Nutrition and Neurodisability

Edited by Peter B. Sullivan, Guro L. Andersen and Morag J. Andrew

A practical guide from Mac Keith Press

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Foreword

Enough and appropriate food and water are essential for human life. This statement is obvious. Nonetheless, lack of food, and starvation are regular occurring consequences of wars and natural disasters. During such crises, children, but also grown-ups, in particular elderly people, may die, or they become more vulnerable to other disorders, such as infectious diseases. In children, somatic growth and psychomotor development will be impaired.

In other settings where food is sufficient, meals are important elements in our social life, ranging from regular daily meals within the family, with friends or colleagues, to the most advanced tasting menus served in the best restaurants. In the short story, *Babette's feast*, the Danish author Karen Blixen, describes how Babette prepares an exquisite meal in a remote fishing village in Northern-Norway, using ingredients imported directly from Paris. Although the locals considered such a meal to be a sinful act, they felt how the meal lifted them both spiritually and physically, how local disagreement and anger evaporated, and love and peace settled on the table.

Persons with disabilities have a range of challenges related to feeding and nutrition. Among the most severe problems is severe oral-motor dysfunction. In early childhood, persons with such dysfunctions are at risk of being truly starved, and undernutrition may impair growth and neurodevelopment. Chewing and swallowing problems, and gastroesophageal reflux may lead to aspiration of food or gastric content into their airways, followed by pneumonia. The other extreme is overfeeding resulting in overweight and adiposity. The latter is often seen in some syndromes, such as Down syndrome and Prader Willi syndrome. However, a too high proportion of body fat may also be the result of misinterpretation of body composition in persons with disabilities where measures such as body mass index applied in the typical developing population may be misleading.

Ten years ago Mac Keith Press published the book *Feeding and nutrition in children with neurodevelopmental disability* edited by Peter Sullivan. That book became a recommended

textbook for many professionals involved in the care for persons with neurodevelopmental disabilities. As Martin Bax stated in his foreword to that book, it was first towards the end of the 20th century that attention was paid to these problems.

This new book edited by Sullivan, Andersen and Andrews, includes the results of the most recent research and practical guidelines regarding assessment of feeding difficulties and body composition as well as the most recent recommendations regarding treatment. The authors of the various chapters are world-leading experts from Europe, Australia and North-America. The authors address all important aspects of this challenging topic. The practical perspective is essential and will certainly be appreciated by inter-professional teams trying to help optimizing the nutritional status of children and adults with disabilities.

In *Babette's feast* there were some original guests, but none with a clear neurodevelopmental disability. Within a family setting, severe feeding difficulties are likely to affect the family's quality of life. The application of the knowledge provided in this new book should provide a basis for enabling persons with disabilities to take part in, and enjoy any meal both in a private and a public setting, and even to experience such meals as presented in *Babette's feast*. Most importantly, the content in the book should contribute to a lighter daily life in families of persons with disabilities, and for the persons themselves.

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Preface

This book is the third produced on this topic by Mac Keith Press over the last three decades. Acknowledgement for this initiative should go to Martin Bax who as Editor of *Developmental Medicine & Child Neurology* realised that the nutritional needs of children with cerebral palsy were not adequately being met by health care professionals. The early texts on cerebral palsy make little or no mention of the feeding difficulties encountered in children with severe neurological impairment and feeding and nutritional assessment was not part of the routine care of these children. In the late 1980's, it was Martin who saw the advantage of teaming up a paediatric gastroenterologist with an interest in nutrition with a paediatric neurologist; this culminated in the first volume *Feeding the Disabled Child* edited by myself and Lewis Rosenbloom and published in 1996. Following Martin's retirement, Lewis, as Chair of the Editorial Board of Mac Keith Press persuaded me that an update in the form of a practical handbook was required. This lead to the publication of *Feeding and Nutrition in Children with Neurodevelopmental Disability* by Mac Keith Press in 2009. Now some ten years later and with increasing research interest and endeavour and with the appearance of guidelines from various learned bodies on the topic of nutritional and feeding problems in children with neurological impairment, Bernard Dan the current Editor in Chief of *Developmental Medicine & Child Neurology* considered it is necessary again to update the handbook.

This volume is designed to be a practical evidenced-based handbook aimed at health professionals who have responsibility for caring for children with the feeding, nutritional and gastrointestinal problems that ensue from neurological impairment and especially cerebral palsy. This book will be of value both for those new to this clinical field and for more experienced practitioners.

An appreciation of the development of the normal anatomy and physiology of the oral-motor apparatus is essential for understanding of the pathophysiology of oral-motor dysfunction that underlies the feeding problems in children with neurological impairment; these aspects are covered in the opening two chapters. Drooling of saliva is an important additional consequence of oral-motor dysfunction and this problem and its

management is covered in a separate chapter. Oral-motor dysfunction is a component of an overall abnormality in gastrointestinal motility resulting in increased gastro-oesophageal reflux, delayed gastric emptying and constipation. Evaluation and management of these gastroenterological problems, which affect the great majority of children with neurological impairment and especially these children with cerebral palsy is covered in detail. Nutritional impairment is frequently a consequence of the feeding problems encountered by children with cerebral palsy and the impact of such undernutrition on growth, metabolism, cognitive and immune function may be overlooked. Recent research has led to a greater understanding of the adverse consequences of undernutrition and these are detailed in this volume.

Successful nutritional management depends upon accurate assessment and so the heart of this handbook comprises a series of chapters on assessment; these cover growth, energy balance, body composition, macro- and micronutrient intake, and dietetic assessment. Because children with neurodisabilities have risk for compromised bone health attributable to a combination of atypical muscle tone combined with lack of weight bearing resulting in reduced bone size and bone density, this new handbook devotes a whole chapter to this topic. All the assessment chapters describe the range of methods and techniques used in nutritional assessment together with an evaluation of the advantages and disadvantages of each technique and a discussion of the validity for their use in children with neurological impairment. The issue of (lack of) appropriate reference standards in children with neurological impairment for growth and nutritional intake is taken into account in the recommendations made.

Following on from detailed feeding, nutritional and gastroenterological assessment comes the development of a management strategy. Children with neurological impairment, and especially those with cerebral palsy, form a rather heterogeneous clinical group. Accordingly, management strategies must be individualised and targeted and the specific needs of each child. Furthermore, successful feeding, nutritional and gastroenterological management will not be the province of one particular professional discipline but will be the outcome of the input and endeavours of a multi-disciplinary team. These basic principles run through all the chapters on assessment and management. Where appropriate clinical case vignettes are used to illustrate points being made in the text and it is hoped that these will prove to be an instructive and valuable addition to the handbook.

Enteral tube feeding has transformed the landscape of nutritional management of children with cerebral palsy in recent years and whilst it circumvents the problems of feeding inefficiency and unsafe swallow associated with oral-motor impairment, the technique is not without its problems. Amongst these are included the complications of the procedure itself, the potential risk of overfeeding and the significant impact – both beneficial and adverse - that gastrostomy or jejunostomy tube feeding has on parents.

These issues are explored in detail in the penultimate chapter. The handbook ends with a resume of all the take home messages from each of the foregoing chapters.

In producing this handbook, the editors have sought contributions from the acknowledged leaders in each topic from around the world. It is our earnest hope that this handbook will prove to be a useful resource for any health professional engaged in the assessment and management of the feeding, nutritional and gastrointestinal problems in children with neurological impairment.

I would like to acknowledge the continuous help and support given to the editors to produce this handbook from Rosie Outred, Lucy White and Sally Wilkinson from Mac Keith Press.

Peter B Sullivan, Oxford
November 2019

CHAPTER 9

Feeding and Nutritional Management Strategies

Kristie L Bell, Katherine A Benfer and Kelly A Weir

INTRODUCTION

Comprehensive nutritional assessment and management is complex for children with neurological impairment (NI). Poor nutritional status is common and may arise from a variety of causes (Ptomey & Wittenbrook 2015). Many children have oropharyngeal dysphagia (feeding and swallowing difficulties) with subsequent increased risk of pulmonary aspiration and poor respiratory health. Prolonged and stressful feeding results in difficulty consuming adequate food and fluids to maintain good nutritional status, hydration and overall health (Arvedson 2013). As detailed in Chapter 4, gastrointestinal disorders including foregut dysmotility, gastroesophageal reflux disease, delayed gastric emptying and constipation are frequent and can have significant impacts on dietary intakes. Energy requirements are variable; they can be increased for children with high levels of involuntary movements and decreased for those with spasticity and reduced mobility (see Chapter 7). For some children with NI, there is a significant behavioural component to feeding resulting in poor energy intake or imbalanced micronutrient intake and subsequent micronutrient deficiencies.

