ABSTRACT

NUTRITIONAL ASSESSMENT AND INTERVENTION IN CHILDREN WITH SEVERE NEUROLOGICAL DISABILITIES

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Providing adequate nutrition to children with severe neurological disabilities is extremely difficult due to the high prevalence of oral-motor dysfunction in this group. Short stature and light weight for height are common in disabled children and undernutrition is believed to play a role in this poor growth.

This programme of study investigated the effect of gastrostomy-tube feeding in disabled children with oral-motor dysfunction and evaluated the energy balance and body composition of disabled children fed both orally and via gastrostomy-tube over twelve months. The Quality of Life of the children and their carers was also evaluated.

Energy intake was measured using three-day dietary diaries and energy expenditure with indirect calorimetry and doubly labelled water. Total body water using oxygen-18 dilution was used to evaluate body composition along with standard anthropometry.

Improved growth, nutritional status and general health were seen at six and twelve months after gastrostomy-tube placement. The Quality of Life of the children and their carers also significantly increased. Both energy intake and energy expenditure were found to be lower than reference standards, but energy balance was positive indicating that inadequate nutrition was not the sole cause of poor growth. Body composition was also found to be significantly different from reference. Fat-free mass was significantly low for age and for height. Fat mass was higher in gastrostomy-tube fed children, but lower or normal in disabled children fed orally. Physical activity levels were low for the entire group of disabled children yet the gastrostomy-tube fed children displayed much higher levels of disability.

Gastrostomy-tube feeding has a positive impact upon the growth, health and Quality of Life of disabled children and their carers. Careful follow-up is critical in order to optimize health and body composition.

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DEDICATION:

For Daddy and Andrew, who should have been the Rhodes Scholars.

ACKNOWLEDGEMENTS:

Thank you to:

Angharad Vernon-Roberts, Dr. Peter Sullivan, Dr. Jonathan Wells, Dr. Justin Warner, and Lyn Stirling for their contributions and support.

And to:

Mr. Hugh Grant, Bridget Lambert, Ed Juszczak, Crispin Jenkinson, and Dr. Jeya Henry.

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SECTION ONE: INTRODUCTION

1.1 CEREBRAL PALSY AND FEEDING DIFFICULTIES

Definition

"Little's disease", or "cerebral palsy" (CP), was first described by William Little (1810-1894) as "spastic rigidity of the limbs of newborns" in The Lancet, 1844. Drs. MacKeith and Polani suggested "a persisting qualitative motor disorder appearing before the age of three years, due to a non-progressive disorder of the brain" as a functional definition for CP and presented it to the "Little Club" (a group of paediatricians and neurologists) for discussion in 1958 (MacKieth, MacKenzie et al. 1959).

This definition, still in use today, infers nothing about pathology, aetiology or prognosis, but is an umbrella term used to describe a range of cerebral disorders in which there is motor impairment due to a malfunction of the brain that manifested itself early in life. Improved diagnostic and imaging techniques (such as chromosomal analyses) have made it possible to exclude or re-classify many cases of childhood motor impairment that would have been considered CP at an earlier date. Conditions that are always excluded are neurodegenerative conditions, neuromuscular disorders, neural-tube defects of the spine, and tumours. Conditions that may be excluded are genetic syndromes, metabolic disorders, syndromes with vascular defects and encephalocele (Badawi, Watson et al. 1998).

Prevalence

A 1987 analysis by Pharoah et al. reported that the mean birth prevalence of CP is 1.51 per 1000 live births (Pharoah, Cooke et al. 1987). The prevalence of CP in low birth weight infants (<1500g) is higher: approximately 1 in 20 low birth weight babies who survive infancy will have CP (Stroke 2003). As survival rates for premature and low birth weight infants improve, the actual number of cases of CP is increasing, yet the prevalence rates among infants of 2500g or more has remained stable. A British Medical Journal report by Tin et al. concluded that the "survival in babies of 24-27 weeks gestation has improved in the past 12 years," but "the proportion of survivors with severe disability (25%) has not changed" (Tin, Wariyar et al. 1997). A study of CP cases in northeast England supports this claim. Although the prevalence rate rose from 1.68 per 1000 live births (1964-1968) to 2.45 (1989-1993), only one third of the cases in the first period consisted of low birth weight infants, compared to half in the second (Colver, Gibson et al. 2000).

Types of CP

CP, a blanket term to incorporate many types of cerebral damage, has several manifestations. Most commonly, CP is classified according to type and topography. The four main types of CP are spastic, athetoid, ataxic and mixed (Stanton 1992). Spastic (pyramidal) CP is caused by damage to the cortex of the brain and results in stiffness of the limbs whereas athetoid CP (extra-pyramidal) results from damage to the basal ganglia or cerebellum and causes involuntary movements and low muscle tone. Children with ataxic CP are usually very unsteady, sometimes shaky, and have poor coordination. The fourth type of CP

is "mixed", indicated when a child does not fit precisely into any of the previous three categories, and may exhibit signs of more than one type. Table 1.1 lists the distribution of these types of CP.

