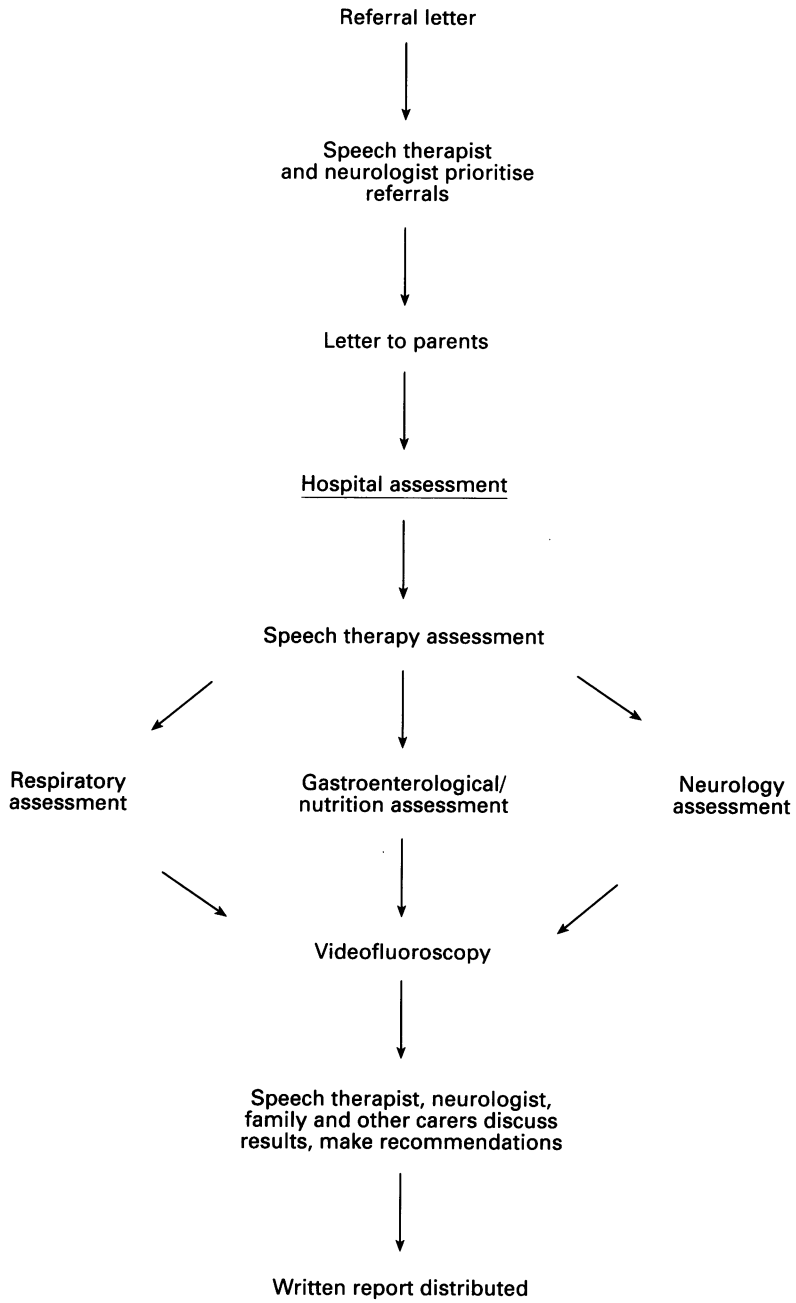
Swallowing consists of two voluntary phases (oral preparatory and oral) followed by two reflex phases (pharyngeal and oesophageal). Each phase depends on the phase preceding it, but in children with neurological disorders this sequence may be disrupted. In the *oral preparatory phase* food is formed into a bolus. This requires sealing of the lips, chewing, and the cupping of the bolus in a depression in the tongue. Abnormal oral sensation, involuntary movements, or learnt behavioural can interfere with this phase. In the *oral phase* the bolus is propelled backwards by the tongue. Many children with cerebral palsy have involuntary tongue thrust, where the tongue moves anteriorly before moving posteriorly.

When the bolus passes the anterior fauces into the pharynx the *swallowing reflex* is triggered: from this point the process is involuntary. In this *pharyngeal phase* the soft palate rises against the posterior pharyngeal wall and seals the nasopharynx against regurgitation. The bolus is propelled by peristalsis of the pharyngeal constrictors to the cricopharyngeal sphincter. Simultaneously, the larynx moves upwards and forwards, closing the larynx at the epiglottis, aryepiglottic folds, and vocal cords. This movement enlarges the pharynx and opens the oesophagus by relaxing the cricopharyngeal sphincter. The bolus then passes down the oesophagus by peristalsis, the lower oesophageal sphincter relaxes, and the bolus passes into the stomach (the *oesophageal phase*).