THE MULTIDISCIPLINARY TEAM IN THE NUTRITIONAL MANAGEMENT OF A CHILD WITH NEURODISABILITY

Given the complex aetiology of poor nutrition for children with NI, assessment of nutritional status should be conducted by a multidisciplinary team (MDT) with a range of

knowledge, skills and expertise; assessment should also use multiple methodologies (Ptomey & Wittenbrook, 2015; Romano et al. 2017). Thorough, coordinated evaluation and treatment planning are essential for successful interventions.

The MDT brings together professionals from multiple disciplines to address the child's nutritional status and requirements, feeding and swallowing function, gastrointestinal function, and the child and family's social and emotional needs. This includes the prescription and administration of interventions as well as ongoing monitoring and adjustment of treatments as required.

MDT membership may be highly variable depending on location and available resources, and may include paediatricians, dietitians, speech pathologists, gastroenterologists, surgeons, radiologists, nurses, social workers, psychologists, occupational therapists, physiotherapists, educators, respite carers, and social and community supports. Central to the team are the child's family and primary caregivers whose involvement ensures that interventions are individualised, realistic, targeted, take into account the child's individual preferences, socio-cultural aspects, family and environment factors, and will have the greatest likelihood of success (Craig et al. 2003).

NUTRITIONAL INTERVENTIONS

Given the high prevalence of oropharyngeal dysphagia and undernutrition, interventions for children with NI are frequently focused on increasing nutritional intake to improve nutritional status and overall health (Bell & Samson-Fang 2013; Romano et al. 2017). Interventions can range from relatively straightforward correction of micronutrient deficiencies in children who are able to consume a full range of food and fluid textures without difficulty, to complete enteral tube feeding in those unable to protect their airway during swallowing across all food and fluid textures. **Oral nutrition support** includes strategies to support the child's mealtime environment and positioning, alterations to food/fluid textures and nutrient density, and use of adaptive equipment, caregiver techniques and sensorimotor therapy. **Enteral tube feeding** can be the sole source of nutrition or can be used as an adjunct to oral nutrition support. A simplified decision making tree for determining oral feeding versus tube feeding is shown in Figure 9.1.

This decision tree can be considered in conjunction with a management hierarchy that emphasises the importance and interplay between outcomes of safety, efficiency, skill development and mealtime stress, considered in the sociocultural context (Fig. 9.2).

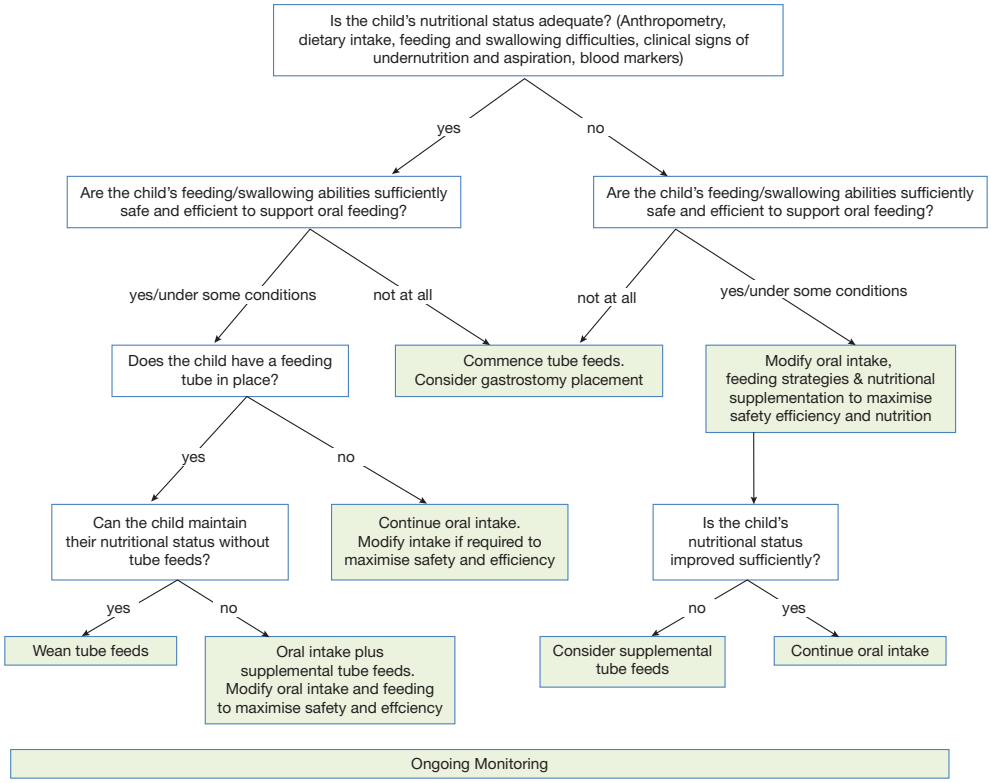
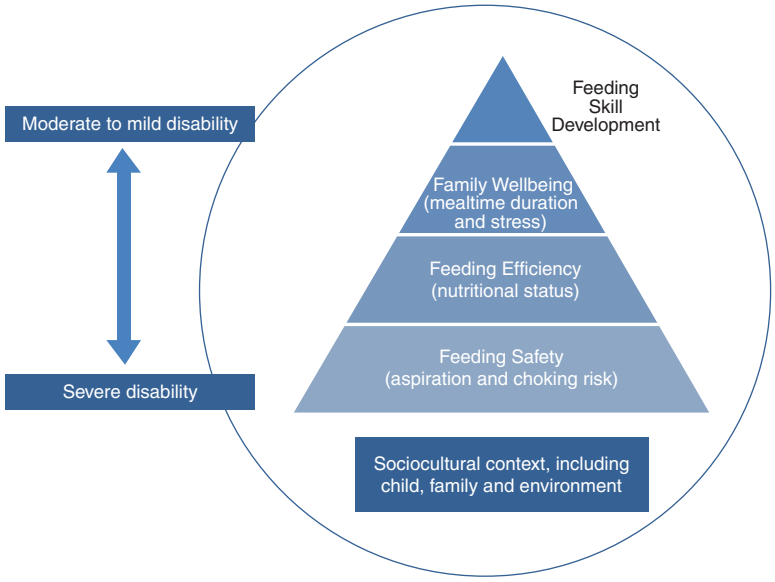


Figure 9.1 Simplified decision-making tree for commencement of tube feeding in children with neurological impairment.

Oral Nutrition Support

Initial intervention for a child who is able to achieve functional feeding and swallowing skills and airway protection will involve a trial of oral nutrition support strategies. Approaches to support oral intake include alterations to food and fluid textures and nutrient density as well as strategies to support the child's mealtime environment, feeding position, adaptive equipment, caregiver techniques and oral sensorimotor therapy. These approaches are commonly combined to holistically support the child's mealtime safety, efficiency and success; but specific aspects may differ depending on the target outcome.



The feeding management hierarchy emphasises the importance and interplay between the outcomes (goals and management prioritiers) of feeding safety and efficiency, mealtime stress and feeding skill development, all in a sociocultural context. Feeding safety is the base of the pyramid and initial consideration, with progression upwards to reflect the order of priorities for oral feeding up to skill development at the top. Feeding Skill Development includes developmental progression of ingestion skills, food and/or fluid textures and utensils.

Figure 9.2 Feeding management hierarchy.

Optimising the Mealtime Environment and Routines

Mealtimes form a central and significant part of family life, and attempts should be made to ensure positive experiences for both the child and the caregiver (Morris & Klein 2000). The primary foundations for mealtime success are to ensure the child's readiness to feed, and to provide a safe, predictable and responsive environment. Depending on the child's pre-mealtime physiological state, either a calming or alerting environment can be facilitated for the child by altering aspects such as temperature, light, visual stimuli (including colour and contrast of utensils) and auditory inputs (Morris & Klein 2000). Minimising environmental distractions should balance maintaining the child's attention whilst encouraging the social aspects of a mealtime.