Table 1.1 The Types and Type Distribution of Cerebral Palsy

Type of CP	Distribution (% of cases)
Spastic	Up to 80%
Athetoid	10%
Ataxic	5-10%
Mixed	10%

(Palsy 2003)

Aetiology

CP is usually the result of vascular accidents, hypoxia, infections, or congenital central nervous system (CNS) anomalies (Badawi, Watson et al. 1998). Damage to the brain may occur in utero, during birth, or during the post-natal period. Often, there is no clear indication of when the damage took place and a diagnosis made only when unmet developmental milestones signal cognitive impairment. Feeding difficulties are often the first indication of disability (Reilly and Skuse 1992).

It has been determined that the overall survival rate of those with CP at 30 years is 87%. Analyses by Strauss and Eyman indicate that mobility and feeding skills are the most important predictors of survival in the disabled (Eyman, Grossman et al. 1993; Crichton, Mackinnon et al. 1995; Strauss, Ashwal et al. 1997; Strauss, Shavelle et al. 1998). Similarly, a study by Crichton et al. reported that

the two most detrimental factors to survival in the disabled were immobility and mental disability (Crichton, Mackinnon et al. 1995).

Normal Oral-Motor Development

Infants are born with several feeding reflexes (suck-swallow, rooting, biting, gagging and Babkin's) that gradually disappear as the child develops. Mature feeding skills are attained via a combination of CNS developmental changes and experiential learning (Stevenson and Allaire 1996). Individual feeding skills can be classified as oral, hand to mouth, body positioning or communication. As weaning progresses, children learn and develop the motor abilities to take food from a spoon, tolerate thicker and lumpier foods, feed themselves with their fingers and hold a cup or bottle (Pridham 1990).

Feeding Skills in CP

As mature swallowing involves 31 pairs of striated nerves and four phases (oral-preparatory, oral, pharyngeal and oesophageal) it is not surprising that some children with motor impairment have difficulty developing the motor skills required to feed and swallow (Stevenson and Allaire 1996). Common oral-motor deficits disabled children include:

- Poorly coordinated breathing
- Choking
- Difficulties with sucking and swallowing
- Persistence of the bite reflex
- Tonic biting
- Jaw thrusting

- Tongue thrusting
- Decreased tongue movements
- Failure of tongue lateralization
- Poor lip closure
- Lip retraction
- Drooling
- Hypo- or hypersensitive gag response

(Sullivan and Rosenbloom 1996).

There are numerous other causes of feeding difficulties in disabled children in addition to oral-motor deficits. Infant feeding reflexes often perpetuate, and postural deformity, immobility, dystonia and impaired hand function may create logistical feeding problems. Visual impairments and deafness, as well as cognitive impairment and behavioural problems may hinder the communication required for the development of mature feeding skills. Finally, gastrointestinal dysfunction, which may include gastro-oesophageal reflux (GOR), recurrent aspiration pneumonia and constipation, creates a barrier to feeding (Sullivan and Rosenbloom 1996).

Evidence for the high prevalence of feeding dysfunction in disabled children is overwhelming, yet the phenomenon has been little studied. The proportion of disabled children with feeding problems has been reported as low as one third (Thommessen, Heiberg et al. 1991) and as high as 90% (Reilly, Skuse et al. 1996). Examples of the feeding difficulties experienced range from clinical worries such as choking and aspirating on food to the practical problem of

prolonged feeding times. A recent epidemiological study, the Oxford Feeding Study, revealed that of the children listed on the Oxford Register of Early Childhood Impairments as having oral-motor dysfunction, 89% needed help with feeding and 56% choked with food. Twenty-eight percent of carers reported feeding times of 3 hours or longer per day and 20% said that feeding was stressful and unenjoyable (Sullivan, Lambert et al. 2000). Observational studies have demonstrated that disabled children may require up to 15 times longer to eat a mouthful of food than normal (Gisel and Patrick 1988).

The association between the severity of the oral-motor dysfunction and the severity of the underlying disability is strong. The link between poor nutritional status and extensive oral-motor problems is also clear (Krick and VanDuyn 1984; Thommessen, Heiberg et al. 1991; Thommessen, Kase et al. 1991; Dahl, Thommessen et al. 1996; Sullivan, Lambert et al. 2000; Troughton and Hill 2001; Fung, Samson-Fang et al. 2002).