Initiation of the swallowing reflex is often delayed or absent in children with cerebral palsy so that the airway is not protected. If the reflex is not triggered food can accumulate in the valleculae (the spaces between the epiglottis and the base of the tongue) or in the pyriform sinuses (the spaces between the sides of the larynx and the pharyngeal sphincters) and then be aspirated. Oesophageal function in these children is often abnormal, with poor peristalsis and gastro-oesophageal reflux.

## Speech therapist's assessment

The speech therapist gathers information about the child's feeding and swallowing by




*Assessment of the child with neurodevelopmental handicap and feeding difficulties.*

taking a detailed feeding history, examining oral structure and movement, and by assessing the current feeding skills.

The therapist asks the parents and accompanying carers about the child's feeding skills and defines the main difficulties. She asks when the child first sucked effectively, when they started solids, and about chewing. How skilfully and how quickly can they take liquids and solids of different consistencies? Which foods can they tolerate? Are they distressed during feeds? Is there coughing or choking or regurgitation? Has the child ever needed non-oral feeding?

In the orofacial examination, structural abnormalities of the jaw, tongue or palate, and abnormal oral, pharyngeal, or laryngeal movement are recorded. For example, many children with cerebral palsy have upward and forward tongue movements but little lateral movement. Oral hypersensitivity is tested by the reaction to stimulation of the tongue and lips. How does the child deal with saliva?

The therapist then observes how the child copes with small amounts of various foods (this is done in more detail during the radiological examination). The consistencies the child can manage, the feeding utensils and the seating position used for feeding, the duration of feeds, and taste and temperature preferences are all noted, along with an observation of what the child does with the food in the mouth and the pharynx.

Feeding disorders in children with neurological disorders can be categorised in a variety of ways. For example, there may be abnormal sensitivity so that the child cannot tolerate certain textures. There may be abnormal or immature patterns of movement, such as tongue thrust or the inability to form a bolus or to chew. Occasionally there is an undiagnosed structural abnormality such as a submucous cleft palate with nasal reflux. In many cases it is possible to identify clinically at which phase of the swallow the problems arise, but in others the diagnosis depends on the radiological assessment.

## Neurologist's assessment

All children attending the clinic have a detailed neurological examination. The aims are to identify specific symptoms such as dystonia or dyskinesia that may be contributing to the child's feeding difficulties[7 10 11] and to review the diagnosis of the underlying neurological disorder.

Sixty per cent of the 77 children that we have seen in the clinic have suffered from cerebral palsy. Most children in this group had spastic quadriparesis, 60% had severe cognitive impairment, and half suffered from epilepsy. In 22% of all the referrals there was another specific neurological disorder, such as Rubinstein-Taybi syndrome, Möbius' syndrome, mitochondrial cytopathy, or congenital muscular dystrophy. In the remaining 18% of children, there were feeding problems associated with developmental delay but no other identifiable diagnosis. Overall, 70% of the children referred had severe mental and physical handicap, over half had sensory impairment, and two thirds had no useful mobility.

In the neurological examination of these children, careful attention should be paid to ophthalmoplegia, facial and tongue movements, a pharyngeal gag reflex, and the presence of a jaw jerk. Most of the children have visual impairment and communication difficulties that limit management. Dyskinesia (involuntary movements) and dystonia (sustained abnormal posture) are often missed. In some children involuntary movements or seizures interfere greatly with feeding. Extensor dystonia can narrow the upper airway, causing respiratory distress and stridor. A change in the positioning of the child during a feed, with flexion of the hips, knees, and trunk can reduce such distressing dystonic reactions.

Difficulty in feeding and stridor can also occur if there is marked hypotonia so that the

tongue and jaw fall backwards, obstructing the airway. These symptoms can sometimes be relieved by gentle forwards pressure on the angles of the jaw during feeds, or by using a moulded soft cervical collar, and by achieving a more secure seating posture.

In many children with severe neurological handicap, abnormal learned behaviour compounds the child's physical difficulties in feeding.[10 11] These children have often had repeated unpleasant experiences associated with feeding, such as choking, vomiting, or having nasogastric tubes inserted. These experiences negatively reinforce the feeding problems, and the child may learn to refuse to take any foods orally, or develop aversive responses to stimulation around the mouth, such as extensor dystonia.

## Respiratory assessment

Recurrent respiratory symptoms are common in children with neurodevelopmental handicap and feeding problems.[5 6 12] Respiratory infection is one of the commonest causes of death in these children.[10] Symptoms range in severity from a mild cough with drinks to recurrent pneumonia, bronchiectasis, and respiratory failure. The roles of the respiratory paediatrician are to assess if a child has significant respiratory disease, what the causes are, and what treatment, if any, is required.