More complex food/fluid textures should be included in mealtimes when the child is most alert, interested and feeds most effectively. Children with moderate oral motor involvement may benefit from smaller more frequent meals during the day, limited to 30–40 minutes duration (Reau et al. 1996). Mealtime schedules may need to be flexible and responsive to the day-to-day variability in the child's mealtime performance, and also energy fluctuations and fatigue through the day.

A predictable mealtime routine can help children with mealtime expectations (including cultural behaviours such as sitting at the table), particularly for children with cognitive/learning difficulties, impaired vision or hearing. Children can better prepare their body and cognition for the approaching meal if provided with consistent mealtime signals, such as presenting their spoon visually/tactilely, or with consistent verbal cues. Other aspects include a consistent feeder (particularly in institutional settings), consistent positioning and consistent utensils (Burklow et al. 2002). Consistent verbal and visual cues can remind children of specific ingestion functions or behaviours, such as 'single bites' or 'chew and swallow'.

Developing the child's ability to effectively communicate (through formal or informal communication systems), and the caregiver's sensitivity and responsiveness to the child's cues, assists the child to express food preferences, enjoyment, pain or discomfort, and their desire to continue or cease the meal (Mathisen et al. 1989). A focus on the child–caregiver interactions during mealtimes also facilitates the rich language and social learning opportunities a mealtime avails.

Postural Management and Positioning when Eating

Optimal positioning to improve head and trunk stability during mealtimes provides a critical foundation for both safety and efficiency, and is a priority for all children with feeding difficulties (Benfer et al. 2013). Optimal mealtime positioning influences tone and overall patterns of movement, improves coordination of oral motor movements, enhances respiration and airway protection, provides a mechanical advantage for bolus dynamics, positively influences reflux and gut motility, and improves self-feeding (Hulme et al. 1983). Modification of a child's sitting position from one of generalised extension to greater flexion (particularly at the hips and knees) can facilitate jaw stability and head flexion (Stratten 1981). A stable and aligned head position, achieved both through overall body positioning and specific head support (including head rests or occipital rolls), may improve position, mobility and coordination of the lips, tongue and oral anatomy (Lanert & Ekberg 1995).

Ideal mealtime positioning involves the child seated upright, with 90-degree hip flexion, feet supported, head in midline and aligned on the anterior–posterior plane, and chin slightly tucked. However, no single optimal position exists for all children. Recommendations for mealtime position should be made in collaboration with the child's physical or occupational therapist, incorporating individualised findings from videofluoroscopy when appropriate and available (Lanert & Ekberg 1995; Gisel et al. 2003). Options for improving mealtime positioning may include specialised seating (infant feeder seats, wheelchairs or supportive chairs); the adaptation of regular seating using pillows, rolled towels, foam and support straps; or postural support by the caregiver's body. A tray may provide additional postural support and allow stabilisation of

the upper limb and shoulder girdle, to achieve a functional sitting position (Stavness 2006). Whilst an upright position is generally advocated, up to 30 degrees of recline, for children who are unstable in an upright position, reduces lip pursing, gag and tongue thrust (Lanert & Ekberg 1995). The upright position may be more beneficial than recline for children with poor pharyngeal clearance or those requiring a slower bolus flow rate (Morton et al. 1993). Flexed head position and chin tuck improves protection of the airway, decreases risk of laryngeal penetration and aspiration and is particularly helpful for children with a delayed swallow initiation (Lanert & Ekberg 1995). Preliminary evidence suggests that reductions in aspiration from improved position, combined with texture modification of food and fluids, translate into longer-term improvements in respiratory function for children with severe feeding difficulties (Gisel et al. 2003).

Caregiver Mealtime Techniques

Training parents in techniques including provision of jaw and cheek support, appropriate bolus size and placement in the mouth, and pacing techniques can be highly effective for improving the child's mealtime safety and efficiency. In addition, the consistent incorporation of behavioural strategies by caregivers, into all meals and snacks, provides maximum opportunities to enhance mealtime success. Behavioural training approaches aim to reduce feeding behaviours related to food refusal and selective eating (Sharp et al. 2010). While strong evidence exists for their use in certain subgroups of children, it is critical when using behavioural strategies with children with NI that underlying oral sensorimotor and gastrointestinal issues are resolved in parallel (Morris & Klein 2000). Behavioural strategies can be understood broadly as (1) operant training approaches, which aim to increase or decrease specific mealtime behaviours through positive and negative reinforcement (Babbitt et al. 1994); (2) behavioural approaches to skill acquisition, which simplify the mealtime task to aid learning, and may include shaping, prompting and modelling (Babbitt et al. 1994); and (3) food chaining and systematic desensitisation hierarchies which aim to gradually expose the child to new mealtime experiences, particularly tastes, textures or foods by building on the child's existing food repertoire in a gradual stepwise method (Toomey & Ross 2011).

Provision of jaw and/or cheek support can effectively create a base of stability for the lips, tongue and cheeks, thereby enhancing mealtime efficiency. There are many detailed accounts on types of oral support in dedicated mealtime texts (Morris & Klein 2000; Winstock 2005) which have demonstrated effectiveness in infants and young children (Hwang et al. 2010). Jaw support may not be necessary if the child can be adequately positioned in a neutral-flexed posture, and so should be considered secondary to optimal seated positioning. While maladaptive oral patterns may be reduced through provision of jaw/cheek support, careful consideration must be given to the function of the oral pattern for ingestion (e.g. forward–back tongue pattern may be necessary for oral transport).

Bolus size may be manipulated by the caregiver specific to the properties associated with the bolus consistency (e.g. fluid or chewable), and depending on the particular oral sensorimotor difficulties of the child (Arvedson 1998). Large boluses have been associated with an increased risk of aspiration in children with NI, and so limiting spoon and bite size is recommended (Mirrett et al. 1994). However, bolus size should be individually evaluated in the context of the child's oral sensorimotor skills, because larger bolus volumes may provide greater sensory input to the mouth (allowing for improved bolus formation and transit) (Arvedson 1998), and decrease pharyngeal delay times in adults with dysphagia (Bisch et al. 1994).

Specific bolus placement techniques differ depending on the texture of the bolus, utensil used, and the child's individual oral sensorimotor skills and goals. Generally, for foods given via spoon, presentation from the midline and chest level upward will promote alignment of the head and a chin tuck position. Touching the spoon to the child's lips can alert them to the oncoming bolus and encourage mouth opening. Gentle downward pressure can be provided through the spoon to the tongue to provide sensory feedback and may inhibit tongue thrust (Helfrich-Miller et al. 1986). The caregiver can be encouraged to allow adequate time for upper lip clearance of the spoon, and to gently tilt the spoon to make contact with the upper lip (Helfrich-Miller et al. 1986). Chewable or lumpy foods may be more appropriately placed laterally, over the molars to encourage mastication. This is particularly important for children with reduced tongue lateralisation to ensure food is adequately chewed for the swallow, thereby reducing any risk of choking.

Slowing the pace of the meal by incorporating pauses between boluses allows the child time to breathe and re-establish their feeding rhythm (Arvedson 1998) and ensures adequate time to clear the bolus (from the oral cavity and pharynx) before subsequent boluses are presented (Logemann 1998). Specific strategies can include teaching caregivers to count the number of sucks when bottle feeding before tilting the bottle for a breath, and helping the caregiver learn to observe the timing of the swallow (through visual or tactile means) (Law-Morstatt et al. 2003). Using information gained from instrumental assessments can provide caregivers with specific strategies to aid their child.

Adaptive Equipment

Utensils: Depending on the child's developmental age and oropharyngeal swallowing skill, a range of feeding utensils may be used to provide nutrition safely and efficiently, and to assist in the development of feeding and swallowing skills. If a child is breastfed, the mother can use equipment such as nipple shields and supplementary feeders to enhance feeding outcomes. A range of nipples/teats, spoons, forks, knives and cups are available which can be matched to the child's specific oropharyngeal swallow function. A short discussion of these is presented in Table 9.1 (Morris & Klein 2000).