1.2 GROWTH AND NUTRITIONAL STATUS IN CHILDREN WITH CEREBRAL PALSY

Photograph 1.1 A 15 year-old undernourished Boy with Severe Cerebral Palsy

Normal Growth

Growth is determined by a variety of influences including ethnic, familial, nutritional, and endocrine factors (Tobis, Saturen et al. 1961). Children grow

from the moment they are conceived until they mature at approximately 21 years. The fastest rate of growth occurs during the first months in utero, followed by the rate in the first year of life. Growth slows slightly after that and accelerates again during puberty.

Different terms describe deviation from normal growth. *Stunting* is defined as abnormally short stature for age and *wasting* as low weight for height. *Growth velocity* is the rate of change of stature over time and *growth failure* a deviation from the expected growth curve over time. The existence of a *"critical"* or "*sensitive*" period of growth and the concept of *catch-up growth* are still debated by growth specialists. James Sutphen claims that there is insufficient data to identify this "critical period", or to determine the extent of poor growth that would make catch-up growth impossible (Sutphen 1985).

Growth in CP

The rates of growth and total growth attained by children with CP are far less than those of normal, healthy children and numerous researchers have commented upon this for decades. In 1960, both Sterling and Tobis described how the height and weight of children with CP was less than expected when compared to age and sex matched controls (Sterling 1960; Tobis, Saturen et al. 1961). They also noted that the more severe the disability the greater the deviation from normal and that height was more adversely affected than weight. These observations persist in disabled children today, and high risk factors for poor growth have been identified. Stevenson et al. measured the growth of 171 children with CP in 1994 and found that the mean standard deviation (Z) score

for height was –1.65, and for weight –1.61. They noted that the older the child, the larger the deviation from normal, and that the children at greatest risk for poor growth were those who suffered from seizures, had spastic quadriplegic cerebral palsy (SQCP) and were non-ambulatory (Stevenson, Hayes et al. 1994). Growth failure was identified in a different group of disabled children by Samson-Fang et al. in 1998. They concluded that those most at risk had extrapyramidal or mixed CP, cognitive impairment, malnutrition, microcephaly and were immobile (Samson-Fang and Stevenson 1998).

Nutritional and Other Influences on Growth

The reasons for poor growth in children with neurological disabilities are many and complex. Nutritional supplementation is the only currently used treatment for growth failure (Roberts, Vogtle et al. 1994), yet it has been demonstrated that nutritional factors account for only 10-15% of linear growth failure (Stallings, Charney et al. 1993). Improved nutritional intake in disabled children has been associated with improved nutritional status, increased weight and moderate changes in linear growth by many research groups (Shapiro, Green et al. 1986; Rempel, Colwell et al. 1988; Stallings, Charney et al. 1993; Reilly, Hassan et al. 1996).

The feasibility of catch up growth in this group has been questioned because of reported observations of greatly improved weight, but merely moderate improvement in linear growth. Sutphen has stated that the rate of catch-up growth will depend on the child's age, the amount of nutrients provided, the size of the deficit and the nature of the underlying disease (Sutphen 1985). He also

notes that improvements in linear length and mid-upper arm muscle, which indicate a gain of lean body mass, respond much more slowly to nutritional intervention and need to be monitored over longer lengths of time.

The investigated non-nutritional factors contributing to poor growth in disabled children include medications, endocrine status, ambulation and the CNS injury itself. Kurowski et al. examined the growth of children taking anti-convulsant medications in 1993 and concluded that these drugs did *not* negatively affect linear growth (Kurowski, Gospe et al. 1993). Low levels of growth hormone (GH) were found in a group of disabled children in 1996. Although mild malnutrition was observed in the group, the GH pattern observed was not that characteristic of the malnourished. The researchers postulated that the CNS damage responsible for the children's disability had also caused either a change in the hypothalamic-pituitary axis or in the way the children responded to GH (Coniglio, Stevenson et al. 1996). Krick has explained that non-ambulation could play a major role in explaining poor linear growth. Lack of weight-bearing exercise results in decreased bone formation and increased bone resorption, both of which contribute to decreased bone growth and inhibit the release of growth-stimulating hormones. A study by Chad et al. supports this explanation as bone mineral density, bone mineral content and bone-mineral-free lean tissue were all found to be low in a group of nutritionally adequate children with SQCP (Krick, Murphy-Miller et al. 1996; Chad, McKay et al. 2000). In addition, high muscle tone or spasticity, often observed in disabled children, can inhibit bone growth.

Indisputable support for the role of non-nutritional factors contributing to the poor growth seen in disabled children comes from a study by Stevenson and Roberts. Investigating the skeletal maturation of children with hemiplegia and adequate nutritional status, they found that the mean difference in bone age between the affected and non-affected side was 7.3 months. This indicates that the underlying disability has a significant impact on growth, regardless of nutritional status (Roberts, Vogtle et al. 1994; Stevenson, Roberts et al. 1995).