Feeding depends on coordination of swallowing and breathing: the child with impaired swallowing has a poorly protected airway and is at high risk of aspiration.[12] Aspiration at the beginning of a feed, before swallowing has occurred, suggests poor tongue control or an abnormal swallow reflex. Aspiration during swallowing indicates failure of laryngeal closure. Aspiration can follow swallowing with inhalation of residual food from the pharynx, or secondary to gastro-oesophageal reflux.[12] Other factors, such as immobility, weak respiratory muscles, and poor cough predispose these children to respiratory illness. Many have chest wall deformities. Their immune defences may be impaired because of poor nutrition.

Inhalation of food into the respiratory tract can produce a variety of pathological and clinical responses.[5 6] Aspiration of milk produces acute inflammation in the airways and alveoli. The child may cough and become distressed and there may be recurrent wheezing or rattly breathing. In the infant, laryngeal aspiration can cause life threatening apnoea. If aspiration recurs over months or years, it can lead to interstitial fibrosis, obliterative bronchiolitis, and persistent atelectasis. Secondary infection results in recurrent pneumonia and in some children to bronchiectasis with a chronic productive cough.[5]

The clinical history is important: coughing, choking, respiratory distress, stridor, or wheeze during or after feeds suggest aspiration. However, in some children with lung disease due to aspiration, the diagnosis is delayed because aspiration occurs without these symptoms. This is because many children with chronic aspiration have a blunted or absent cough reflex.[5] The history is therefore not enough to detect aspiration: a radiological examination is needed to detect this 'silent aspiration'. As well as aspiration 'from the top end' during feeding, chest symptoms can follow aspiration secondary to the gastro-oesophageal reflux from which so many of these children suffer. Even in the absence of aspiration reflux oesophagitis can cause reflex bronchospasm and wheeze.[5 6]

Although aspiration is the commonest cause of respiratory symptoms in this group of children, other factors are important. Parental smoking increases the frequency and severity of respiratory symptoms and is discouraged.[13] A personal or family history of atopic disease in the child with wheeze and cough may suggest coexisting asthma and the need for a trial of antiasthma treatment.

The clinical examination is often unhelpful in assessing the respiratory status in these children. The presence of spinal or chest deformities and of abnormal noises such as rattly breathing, stridor, or wheeze should be noted. We have seen finger clubbing with bronchiectasis and severe fibrosis. A chest radiograph should be performed to look for chronic inflammatory changes or persistent collapse. Recently, pulse oximetry has been used to measure hypoxaemia during feeding in children with cerebral palsy. It is useful to assess different feeding regimens and to decide if gastrostomy feeding is indicated.[14]

## Gastroenterologist's assessment

The role of the gastroenterologist is to assess the child's growth and nutrition and to offer advice on the management of gastro-oesophageal reflux.

Gastro-oesophageal reflux occurs in up to 75% of children with cerebral palsy because of abnormal peristalsis and lower oesophageal sphincter function. It can occur without overt vomiting.[15] As well as lung disease reflux can cause chronic oesophagitis with painful swallowing, anaemia, and stricture formation. The history and videofluoroscopy are insensitive indicators of reflux. Oesophageal pH monitoring is the only reliable measure of the frequency and duration of episodes of reflux. Oesophagoscopy should be performed if there is severe reflux.[15] Medical treatment with thickeners, alginate/antacid compounds (Gaviscon, Reckitt and Colman), and cisapride is often disappointing,[16] and in children with severe complications antireflux surgery is often required.[15 17]

Many children with severe neurodevelopmental disease exhibit malnutrition and growth retardation.[1–4] Poor growth is most severe in quadriplegic cerebral palsy, it is often evident from infancy and worsens with age. Many factors contribute to poor growth.[18] A direct neurological effect on growth is controversial. Inadequate nutrition is undoubtedly important: several studies of gastrostomy or nasogastric feeding of these children with energy and protein-rich foods have shown a

rapid correction of wasting, an increase in their weight/height ratio, and an improvement in their general wellbeing.[3 4 19]

We need objective measures of growth to assess the adequacy of nutrition and the response to changes in feeding regimen. There is no agreed method of estimating the energy needs of these children: accounting for body mass, tone, and activity is more accurate than using standard recommendations.[20] The usual definition of wasting (reduced weight for height) may be inappropriate, but muscle mass and body fat can be estimated by measurements such as upper arm circumference and skinfold thickness.[19] If height or length cannot be measured because of skeletal deformity, linear growth can be assessed using upper arm and lower leg lengths.