Table 9.1 Features of feeding utensils

Utensil	Feature	Explanation
Nipples/ Teats	Number of holes	Holes usually drip at a given rate for a specific age group (e.g. Premmie teat for below term age; slow flow: 0–3 months; medium flow: 4–6 months; fast flow: over 6 months of age). However, flow rates can be highly variable across brands, due to type of material and bottle construction.
	Slit or Y cut	Non-drip teats which open to allow fluid flow when child is actively sucking and close during suck-pauses. These are helpful for children with reduced respiratory support/stamina.
	Variable flow	Provides a range of flow rates depending upon the orientation of the teat with the child's nose.
		Allows for feeder to change flow rates during the feed to respond to child's suck swallow breathe coordination and stamina/fatigue.
Bottles	Squeeze bottles	Soft silicon or 'squeeze' bottles allow feeder to provide pressure to the bottle to support fluid flow for a child with a weak suck. Feeder must coordinate squeeze with child's sucking and stop during suck-pauses or rests.
	Sports bottles	Often popular as non-spill bottles; however, they present an aspiration risk as children often drink from sports bottles with their head tilted back and their neck extended. This posture opens their airway and results in frequent coughing during drinking. Bottles with straws allow the child to maintain chin tuck or a neutral head position for better airway safety.
Cups	Straw cups	Encourages chin tuck position which supports more active airway protection. Requires good lip closure, cheek strength and palate closure to create and sustain negative oral pressure and suction.
	Spout cups	If spout cup without a valve is used, this allows flow of fluid for child with poor oral suction and controls the volume/flow rate. If a valve is used, the child must be able to create negative suction pressure to extract fluid.
		Penetration-aspiration risk if head is tipped back to get fluid from bottom of the cup.
	Open cup	Developmental target. Child must be able to maintain a stable jaw position and bottom lip contact with the cup. Curved surface on the cup rim will enhance lip–rim contact. This cup is good for thickened fluids.
	Cut-out cup	Rim of cup is cut out on the top surface. Allows the child to drink from the cup whilst maintaining a chin tuck or neutral head position by allowing cup tilt with space for the nose.
Spoons	Shallow bowl	Requires less active upper lip closure to remove bolus from spoon. Helpful for children with lip weakness.
	Deep bowl	Requires more active lip closure/pressure and may provide a bigger bolus.
	Broad base	Enables feeder to use deep pressure sensory input with spoon presentation to minimise tongue protrusion and encourage containment of the tongue within the oral cavity.
Forks/ Knives	Built up handles	Forks, knives and spoons with curved or built up handles may be suitable for young children or those with upper limb motor involvement and grip difficulties. These may aid independent eating and development of utensil use.

Other Therapeutic Techniques

Oral Sensorimotor Treatment (OSMT) is commonly used in children with NI and dysphagia as part of a comprehensive management programme, although efficacy research has focused on moderate–severely physically impaired children. OSMT includes specific tasks using food to improve oral musculature strength, precision and range of movement to support the functional aspects of the oral phase of swallowing. Improvements such as lip closure during spoon feeding, straw drinking and chewing, tongue lateralisation during chewing, bolus containment, shorter chewing time and faster oral transfer have been demonstrated. No improvement to suction strength during straw drinking, the pharyngeal phase of swallowing (e.g. aspiration or post-swallow pharyngeal residue), mealtime efficiency or weight gain have been shown (Gisel 1996; Snider et al. 2011; Kaviyani Baghbadorani et al. 2014). Functional Chewing Training (Inal et al. 2017) has had promising results in improving chewing function by positioning food or a chewing tube to the molar area to stimulate lateral and rotary tongue movements, massage the upper and lower gums, and gradually increase food consistency. Specific oral sensorimotor treatment strategies and activities for various types of oral motor dysfunction during feeding are described extensively elsewhere (Morris & Klein 2000).

Robotic Assistive Feeding Devices, Oral Appliances and Use of Neuromuscular Electrical Stimulation

Robotic assistive feeding devices such as the 'Robotic Aid to Eating' support independent feeding and consistent food presentation via a spoon to enhance feeding skills and efficiency. Improvements in mastication and swallowing have been found whilst using the device, but not retained over time. No benefits for energy or protein consumption, increased food intake, weight gain or feeding efficiency have been noted (Snider et al. 2011). Use of an intraoral appliance such as the Innsbruck Sensorimotor Activator and Regulator (ISMAR) includes the fitting of an intraoral appliance specifically fabricated on the child's own dental cast. Moderate evidence supports use of the ISMAR to improve oral postural control and oral sensorimotor skills such as spoon feeding, biting and chewing, and cup and straw drinking compared to no or alternate therapies, but there is less evidence to show positive effects in time taken for meals (feeding efficiency) or weight gain (Snider et al. 2011). Neuromuscular Electrical Stimulation (NMES) treatment is an emerging treatment option involving neuromuscular electrical stimulation via bipolar surface electrodes to the submental/anterior neck muscles. The only published paediatric study of 95 children receiving a course of 22 sessions (mean) over 10 weeks found no significant difference between NMES compared to usual care with dietary manipulation overall (Christiaanse et al. 2011). Further research is required for all of these interventions.

Texture Modification of Food and Fluids

Modification of fluid consistencies and food textures is commonly recommended to optimise feeding efficiency and swallowing safety for children with oropharyngeal dysphagia. Recommendations for fluid and food textures should be based on a thorough clinical and instrumental evaluation and tailored to the child's specific oral sensorimotor and swallowing skills, feeding efficiency, aspiration risk/safety, fatigue levels and self-feeding independence level by a speech pathologist. The International Dysphagia Diet Standardization Initiative has developed a framework to describe seven levels of fluid/food, with five fluid levels (thin fluids, slightly, mildly, moderately and extremely thick fluids) crossing over five diet levels ranging from liquidised to a regular diet (liquidised, pureed, minced & moist, soft & bite-sized, regular) (Cichero et al. 2017). Different food/fluid consistencies require different levels of oral sensorimotor competency and swallow response. Thin fluids flow quickly and require a prompt swallow response and intact airway closure to prevent aspiration. Thickened fluids, purees, mashed foods and solids are less likely to cause pharyngeal penetration/aspiration (Weir et al. 2011; Steele et al. 2015); however, they are more likely to have associated pharyngeal residue with its own associated aspiration risk (Weir et al. 2009).

A finding of consistent aspiration on a given texture or fluid consistency often results in that consistency being restricted or eliminated from that individual's dietary repertoire. **Thickening fluids** is a common intervention for thin fluid aspiration, with growing evidence to suggest a reduction in laryngeal penetration-aspiration correlates with increasing fluid viscosity (Steele et al. 2015). Care should be taken to thicken fluids only to the extent required to ensure safety, whilst matching the fluid to utensils used to allow appropriate flow rate for safety, efficient intake to meet nutritional requirements, and optimal independence relative to the child's physical function. Infants commonly tolerate 'slightly thick' or 'antiregurgitation' thick fluids through medium- or fast-flow teats whilst maintaining safety and efficiency. If non-drip teats are used with thickened fluids, the infant will need to produce sufficient lip and velopharyngeal closure to achieve adequate suction. Thickened fluids are often used to assist a child to transition from a spout cup to an open cup (e.g. slightly to mildly thick fluids) as the increased viscosity provides increased sensory information and slows the fluid flow, reducing laryngeal penetration-aspiration risk. Liquid medications commonly used with children should be thickened to the prescribed thickness; however, consultation with a pharmacist may be required to check the impact of thickening agents on medication uptake.

When used appropriately, thickeners can assist many children to obtain full fluid requirements orally and reduce aspiration risk (Gosa et al. 2011). Whilst a range of commercial thickeners are available and include thickening agents such as carob bean, xanthan gum, corn or maize starch, care should be taken to determine whether the product can be used with infants with respect to gestational age and gastrointestinal

issues as well as those with allergy. Use of carob bean gum thickeners for gastroesophageal reflux in preterm infants led to fatal necrotising enterocolitis in two preterm infants and development of necrotising enterocolitis in a further 15 infants (Gosa et al. 2011). Thus thickeners should not be used in infants aged less than term corrected age, or those with a recent history of necrotising enterocolitis. Natural thickeners such as rice cereal may be used; however, the cereal may clump, obstruct teats, not thicken fluids uniformly and may also provide additional calories if used to thickened full fluid requirements orally.

Modification of food textures can improve feeding safety and efficiency and reduce fatigue levels. Soft and tough chewable foods require fine motor coordination of the oral phase, and coordination with the pharyngeal phase of swallowing and respiration. Children with mild feeding difficulty may often eat a full range of food textures and chewable foods, and may require simple changes such as softer, slow-cooked meats rather than tough chewable meats or soft, bite-sized portions for chewable foods to maintain efficiency.

Children with severe gross motor impairments may have greater impairment of the oral phase of swallowing and greater risk for choking and asphyxiation. Restricting chewable foods and providing pureed, mashed, 'minced & moist' foods can provide the range of food types in a safer and more easily ingested form, whilst reducing choking risk (Croft 1992).