The Risks of Undernutrition

Diminished growth is perhaps the most obvious consequence of poor nutritional status, but there are many other serious concerns. A decrease in muscle strength may occur and perpetuate poor muscular control and function (Russell, Leiter et al. 1986; Rigaud, Moukaddem et al. 1997). Weak musculature in the respiratory system reduces the effectiveness of the cough reflex and increases the risk of aspiration pneumonia (Efthimiou, Fleming et al. 1988), especially when compounded by the predisposition to infections (secondary to immune system weakness) that can result from a poor nutritional status (Santos 1994). A prolonged circulation time and diminished cardiac work capacity have been observed in many malnourished children and manifest as cold peripheries and a susceptibility to congestive heart failure if placed under cardio respiratory stress (Viart 1977; Viart 1978). Finally, a common problem in this group of children, gastro-oesophageal reflux, has been shown to improve with nutritional rehabilitation (Lewis, Khoshoo et al. 1994).

Chronic undernutrition may also exacerbate the children's neurological impairment and have a negative impact upon socialization and quality of life. Improvement in nutritional status has been linked to significant developmental and motor improvements, as well as cognitive development (Sanders, Cox et al. 1990; Granthan-McGregor, Powell et al. 1991; Husaini, Karyadi et al. 1991). Irritability, decreased energy for play, decreased exploratory activities and lowered socialization have also been linked to undernutrition (Stewart, Sheppard et al. 1980; Stallings, Charney et al. 1993; Samson-Fang, Fung et al. 2002).

Overnutrition

Overnutrition is starting to emerge as a problem in disabled children. Consequences of overnutrition and obesity in this group include worsened spinal problems and poor respiratory and cardiac function. Practical problems for the children's carers, such as having to lift and bathe a heavy child, may also arise (Bax 1993).

Nutritional Assessment

Growth has traditionally been the most reliable and commonly used measure of nutritional status in children (Sutphen 1985). Height and weight are relatively easy measures to take, and growth charts were established for clinical use in the 1940s. In children with CP, however, the assessment of growth is often very difficult. Many disabled children are unable to stand on a weighing scale or at a stadiometer, and muscle/joint contractures or scoliosis may prevent an accurate measurement of full body length. To combat these problems special bed or chair scales have been developed to ensure accurate weights are obtainable in this

population. Segmental limb lengths (lower leg or upper arm) are advocated to monitor linear growth (Stevenson 1996).

Skinfold thickness measures are an alternative measure of nutritional status used in both disabled and healthy children. The amount of subcutaneous fat under the skin at four popular sites (triceps, biceps, subscapular and suprailiac) is viewed as an index of total body fat stores. Circumference measures, most commonly the head and upper arm, are also used as indicators of nutritional status. Less frequently used (but still considered reliable) markers of nutritional status are anthropometric ratios (Body Mass Index, waist- to hip ratio), pubertal status, and dental and bone growth (Sutphen 1985).

Laboratory tests of nutritional status are most frequently employed in acute or research settings. These tests are mainly used to measure micronutrient status, although energy and protein intake can be indicated by albumin status, as shown in the table 1.2.

Table 1.2 Common Laboratory Tests for Nutritional Status

Nutrient	**Laboratory Test**
Energy and Protein	serum albumin, pre-albumin
Iron	haemoglobin, haematocrit, red cell indices, serum iron, total-iron binding capacity, transferrin, ferritin,
Folate	RBC indices, serum folate
Ascorbic Acid	Serum and leukocyte ascorbic acid
Vitamin A	Serum retinol, retinyl ester

Vitamin D	Cholecalciferol, 1,25 dihydroxycholecalciferol
Vitamin E	Serum tocopherol, RBC haemolysis
Vitamin K	Abnormal prothrombin antigen assay
Vitamin B12	Serum and RBC B12
Niacin	Urinary N-methylnicotinaminde
Riboflavin	RBC glutathione reductase activity
Thiamine	RBC transketolase
Zinc, Magnesium, Copper (other micronutrients…)	Serum concentrations

(Gibson 1990; Stallings and Zemel 1996)

Just as children with CP have been reported to be abnormally small and light for their age and sex, their nutritional status as indicated by other measures is also poor. Skinfold measures are routinely below normal, especially at the triceps (Spender, Cronk et al. 1988; Stallings, Cronk et al. 1995; Samson-Fang and Stevenson 2000). Head circumference, arm circumference, and anthropometric ratios are also affected.