## Radiologist's assessment

Although clinical assessment is vital, the radiological examination is the only way to observe oropharyngeal function directly in these children. The radiological appearances of normal and abnormal swallowing are well described.[7 21–3] Oral control, bolus formation and propulsion, and the nature of the swallow reflex can be assessed. Aspiration, and in those who aspirate, the presence and efficacy of a cough reflex, can also be seen.

Each videofluoroscopic examination is tailored to the child. The examination involves the parents, the specialist speech therapist, and other carers who can describe the feeding difficulties and advise which foodstuffs should be tested. We seat the child in a 'tumbleform' chair in their normal feeding position and use their own feeding utensils. We assess swallowing with foods of different thicknesses and textures: liquids, rusk, yoghurt, cereal, or chocolate buttons can all be rendered opaque with barium. The food that is normally best tolerated is given first in gradually increasing volumes. Other foods of different consistencies are then given. Swallowing is visualised fluoroscopically using the lateral position to show the sequence of movements from the lips, jaw, tongue and oropharynx to the upper oesophagus, although other views may be helpful. In some children we assess feeding in different seating positions. All examinations are recorded on tape for analysis.

We observe oral handling, tongue and jaw movement and note sucking, chewing, and bolus formation. Most children with cerebral palsy and feeding difficulties do not have normal bolus formation and propulsion. They therefore cannot have normal triggering of the swallow reflex, relying instead on pharyngeal distention or stimulation for triggering. There may be propulsion of food from the mouth to the pharynx or oral escape under gravity. We record the timing and coordination of the swallow reflex, and in those without normal triggering, the degree of pharyngeal distention required to produce an effect. Swallowing efficiency is also evaluated by assessing residual contrast in the mouth and pharynx after each swallow. Oropharyngeal function varies with different foodstuffs, as thicker foods require greater force for propulsion and travel more slowly. Swallowing may be affected by tiredness, by upset, and by the child's posture, and these factors must be recognised.

We pay close attention to whether contrast is aspirated into the tracheobronchial tree or nasopharynx before, during, or after the swallow reflex. Residual pooling of food in the pharynx, valleculae, and pyriform sinuses indicates a risk of aspiration. As aspiration can occur silently if there is an inadequate cough reflex, we are particularly interested in whether the child coughs if contrast is aspirated.

## Discussion

What have we learnt from this clinic? The first lesson has been that meeting these children and their families has emphasised to us even further the stress and distress that feeding causes to them and their need for effective and objective advice.

In children with no clinical or radiological evidence of aspiration the speech therapist has been able to offer advice on the most appropriate feeding utensils, seating position, and consistency of food or liquids for the individual child. Knowing there is an inefficient but safe swallow allows such changes in treatment to be taken with greater confidence. The speech therapist can also devise specific programmes to improve oral movement, to improve sensitivity, or to desensitise the oral area.[11] If there are behavioural factors contributing to the feeding difficulties, a programme accentuating the positive, pleasurable aspects of feeding, while progressively reducing the negative experiences, is suggested.[11]

In over 40% of the children we have seen their weight was below the third centile or there was other evidence of failure to thrive. Although improving oral feeding and supplementing feeds has sometimes succeeded in achieving adequate nutrition, in some children it has been clear that non-oral feeding was needed. Long term nasogastric feeding has many disadvantages: tubes need to be replaced frequently, are uncomfortable, and may inhibit sucking and swallowing.[11] In those cases where there is no prospect of safe oral feeding being achieved within the foreseeable future we now recommend a feeding gastrostomy.[11 15 24] As many of these children have gastro-oesophageal reflux, and because a gastrostomy may increase reflux, an oesophageal pH study should be performed before surgery.[15] A fundoplication can then be performed with the gastrostomy if necessary.[17] Gastrostomy with fundoplication has also been recommended for severe recurrent respiratory disease due to aspiration in suitable children. Although our experience, like that of others, has been that surgery improves nutrition, decreases respiratory symptoms, and often leads to a marked improvement in the quality of life of child and parents, the possible complications of the surgery need to be balanced carefully against the potential benefits.[15 17 24]

We recognise that in some severely and multiply handicapped children we have been unable to improve their feeding. Even in this group, however, we believe that the detailed assessment has been worthwhile as it has reassured parents and carers that all that can be done is being done at home and by their local services.

Each children's department should have a policy for the investigation and management of children with neurological handicap and feeding disorders. A team approach is essential. Referral to a specialist centre may be necessary. Our experience suggests that such an approach can significantly reduce the stress of feeding and result in a substantial improvement in the quality of the health and life of the child and their family.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