Nutritional Adequacy, Food Fortification and Supplementation

A diet that includes a wide variety of foods encompassing all of the food groups (cereals and grains, meats and meat alternatives, dairy and dairy alternatives, fruits and vegetables) is key to nutritional adequacy (Evans et al. 2018) but can be difficult to achieve in children with NI. Including protein rich foods three times per day will assist with meeting protein requirements. Meats can be pureed, minced or prepared using methods to ensure a soft texture and alternatives such as eggs, lentils, legumes and ground nuts can be used. Dairy products and other calcium rich alternatives are convenient and simple ways of including high energy and high protein foods. Homemade milk drinks prepared using additional dried milk powders, cream, ice cream, yoghurts and flavourings boost protein and energy content. Fruits and vegetables provide valuable micronutrients and fibre, but are typically low in energy and protein. The energy content of vegetables and fruits can be increased through adding extra fats/oils and protein rich foods. Examples of extra fats and oils that can be added to foods to provide 100kcal are included in Table 9.2. These can significantly increase the total energy content of many meals and snacks and assist with weight gain.

Care should be taken when using these 100kcal boosters. A high reliance on dairy products and these high energy additions to foods and fluids may result in displacement of other foods with valuable micronutrient content.

Table 9.2 100kcal boosters for food and fluid fortification

100kcal boosters	Examples of use
15g butter or margarine	Add to meats and vegetables
30mL pouring cream	Add to fruits, breakfast cereals
	Include in milkshakes
20mL double cream	Add to fruits, breakfast cereals
50g mashed avocado	Blend into milkshakes
	Serve with mashed banana
20g ground almond or other nuts	Add to porridge, include in baked goods
30g grated cheese	Stir through mashed vegetables
	Include cheese sauce with main meals
20g peanut butter or other nut spreads	Stir through vegetables for a satay-style flavour
65g egg	As a snack or mashed into vegetables

Micronutrient deficiencies occur in children with NI due to low micronutrient intakes (see Chapter 8) and can be secondary to low energy requirements, a reduced range of foods consumed and high reliance on fluids (Penagini et al. 2015). Dietary intakes of energy, macronutrients and micronutrients should be assessed and compared against estimated requirements for the child's age and sex. Supplementation may be required to ensure intakes are adequate. Numerous commercial supplements are available for oral use. Some can be added to usual foods or fluids to boost intakes of particular nutrients (such as carbohydrate polymers, protein powders, oils, combined carbohydrate and fat supplements, and vitamin and mineral supplements). Protein powders can be used when protein intakes are inadequate and intake cannot be increased sufficiently through the use of foods. Vitamin and mineral supplementation will be required when dietary intakes are inadequate or when micronutrient deficiency is diagnosed (see Chapter 8). Routine supplementation of vitamin D, regardless of dietary intake, has been recommended for all children with physical disabilities at risk of osteoporosis (Ozel et al. 2016). Other milk- or juice-based oral supplements (sip feeds) contribute significant protein and energy in a nutrient dense and convenient way whilst providing additional micronutrients. There are high energy density varieties and fibre containing options depending on the needs of the child. When fortifying foods and fluids using commercial supplements, care must be taken to ensure dietary intakes for nutrients are adequate and that upper limits for individual nutrients are not exceeded (Bell & Samson-Fang 2013).

Enteral Tube Feeding

Enteral tube feeding is indicated for children who have a functioning gastrointestinal tract and are unable to meet their nutritional requirements through oral intake alone.

For children with NI, the need for enteral tube feeding will be highly related to the child's feeding and swallowing function (Fig. 9.1). In circumstances where weight gain or mealtime safety continues to be poor despite a trial of oral nutrition support and the interventions discussed above, adjunctive tube feeding is appropriate. For children with an unsafe swallow on all food and fluid textures and/or with severe undernutrition, enteral tube feeding will be the first treatment option. For these children, a speech pathologist can be consulted to determine the child's safety for oral tastes, and strategies that may be incorporated to encourage oral exploration and sensorimotor input.

Route of Delivery for Enteral Tube Feeding

The choice of route for delivery of tube feeds depends on the anticipated length of time tube feeding is required, gastrointestinal symptoms (gastroesophageal reflux disease [GORD], vomiting), risk of pulmonary aspiration and previous feed tolerance (if relevant). Most often, tubes are inserted via the nasal passage, or through a stoma into the abdominal wall and tube feeds are delivered via the gastric or postpyloric route.

Nasogastric tubes are soft flexible tubes that are inserted into the stomach via the nasal passage for gastric feeding. They are relatively quick to place, do not require a general anaesthetic, and are suitable for short-term (less than six weeks) tube feeding or as a trial run prior to gastrostomy insertion to provide a period of nutritional rehabilitation and determine any issues with feed tolerance (Bell & Samson-Fang 2013). Gastrostomy tubes (e.g. Percutaneous Endoscopic Gastrostomy or low profile button device) require surgical placement directly into the stomach through an opening in the abdominal wall. For children with severe GORD and to minimise risk of aspiration, an antireflux procedure (i.e. fundoplication) may be done at the same time as gastrostomy placement. Nasogastric tubes have higher rates of discomfort and complications (irritation, ulceration and bleeding, particularly of the nasal passage; displacement and blockages) and require more frequent replacement (Romano et al. 2017), thus gastrostomy is usually the preferred route for longer-term tube feeding (see Chapter 10). Both nasogastric and gastrostomy feeds improve nutritional status in children with NI, often accompanied by improved perception of wellbeing (Romano et al. 2017).

For children with severe reflux and vomiting impacting on their ability to gain weight, and those at high risk of aspiration, feeding directly into the jejunum or postpyloric feeding (nasojejunal, gastrojejunal and jejunal) may be considered. Nasojejunal tubes, similar to nasogastric tubes, enter the enteric tract via the nasal passage with the terminal end placed in the jejunum for postpyloric feeding; gastrojejunal tubes are a combination of a gastrostomy with a tube that extends into the jejunum; and jejunal tubes are inserted directly into the jejunum through an opening in the abdominal wall. Since the jejunum is unable to act as a reservoir, jejunal feeds must be given continuously to prevent diarrhoea and dumping syndrome. This, in combination with the high risk of

complications, limits the clinical utility of postpyloric feeding (Romano et al. 2017). Where possible, gastric feeding is the preferred route for enteral tube feeding.

Enteral Tube Feeding Regimens

Enteral feeding regimens can be tailored to suit an individual child's and family's needs. Regimens can include bolus feeds, intermittent or continuous feeds, or a combination of these depending on the child's route of enteral access, feed tolerance, oral intake, volume of feed required, daily activities, and family routine and lifestyle (Bell & Samson-Fang 2013; Romano et al. 2017).

Whilst continuous feeding is necessary for children with postpyloric feeding tubes, breaks in feeding can be provided to allow for activities requiring time away from the feeding pump each day. Continuous feeds are often recommended for children with poor feed tolerance/severe GORD, and those with a high risk of pulmonary aspiration, although published data to support this are limited (Romano et al. 2017). Bolus feeding allows a more flexible feeding schedule, allows development of the hunger–satiety cycle to assist with oral feeding, provides greater opportunity for oral intake, and allows more flexibility for other daily activities. For children able to consume food orally, timing bolus feeds after meals provides opportunity for the development of hunger; and where appropriate can allow for flexibility in the size of the bolus feed, dependent on oral intake. For children with higher energy needs and poor feed tolerance, a combination of overnight continuous feeds and daytime bolus feeds may provide the benefits of both types of feeding regimens whilst achieving adequate nutrition.

Types of Feeds

Formula selection for a child with NI will be dependent on the child's age, energy requirements, need for nutritional rehabilitation or maintenance, gastrointestinal complications (e.g. GORD, constipation) and previous feed tolerance. Standard (1kcal/mL, 4.2kJ/mL) polymeric formulas, with nutrient compositions adapted for different age groups, are suitable; however, because of the high prevalence of constipation in this group, The European Society for Paediatric Gastroenterology, Hepatology and Nutrition have recommended use of an age appropriate, standard polymeric feed with added fibre for children with NI older than 1 year of age (Romano et al. 2017). A high energy density formula (1.5kcal/mL or 6.3kJ/mL) can be used for children with high energy requirements due to high energy expenditure or nutritional rehabilitation, and can also be used for those with poor tolerance of large feed volumes. In these instances, hydration should be carefully monitored (Romano et al. 2017).