Nutritional Intake Reports

Many researchers have focused on measuring the actual food intake of these children. Not surprisingly, given the nutritional status and the prevalence and severity of oral-motor difficulties observed, intake is below normal. In 1965, Hammond investigated the diets of children with CP and found that energy intake was much lower than that recommended for children of their age and sex (Hammond, Nelson Lewis et al. 1966). A 1973 study by Berg concluded that disabled children were receiving only two thirds of their Recommended Daily

Allowance (RDA) (Berg 1973). Fried concluded the same in 1991 (Fried and Pencharz 1991).

The Oxford Feeding Study revealed that energy intake is significantly linked to disability severity and oral-motor dysfunction (Sullivan, Lambert et al. 2000). The nutritional component of this study revealed that the intake of micro and macro nutrients, as well as energy, was significantly below normal for age and sex matched controls, findings which have been reported by several other groups (Thommessen, Riis et al. 1991; Dahl and Gebre-Medhin 1993; Sullivan, Juszczak et al. 2002).

1.3 ENTERAL FEEDING AND GASTROSTOMY PLACEMENT

Photograph 1.2 A 5 year old boy with Cerebral Palsy who has had a Gastrostomy placed (now a Mickey button™)

History

Enteral feeding has its origins in ancient Egypt, where various nutritive elements were administered as enemas to "foster good health" and to treat diarrhoea (Harkness 2002). The first record of tube feeding comes from 1598, when Capivacceus of Venice used a soft tube to pass fluids down the oesophagus of patients. Fabricius ab Aqupendente is credited with creating nasopharyngeal tube feedings, for he used this method to feed patients suffering from tetanus in 1617.

Gastric tube feeding emerged in the early 1700s, but rectal tube "feedings" remained the most popular method of nutrient provision until the early twentieth century. By the second half of the nineteenth century, gastric tube feeding was frequently used in children, especially those suffering from scarlet fever, brain damage, paralysis of the muscles involved in deglutition, or infectious diseases (Randall and Caldwell 1987). Medical acceptance and the technological advancement of gastric tube feeding grew rapidly in the early twentieth century. Feeding pumps were developed in the 1940s, and commercially prepared feeds in the 1950s (Harkness 2002).

Tube Feeding Disabled Children

Tube feeding is frequently used in disabled children when oral-motor dysfunction creates a barrier to optimal oral intake.

Criteria for tube feeding placement include:

- Inability to swallow
- Unsafe swallow or recurrent aspiration

- Oro-aversive behaviour
- Prolonged (>40min/meal) feeding times
- Compromised growth/nutritional status.

The placement of a gastrostomy tube (G-tube) is specifically indicated if the child has had prolonged dependence (> 6 weeks) on naso-gastric tube (NG-tube) feeding (Lloyd and Pierro 1996).

Nasogastric Tube Feeding

When tube feeding is prescribed as a means to improve nutritional intake, NG-tube feeding is usually the first method employed. An NG-tube may be used until the placement of a G-tube can be arranged, or on a trial basis so that health care workers and/or carers can see if there is improvement in the child's nutritional status. An NG-tube consists of a thin tube made of polyethylene, polyvinyl chloride, polyurethane or silicone rubber and is passed through the nose and oropharynx to deliver feed directly into the stomach. NG-tubes are particularly suited to patients whose additional nutritional requirements are short-term as it may cause discomfort in the nasopharynx and on the skin where the tube is taped in place. Furthermore, the tubes are unaesthetic, may hinder oral-motor development in young children, and may promote gastro-oesophageal reflux (GOR) and chronic bleeding from the erosion of the pharyngeal or oesophageal mucosa (Lloyd and Pierro 1996).

Gastrostomy Feeding

A "gastrostomy" is a surgically created external stoma in the stomach wall, through which a latex or silicone catheter device is implanted so that liquefied

formulas can be pumped or infused directly, bypassing the mouth and oesophagus (Thorne, Radford et al. 1997). The first G-tube surgery was performed in a patient suffering from oesophageal carcinoma in 1846 (Randall and Caldwell 1987). In 1891, Witzel created the surgical technique that still bears his name. In 1905, Carrol and Beck at the Rockefeller Institute developed what is now known as the Janeway. As stapling devices and surgical techniques improved, more and more successful G-tube placements took place. Today, many G-tubes are placed endoscopically or laparoscopically, making G-tube placement a relatively quick and simple procedure.

Gastrostomy Types

Stamm Gastrostomy

This type of G-tube requires an open procedure, during which the tube is placed directly into the stomach and a purse-string suture is used to secure the tube's placement (Randall and Caldwell 1987). It is the operation of choice for children who have had previous stomach surgery or who require a concurrent fundoplication (Lloyd and Pierro 1996).