Meeting micronutrient requirements for children with low energy needs can be challenging. Low energy density formulas provide a higher micronutrient composition, relative to

energy density; however, additional micronutrient supplementation may still be required. Care should be taken to ensure upper limits of individual nutrients are not exceeded.

Blended Tube Feeds: Pros and Cons

The use of blended diets as tube feeds involves the preparation of pureed foods, thinned with liquid to a consistency that can be administered through an enteral feeding tube. Largely driven by carers and families, there has been a resurgence of interest in blended tube feeds as alternatives to commercial formula. However, a recent rapid review found little evidence in favour of blended tube feeds, and the risks regarding safety, nutrition and practical issues remain (Coad et al. 2017). There is some limited evidence to support a reduction in diarrhoea in infants (Kolacek et al. 1996). Claims of reduced gagging and retching following fundoplication surgery (Pentiuk et al. 2011) are not supported by controlled trials. Risks include inadequate energy, protein, fluid and micronutrient intakes (Sullivan et al. 2004; Coad et al. 2017) resulting in micronutrient deficiency and inadequate weight gain (Pentiuk et al. 2011; O'Hara 2015). Contamination can occur during feed preparation with increased risks of infection. Blended tube feeds are more viscous than commercially prepared formula and may result in more frequent tube blockages (Sullivan et al. 2004). The balance of evidence remains in favour of commercially prepared formulas utilising a closed enteral feeding system. Commercial formulas are of known nutritional composition, are easily quantifiable and can be administered with confidence that a child will be meeting their nutritional requirements in a safe way. If, when presented with the pros and cons of blended diets as tube feeds, parents/caregivers wish to continue with this method of feeding, caution should be exercised to ensure safety and nutritional adequacy, with regular monitoring to ensure appropriate weight gain and micronutrient status. It is worth noting that the British Dietetic Association do not recommend the use of blended diets and tube feeds; however, more recently, The European Society for Paediatric Gastroenterology, Hepatology and Nutrition have advised caution if they are used (British Dietetic Association 2016; Romano et al. 2017). The British Dietetic Association do recommend that dietitians work in partnership with their patient and carer to ensure that their emotional needs and preferences are taken into account and that an informed decision can be made about the use of blended diets of tube feeds for the child (British Dietetic Association 2016).

TRAINING NEEDS OF CAREGIVERS

Collaboration with caregivers and mealtime support staff is critical for all aspects of mealtime management discussed in this chapter, both oral and enteral nutrition. Working closely with caregivers can assist clinicians in providing meaningful and appropriate strategies that are responsive to both the child and family's needs and capacity. Thorough,

multimodal education and training improves knowledge and skills of caregivers and can reduce the incidence of complications (constipation, diarrhoea and abdominal distension) associated with tube feeding (Chang et al. 2015). By encouraging caregivers to understand the underlying rationale for management decisions as well as the risks associated with not following recommendations, uptake and maintenance of strategies may be improved (Dadds et al. 1984; Chadwick et al. 2002). Recommended strategies to ensure competence include step by step guides, education pamphlets, video recordings and personalised demonstrations by clinicians combined with caregiver return demonstration (Chang et al. 2015). For children commencing tube feeds, information and education is required on the following:

- The goals of tube feeding and anticipated duration
- A written individualised feeding regimen
- Care and cleaning of the feeding tube and skin surrounding the tube
- Methods to confirm tube placement (for nasogastric tubes)
- General hygiene to prevent infection
- Preparation of feeds
- Role and use of equipment including pumps, giving sets, syringes, feed containers etc.
- Troubleshooting and management of potential minor complications
- Advice regarding what to do in an emergency, when to contact a health professional
- Telephone contacts for hospital and community staff
- Detailed information about how to obtain ongoing supplies of equipment and feeds
- Information regarding oral care and hygiene

For children able to consume food orally, tangible and routine goals and adaptive equipment are more likely to be maintained by caregivers than general strategies such as pacing and verbal prompts, and as such these should be emphasised (Chadwick et al. 2002). Further, helping caregivers learn to recognise signs and behaviours during their child's mealtime forms a critical foundation for subsequent strategy use and maintenance, and appropriate and timely professional review (Dadds et al. 1984). Parents/caregivers can learn to identify even specific clinical signs, such as those associated with aspiration, if adequate description and training is provided (Benfer et al. 2015). Practical training in the specific mealtime strategies may include modelling by the therapist, rehearsal or roleplay, and parent quizzes. Implementation at home should ideally be supported by therapist phone contact during the week, in addition to regular face to face appointments to provide feedback and troubleshooting (Dadds et al. 1984).

FOLLOW-UP ARRANGEMENTS

Ongoing MDT monitoring and evaluation of nutrition support for children with NI is essential to ensure ongoing safety, to detect and treat any potential complications, to ensure that nutritional requirements are met and nutritional status is adequate, to re-evaluate the goals of nutrition support and to modify interventions appropriately (see Chapter 7).

Adequacy of energy and protein intake can be monitored objectively through assessment of weight gain and linear growth in children with NI. Individual energy prescription should be altered based on the appropriateness of the child's weight gain, taking into account body composition, as well as changing requirements as children get older. Adequacy of micronutrient intake should be assessed through dietary analysis with measurements of serum levels for individual nutrients when dietary intakes are low. Annual assessment of micronutrient status has been recommended (Romano et al. 2017). Supplementation of calcium should be dependent on diet history as serum levels are not indicative of inadequate intake. Monitoring of gastrointestinal function (for constipation/diarrhoea, GORD, feed intolerance) may lead to alterations in formula and diet prescription, changes to feeding regimens, or alterations to medications. For children with feeding tubes, the integrity of the tube needs to be monitored as well as care of the stoma site.

Frequency of monitoring by the MDT will depend on the age of the child, their nutritional status, nutrient deficiencies, feed tolerance issues, oral sensorimotor/swallowing skill and development, and the general level of support that the family requires. For undernourished children on an initial trial of oral nutrition support, follow-up in 1–3 months is appropriate (Romano et al. 2017). Infants and severely malnourished children will require more frequent follow-up. Children who are gaining weight and growing well should be followed up at a minimum of annually (Mascarenhas et al. 2008). Clinical evaluation of feeding and swallowing should occur annually in children with moderate–severe feeding impairment, with instrumental evaluation occurring when the child's feeding/swallowing has changed or growth-related anatomical change of the head and neck has occurred.

REFERENCES

Arvedson JC (1998) Management of pediatric dysphagia. *Otolaryngol Clin North Am* 31: 453–476.

Arvedson JC (2013) Feeding children with cerebral palsy and swallowing difficulties. *Eur J Clin Nutr* 67(Suppl 2): S9–12.

Babbitt RL, Hoch TA, Coe DA et al. (1994) Behavioral assessment and treatment of pediatric feeding disorders. *Dev Behav Pediatr* 15: 278–291.

Bell KL, Samson-Fang L (2013) Nutritional management of children with cerebral palsy. *Eur J Clin Nutr* 67(Suppl 2): S13–16.

Benfer KA, Weir KA, Bell KL, Ware RS, Davies PSW, Boyd RN (2013) Oropharyngeal dysphagia and gross motor skills in children with cerebral palsy. *Pediatrics* e1553–e1562.

Benfer KA, Weir KA, Bell KL, Ware RS, Davies PSW, Boyd RN (2015) Clinical signs suggestive of pharyngeal dysphagia in preschool children with cerebral palsy. *Res Dev Dis* 38: 192–201.

Bisch EM, Logemann JL, Rademaker AL, Kahrilas PJ, Lazarus C (1994) Pharyngeal effects of bolus volume, viscosity, and temperature in patients with dysphagia resulting from neurologic impairment and in normal subjects. *J Speech Lang Hearing Res* 37: 1041–1049.

British Dietic Association (2016) *Policy Statement: Use of Liquidised Food with Enteral Feeding Tubes*. Birmingham: The British Dietetic Association.

Burklow KA, McGrath AM, Kaul A (2002) Management and prevention of feeding problems in young children with prematurity and very low birth weight. *Inf Young Child* 14: 19–30.

Chadwick DD, Joliffe J, Goldbart J (2002) Carer knowledge of dysphagia management strategies. *Int J Lang Comm Dis* 37: 345–357.