Complication risks particular to Stamm G-tubes are early separation of the stomach from the anterior abdominal wall with leakage of gastric contents into the peritoneal cavity, wound infection and fascial dehiscence (Lloyd and Pierro 1996).

Percutaneous Endoscopic Gastrostomy (PEG)

This G-tube type was first developed and described by Michael Gauderer in 1980 (Gauderer and Ponsky 1981). Using an endoscopic technique, the stomach is inflated with air and a cannula inserted from the exterior. A guide wire is then introduced through the cannula, to be grasped by the endoscope and brought out through the mouth. The feeding tube is attached to the guide wire and pulled back into the stomach, where it is put into place with internal and external bars (Lloyd and Pierro 1996).

The use of this technique has grown exponentially since its introduction in 1981, and today, over 216,000 PEGs (5000 in children) are performed annually in the United States (Gauderer 2001). As a result of its non-invasiveness, it causes minimal discomfort and does not produce an ileus. It can be performed safely in children with severe musculoskeletal deformities and the quickness of the procedure provides an economic benefit.

It has been claimed that complications are more rare with PEGs than with laparotic G-tube placement. The most serious complication risks include laceration of the oesophagus, pneumoperitonium, peritonitis and colonic perforation (with the risk of colo-gastric fistula formation). Anaesthesia and possible catheter tract infections also present risks (Lloyd and Pierro 1996).

Minor complications are extremely common after G-tube placement, regardless of type, and often persist for an extended period. These complications include granulation tissue formation around the stoma, leakage of gastric content (which

may cause erosion of the skin and discomfort), wound infection, and tube dislodgement or catheter migration (Kastner 1992; Kastner, Criscione et al. 1994; Tawfik, Dickson et al. 1997).

The 2002 Evidence Report from the American Academy for Cerebral Palsy and Development Medicine (AACPDM) states that "it is difficult to make meaningful statements about risks and complications [of G-tube placement] from the published data because types and rates of complications are not reported in a standard manner, and some of the children experienced multiple complications" (Samson-Fang, Butler et al. 2002). Retrospectively studying the charts of 70 children who had had PEGs placed, Marin and Glassman found that major complications occurred in 19% of children and minor complications in 22% (Marin, Glassman et al. 1994). According to Tawfik, major complications occur in 3-19% of cases and minor complications in 13-22% (Tawfik, Dickson et al. 1997). Other complication rates have been reported as 3% for major, 13% for minor (Larson, Burton et al. 1987), 8.3% and 12% (Marx, Williams et al. 1996), and an overall late-onset complication rate of 44% (Segal, Michaud et al. 2001).

Despite the varying complication rates reported, many surgeons and gastroenterologists have concluded that PEG placement is a safe and effective treatment option. Others urge caution using any type of G-tube feeding in this group due to several major medical controversies: GOR, aspiration risk, mortality, and the question of improved nutritional status.

Complications of Gastrostomy Placement

Reflux

The debate over whether or not GOR may develop or worsen after G-tube placement continues. Some surgeons advocate a simultaneous anti-reflux procedure with every G-tube, especially when GOR is already clinically evident in a patient, yet others believe that a "wait and see" approach should be taken. A recent study by Razeghi et al. (the only prospective study to date evaluating the prevalence of GOR after G-tube placement in a large group of children) and one of the only studies to use 24 hour pH monitoring (the gold standard test for GOR) as a measure, concluded that there was no evidence of increased GOR after PEG placement (Razeghi, Lang et al. 2002). They did find however, that placement of the PEG in the antrum of the stomach was associated with increased GOR, a finding that supports the earlier claim that PEGs placed in the lesser curvature of the stomach result in less GOR (Collins, Georgeson et al. 1995). Proposed causes for observed GOR problems include decreased lower oesophageal pressure, an altered angle of His, the angle formed between the oesophagus and gastric fundus at the the gastroesophageal junction (an acute angle may help prevent GOR), and an exacerbation of pre-existing GOR due to increased volumes of feed in the stomach (Coben, Weintraub et al. 1994; Razeghi, Lang et al. 2002). Interestingly, a study by Lewis et al. investigating the impact of nutritional rehabilitation of GOR in children with PEGs concluded that improved nutritional status had a significant positive impact upon GOR symptoms in children with severe neurological impairment (Lewis, Khoshoo et al. 1994).

Aspiration

One of the main clinical indications for G-tube (or any tube) feeding is an unsafe swallow and/or recurrent aspiration. The aim therefore is to decrease the incidence of this aspiration and subsequent respiratory infection risk after tube feeding is initiated. Unfortunately, numerous groups have shown that tube feeding does not eliminate aspiration (Bui, Dang et al. 1989; Kadakia, Sullivan et al. 1992; Fox, Mularski et al. 1995). Kadakia et al. actually claim that aspiration may be promoted by PEG feeding but Jonathan Merrill disagrees and points out that aspiration is a complication of feeding, "quite separate from the choice of operative technique" (Kadakia, Sullivan et al. 1992; Merrill 1993).

Mortality

The lack of a resolution in the aspiration-G-tube feeding debate also complicates the discussion on mortality and tube feeding. Mortality during PEG placement is extremely rare, with Tawfik et al. reporting a mortality rate of 1% (Tawfik, Dickson et al. 1997). Much more controversial however, is the mortality risk that has been associated with tube feeding in general. Mortality prediction analyses in disabled children have indicated that one of the most important predictors of life expectancy is feeding ability (Kastner 1992; Eyman, Grossman et al. 1993; Kastner, Criscione et al. 1994; Strauss, Eyman et al. 1996; Strauss, Ashwal et al. 1997; Strauss, Kastner et al. 1997; Strauss, Shavelle et al. 1998; Eyman 2001; Strauss and Shavelle 2001). It is true that G-tube feeding is often initiated in those children with the most severe disabilities and hence already compromised health, but a study by Strauss and Kastner in 1997 suggested that there might be increased mortality in children with less severe motor disabilities fed via G-tube

(Strauss, Kastner et al. 1997). They hypothesized that increased mortality was due to "a differential increase in pulmonary disease secondary to vigorous nutritional maintenance and subsequent aspiration after tube placement."

Micronutrients/Improved Nutrition

Very recently the "improved nutritional status" reported in children fed via G-tube has been questioned by several research groups. A case report by Jones et al. describes a young boy with CP, fed via G-tube, who presented with scurvy due to Vitamin C deficiency as well as deficiencies of Vitamin A and zinc (Jones, Campbell et al. 2001). This group pointed out that children receiving elemental feeding formulas might be at risk for nutrient deficiencies due to a low concentration of micronutrients. Piccoli agrees, and cautions that children fed commercial enteral products may be at risk as well (Piccoli, Gelio et al. 2002). Enteral feeds are usually prescribed based on energy requirements and the low energy needs of disabled children mean that many of these children receive less than the RDA for vitamins and minerals, particularly calcium, iron and Vitamin D. It is well known that children who feed orally may receive under the Dietary Reference Value (RNI) for selected vitamins and minerals. The Oxford Feeding Study results, for example, revealed that only 46% of children achieved 100% of the RNI of iron, 43% for selenium and 44% for zinc (Sullivan, Juszczak et al. 2002). Yet it is often assumed, perhaps wrongly according to the latest reports, that the initiation of G-tube feeding will remedy this problem.

Benefits of Gastrostomy Tube Feeding

Despite the controversies, numerous groups report that G-tube feeding is associated with both improved growth and nutritional status in disabled children

(Patrick, Boland et al. 1986; Rempel, Colwell et al. 1988; Sanders, Cox et al. 1990; Marian 1993; SugarmanIsaacs, Georgeson et al. 1994; Corwin, Sugarman-Isaacs et al. 1996; Tawfik, Dickson et al. 1997; Brant, Stanich et al. 1999; Smith, Camfield et al. 1999).

G-tube feeding also increases the ease with which fluids and medications can be administered to the child, and may decrease the choking and coughing often seen with oral feeding, thereby decreasing the risk of aspiration and aspiration pneumonia (Tawfik, Dickson et al. 1997; Smith, Camfield et al. 1999).

Social Implications

When considering G-tube placement it is imperative to consider the social and practical implications/reasons as well as the medical indications. Familial benefits of G-tube feeding include decreased feeding times, decreased caregiver stress, and increased caregiver satisfaction regarding feeding and care for his/her child (McGrath, Splaingard et al. 1992; Tawfik, Dickson et al. 1997; Smith, Camfield et al. 1999). The fact that the G-tube is unobtrusive and "hidden" from view in comparison to NG feeding tubes (an important feature to many parents who wish to keep their children as "normal" as possible) and the observation that many children become more receptive to oral and facial contact (e.g. a kiss) are social benefits (Thorne, Radford et al. 1997). The quality of life of the child is also a critical factor to consider and reports of children's awareness and energy levels improving after G-tube placement are obvious benefits in this area (Rempel, Colwell et al. 1988; McGrath, Splaingard et al. 1992; Thorne, Radford et al. 1997).

Regardless of post-G-tube benefits, Sally Thorne points out that the decision to have a G-tube placed is extremely difficult for caregivers. Some families perceive G-tube feeding as "giving up hope" or "relinquishing normal", and may be frustrated at the lack of information provided before the surgery (Chaplen 1997; Thorne, Radford et al. 1997). Experts claim that health care workers must ensure that families are provided with adequate information and support, before and after G-tube placement, to ensure that an appropriate feeding regimen is established and maintained. Rickman, who studied the impact of gastrostomy feeding on adult subjects and their carers, claimed "those who coped best were those who felt well informed and supported by professionals" (Rickman 1998).