Chang SC, Huang CY, Lin CH, Tu SL, Chao MS, Chen MH (2015) The effects of systematic educational interventions about nasogastric tube feeding on caregivers' knowledge and skills and the incidence of feeding complications. *J Clin Nurs* 24: 1567–1575.

Christiaanse ME, Mabe B, Russell G, Simeone TL, Fortunato J, Rubin B (2011) Neuromuscular electrical stimulation is no more effective than usual care for the treatment of primary dysphagia in children. *Pediatr Pulmon* 46: 559–565.

Cichero JA, Lam P, Steele CM et al. (2017) Development of international terminology and definitions for texture-modified foods and thickened fluids used in dysphagia management: the IDDSI framework. *Dysphagia* 32: 293–314.

Coad J, Toft A, Lapwood S et al. (2017) Blended foods for tube-fed children: a safe and realistic option? A rapid review of the evidence. *Arch Dis Child* 102: 274–278.

Craig GM, Scambler G, Spitz L (2003) Why parents of children with neurodevelopmental disabilities requiring gastrostomy feeding need more support. *Dev Med Child Neurol* 45: 183–188.

Croft RD (1992) What consistency of food is best for children with cerebral palsy who cannot chew? *Arch Dis Child* 67: 269–271.

Dadds MR, Sanders MR, Bor B (1984) Training children to eat independently: Evaluation of meatlime management training for parents. *Behav Psych* 12: 356–366.

Evans C, Hutchinson J, Christian MS, Hancock N, Cade JE (2018) Measures of low food variety and poor dietary quality in a cross-sectional study of London school children. *Eur J Clin Nutr* 72(11): 1497–1505.

Gisel EG (1996) Effect of oral sensorimotor treatment on measures of growth and efficiency of eating in the moderately eating-impaired child with cerebral palsy. *Dysphagia* 11: 48–58.

Gisel EG, Tessier MJ, Lapierre G, Seidman E, Drouin E, Filion G (2003) Feeding management of children with severe cerebral palsy and eating impairment: an exploratory study. *Phys Occ Ther Pediatr* 23: 19–44.

Gosa MM, Schooling T, Coleman J (2011) Thickened liquids as a treatment for children with dysphagia and associated adverse effects: A systematic review. *ICAN* 344–350.

Helfrich-Miller KR, Rector KL, Straka JA (1986) Dysphagia: its treatment in the profoundly retarded patient with cerebral palsy. *Arch Phys Med Rehabil* 67: 520–525.

Hulme JB, Poor R, Schulein M, Pezzino J (1983) Perceived behavioral changes observed with adapted seating devices and training programs for multihandicapped, developmentally disabled individuals. *Phys Ther* 63: 204–208.

Hwang Y, Lin C, Coster WJ, Bigsby R, Vergara E (2010) Effectiveness of cheek and jaw support to improve feeding performance of preterm infants. *Am J Occ Ther* 64: 886–894.

Inal O, Serel Arslan S, Demir N, Tunca Yilmaz O, Karaduman A (2017) Effect of Functional Chewing Training on tongue thrust and drooling in children with cerebral palsy: a randomised controlled trial. *J Oral Rehab* 44: 843–849.

Kaviyani Baghbadorani M, Soleymani Z, Dadgar H, Salehi M (2014) The effect of oral sensorimotor stimulations on feeding performance in children with spastic cerebral palsy. *Acta Med Iran* 52: 899–904.

Kolacek S, Grguric J, Percl M, Booth IW (1996) Home-made modular diet versus semi-elemental formula in the treatment of chronic diarrhoea of infancy: a prospective randomized trial. *Eur J Pediatr* 155: 997–1001.

Lanert G, Ekberg O (1995) Positioning improves the oral and pharyngeal swallowing function in children with cerebral palsy. *Acta Paediatrica* 84: 689–692.

Law-Morstatt L, Judd DM, Snyder P, Baier RJ, Dhanireddy R (2003) Pacing as a treatment technique for transitional sucking patterns. *J Perinatol* 23: 483–488.

Logemann JA (1998) *Evaluation and Treatment of Swallowing Disorders.* Austin, TX: PRO-ED.

Mascarenhas MR, Meyers R, Konek S (2008) Outpatient nutrition management of the neurologically impaired child. *Nutr Clin Pract* 23: 597–607.

Mathisen B, Skuse D, Wolke D, Reilly S (1989) Oral-motor dysfunction and failure to thrive among inner-city infants. *Dev Med Child Neurol* 31: 293–302.

Mirrett PL, Riski JE, Glascott J, Johnson V (1994) Videofluoroscopic assessment of dysphagia in children with severe spastic cerebral palsy. *Dysphagia* 9: 174–179.

Morris SE, Klein MD (2000) *Pre-Feeding Skills, Second Edition: A Comprehensive Resource for Mealtime Development.* United States: TSB/Harcourt.

Morton RE, Bonas R, Fourie B, Minford J (1993) Videofluoroscopy in the assessment of feeding disorders of children with neurological problems. *Dev Med Child Neurol* 35: 439–448.

O'Hara C (2015) Scurvy related to the use of a homemade tube feeding formula. *Inf Child Adolesc Nutr* 7: 381–384.

Ozel S, Switzer L, Macintosh A, Fehlings D (2016) Informing evidence-based clinical practice guidelines for children with cerebral palsy at risk of osteoporosis: an update. *Dev Med Child Neurol* 58: 918–923.

Penagini F, Mameli C, Fabiano V, Brunetti D, Dilillo D, Zuccotti GV (2015) Dietary intakes and nutritional issues in neurologically impaired children. *Nutrients* 7: 9400–9415.

Pentiuk S, O'Flaherty T, Santoro K, Willging P, Kaul A (2011) Pureed by gastrostomy tube diet improves gagging and retching in children with fundoplication. *J Parent Enter Nutr* 35: 375–379.

Ptomey LT, Wittenbrook W (2015) Position of the Academy of Nutrition and Dietetics: nutrition services for individuals with intellectual and developmental disabilities and special health care needs. *J Acad Nutr Diet* 115: 593–608.

Reau NR, Sentunce YD, Lelailly SA, Christoffel KK (1996) Infant and toddler feeding patterns and problems: Normative data and a new direction. *J Dev Behav Pediatr* 17: 149–153.

Romano C, Van Wynckel M, Hulst J et al. (2017) European Society for Paediatric Gastroenterology, Hepatology and Nutrition guidelines for the evaluation and treatment of gastrointestinal and nutritional complications in children with neurological impairment. *J Pediatr Gastroent Nutr* 65: 242–264.

Sharp WG, Jaquess DL, Morton JF, Herzinger CV (2010) Pediatric feeding disorders: a quantitative synthesis of treatment outcomes. *Clin Child Fam Psych Rev* 13: 348–365.

Snider L, Majnemer A, Darsaklis V (2011) Feeding interventions for children with cerebral palsy: a review of the evidence. *Phys Occ Ther Pediatr* 31: 58–77.

Stavness C (2006) The effect of positioning for children with cerebral palsy on upper-extremity function. *Phys Occ Ther Pediatr* 26: 39–53.

Steele CM, Alsanei WA, Ayanikalath S et al. (2015) The influence of food texture and liquid consistency modification on swallowing physiology and function: a systematic review. *Dysphagia* 30: 2–26.

Stratten M (1981) Behavioural assessment scale of oral functions in feeding. *Am J Occ Ther* 35: 719–721.

Sullivan MM, Sorreda-Esguerra P, Platon MB et al. (2004) Nutritional analysis of blenderized enteral diets in the Philippines. *Asia Pac J Clin Nutr* 13: 385–391.

Toomey KA, Ross ES (2011) SOS Approach to feeding. *SIG 13 Persp Swall Swall Dis (Dysphagia)* 20: 82–87.

Weir K, McMahon S, Barry L, Masters IB, Chang AB (2009) Clinical signs and symptoms of oropharyngeal aspiration and dysphagia in children. *Eur Resp J* 33: 604–611.

Weir KA, McMahon S, Taylor S, Chang AB (2011) Oropharyngeal aspiration and silent aspiration in children. *Chest* 140: 589–597.

Winstock A (2005) *Eating and Drinking Difficulties in Children: A Guide For Practitioners.* New York: Routledge.

Conclusion

Guro L Andersen

In this volume some of the world's leading experts in the field have contributed their knowledge and expertise. This work is intended to assist those multidisciplinary clinical teams responsible for follow-up and treatment of children with neurodisability by providing an up-to-date handbook to aid their decisions regarding assessment and management in these children.

The handbook is a further elaboration of two previous books (1996 and 2009) published by Mac Keith Press dealing with the challenges of feeding and nutrition in children with neurodisability. Because of growing interest and research in this field during the last decade, it seemed timely to produce an update. Thus, the overall aim of this book has been to produce a practical handbook useful for both clinicians new in the field and those more experienced. Many of the chapters have included case reports to underline the message of the chapters.

The first chapter of the book, 'The Normal Development of Oral Motor Function: Anatomy and Physiology', provides a sound basis for understanding the various forms of oromotor problems and feeding difficulties children with neurodisability may experience.

In Chapter 2, '"When Things Go Wrong": Causes and Assessment of Oral Sensorimotor Dysfunction', Diane Sellers has used the International Classification of Functioning, Disability and Health as a framework to explore possible challenges and deviations from typical development of eating and drinking. She emphasises that 'a child's ability

to respond automatically, efficiently and comfortably to eating and drinking experiences will be affected by disturbances to sensory processing which include altered registration of sensory input, excessive or low levels of reaction to sensation, limited sensory discrimination, difficulty integrating information and difficulty planning motor responses.' Some standardised clinical assessment tools and eating and drinking ability scales are listed as well as suggestions for instrumental assessments (videofluoroscopy of swallowing and fibreoptic endoscopic evaluations of swallow) and their advantages and disadvantages. Regarding the instrumental assessments, Dr Sellers concludes that the results of investigations must always be interpreted in the context of the clinical picture and the child's quality of life.

Chapter 3, 'Oral Health and Sialorrhea', confirms that there are no intraoral anomalies unique to children with neurodisabilities. However, challenges with oral health and drooling (sialorrhea) are more common than in the typically developing child. Anterior drooling is visible, may cause skin breakdown, predispose to *Candida* infection and has social implications. On the other hand, posterior drooling is not visible but is associated with more clinically significant morbidity. Dr Laurie Glader recommends using the Teacher Drooling Scale for quantifying anterior drooling while posterior drooling is diagnosed by history taking (asking about cough, gagging, choking and recurrent respiratory infections), by clinical examination and/or by identifying aspiration by fiberoptic nasopharyngoscopy and laryngoscopy. Advice is given on possible therapeutic interventions and pharmacological interventions including anticholinergic medications, glycopyrrolate and/or botulinum toxin injection.

Chapter 4, 'Gastrointestinal Problems in Children with Neurodisability: Causes, Symptoms and Management', gives an overview of the most common gastrointestinal problems encountered in children with neurological impairment. Overall, more than 90% of children with neurodisability have gastrointestinal problems like dysphagia/oropharyngeal dysfunction, gastroesophageal reflux or chronic constipation. Oropharyngeal aspiration is present in almost 70% of the most severely impaired children and may cause severe morbidity, so Ilse Broekaert recommends that oropharyngeal dysfunction should be considered in all children with neurodisability even in the absence of obvious clinical signs and symptoms. To diagnose aspiration, imaging diagnostic techniques should be used, of which the gold standard is videofluoroscopy. Gastroesophageal reflux disease is another very common problem and, as these children may be very fragile, a trial of proton pump inhibitors with careful clinical follow-up is an acceptable management. Upper gastrointestinal endoscopy is the method of choice to evaluate oesophageal damage and lower oesophageal pH studies can quantify the exposure of the oesophageal mucosa to acid. Treatment in children consists of lifestyle changes, pharmacological therapies and surgical treatment but the use of proton pump inhibitor treatment is regarded as the most appropriate and cost-effective means of managing long-term gastroesophageal reflux disease in neurologically impaired children.

Chronic constipation affects up to 70% of children with neurodisability and is generally believed to be the result of both neurological and lifestyle factors. Dietary intake of water and fibre is often below the recommended amount and a number of drugs may adversely affect bowel intestinal transit time. Investigations may include transabdominal ultrasound to assess the rectal filling state, or exceptionally an abdominal radiograph. Treatment should follow the standard for typically developing children.

Chapter 5, 'Consequences of Nutritional Impairment' by Jessie M Hulst, gives an overview of clinical consequences of undernutrition, malnutrition and poor nutritional status due to inadequate nutritional intake such as growth failure, cerebral dysfunction, decreased muscle strength and micronutrient deficiencies. The importance of systematic nutritional assessments for all children with neurodisability to avoid nutritional-related comorbidities is emphasised.

In Chapter 6, 'Assessment of Nutritional State: Growth, Anthropometry and Body Composition', Jane Hardy and Hayley Kuter provide an outline of different anthropometric measures relevant for children with neurodisability. In general, they state that weight cannot be used in isolation to assess nutritional status and they emphasise the need for body composition assessment in this group of children.

In Chapter 7, 'Assessment of Nutritional State: Dietetic, Energy and Macronutrients', Kristie Bell and Jacqueline Walker describe possible methods of dietary assessment including the advantages, disadvantages and validity of use in children with neurodisability as well as the clinical utility of each method. They conclude that there is no one method that will assess dietary intake accurately and that the choice of method will depend on the purpose of the dietary intake assessment, the setting and the ability of the parents/carers to be involved. The chapter also includes recommendations on how to estimate energy requirements which are generally lower than in typically developing children while macronutrient, micronutrient and fluid requirements should be based on recommendations for typically developing children and adjusted as required.

In Chapter 8, 'Assessment of Nutritional State: Micronutrient Deficiencies and Bone Health', Steven Bachrach and Heidi Kecskemethy include specific recommendations on how to assess, diagnose and treat compromised bone health in individuals with neurodisability. In children with neurodisability the combination of atypical muscle tone combined with lack of weight bearing results in reduced bone density. It is thus important to ensure sufficient dietary intake of calcium, phosphorus and vitamin D. While adults are treated with a number of different medications and the decision is based solely on the results of bone density assessments, children are sometimes treated for low bone density alone, while others are treated only after a fragility fracture has occurred. Ensuring adequate intake of vitamin D and calcium is essential to help reduce the incidence of fragility fractures but often bisphosphonates are indicated in the treatment of osteopenia/osteoporosis in children with cerebral palsy.

In Chapter 9, 'Feeding and Nutritional Management Strategies', Kristie Bell, Katherine Benfer and Kelly Weir strongly recommend that multidisciplinary teams are needed to evaluate and plan treatment and interventions of nutritional challenges in children with neurodisability. Examples of interventions include correction of micronutrient deficiencies, initiating complete enteral tube feeding, support of mealtime environment and positioning, alterations to food/fluid textures and nutrient density, use of adaptive equipment, caregiver techniques and sensorimotor therapy. In addition, this chapter includes a comprehensive list of possible feeding utensils to provide nutrition safely and efficiently as well as to assist in the development of feeding and swallowing skills.

Chapter 10, 'Enteral Tube Feeding: Practical and Ethical Considerations', starts by stating that although at least a third of children with moderate to severe cerebral palsy will have feeding difficulties, malnutrition should not be considered normal in any child with cerebral palsy. The chapter gives an overview of indications of gastrostomy, methods of insertion, complications, benefits and some considerations about timing of insertion. The chapter also includes ethical considerations regarding the difficult decision parents are required to face when deciding whether or not their child should have a gastrostomy. An important point to remember is that most studies show that the majority of parents would have agreed to earlier gastrostomy feeding of their children had they been fully aware of its potential benefits. The great majority of studies to date report significant weight gain after gastrostomy with the obvious corollary that there is little or no weight gain in undernourished children with cerebral palsy without intervention.

Index

NOTE: Figures and tables are denoted with a lower case, italicised *f* or *t* respectively and then their number. (ie. 1*f*1.1)

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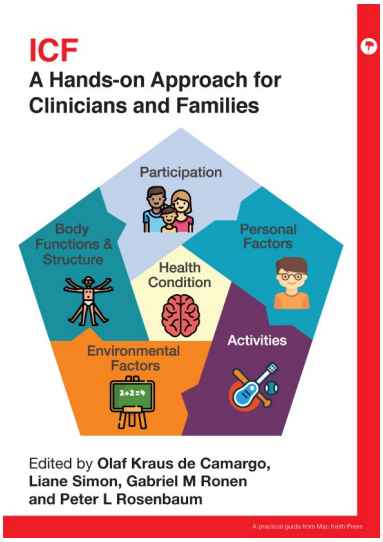

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