1.4 COMMERCIAL ENTERAL FEEDING PRODUCTS

The history of enteral feeding was briefly described in section 1.3. Although tube feeding has been utilized in medicine for centuries, the development of specialized tube feeds is relatively recent (Harkness 2002).

Governmental nutritional guidelines dictate the formulation of enteral feeding products. In the UK, companies must consider the World Health Organization (WHO) nutrient requirements as well as the UK Department of Health's Dietary Reference Values (RNI) when formulating enteral products, unless the feed is being created to meet the needs of a particular disease state (Barrett 2003). In March 1999 the Official Journal of the European Communities published a Commission Directive on Dietary Foods for Special Medicinal Purposes (EC Commission Directive 1999). The directive

- Defined and categorized the products covered by the new directive,
- Included compositional guidelines for the micronutrient content of products,
- Set out specific labelling requirements, and
- Set dates of implementation of the new regulations.

The deadline for companies to comply with the new regulations was 1 November, 2001.

Paediatric Feeds for CP

Two paediatric enteral feeds commonly prescribed for children with CP and feeding difficulties are Nutrini™ (Nutricia) and Paediasure™ (Abbott/Ross). Table 1.3 gives the nutritional composition per 100mL of these two feeds.

Table 1.3 Nutritional Information per 100mL of Paediasure and Nutrini

Nutrient	**Units**	**Paediasure**	**Nutrini**
Energy	kcal	101	100
Protein	g	2.80	2.75
Carbohydrate	g	11.20	12.30
Of which sugars	g	3.90	1.00
Fat	g	5.00	4.40
Of which saturates	g	1.50	0.40
VITAMINS			
Vitamin A (RE)	ug	45.00	41.00
Vitamin D	ug	1.00	1.00
Vitamin E	mg	1.50	1.30
Vitamin C	mg	5.00	10.00
Thiamin	mg	0.15	0.15
Riboflavin	mg	0.20	0.16
Niacin	mg	1.20	1.10
Vitamin B6	mg	0.10	0.12
Folacin	ug	15.00	15.00
Vitamin B12	ug	0.20	0.17
Biotin	ug	5.00	4.00
Pantothenic Acid	mg	0.30	0.33
Vitamin K	ug	4.00	4.00
MINERALS			
Sodium	mg	60.00	60.00
Calcium	mg	56.00	60.00

Phosphorus	mg	53.00	50.00
Iron	mg	1.00	1.00
Magnesium	mg	16.00	11.00
Zinc	mg	1.00	1.00
Iodine	ug	10.00	10.00
Potassium	mg	110.00	110.00
Chloride	mg	100.00	95.00
Copper	ug	100.00	90.00
Manganese	mg	0.10	0.15
Selenium	ug	2.80	3.00
Molybdenum	ug	4.00	4.00
Chromium	ug	2.50	3.50

(Nutricia Clinical Care 2000; Abbott Nutrition 2002)

The feeds are extremely similar in terms of macro and micro nutrient composition. Extensive "Nutrini" and "Paediasure" ranges exist to provide options for children who do not fare well with either of the basic products. Examples from the Nutrini range include "Nutrini Extra", a more calorie-dense feed, "Nutrini Multifibre", a feed providing more fibre than Nutrini, and "Infatrini", designed specially for infants (Nutricia Clinical Care 2000).

1.5 BODY COMPOSITION

Components

In 1992 Zi-Mian Wang developed a five-component model to describe the numerous different components of the human body from simple to complex. Since atoms are the fundamental building blocks of the human body, the first level in is "atomic". There are 50 elements found in the human body and six (oxygen, carbon, hydrogen, nitrogen, calcium and phosphorus) comprise more than 98% of the body's total weight. Level two is "molecular". There are over 100 000 chemical compounds found in the human body that can be classified into five groupings based on their chemical composition: water, protein, glycogen, mineral and lipid. At the cellular level, evidence of life becomes apparent, as each cell possesses the ability to metabolize, grow and reproduce. On this third level, the three main compartments are the cells themselves, extracellular fluid, and extracellular solids. Tissue systems comprise the fourth level of body composition. The tissues paramount to body composition research are bone, adipose, and muscle, which together make up approximately 75% of a reference man's total body weight. The whole human body itself is the fifth and final level (Wang, Pierson et al. 1992).

Body composition (BC) studies usually focus on the fourth and fifth levels. Size, shape, exterior physical characteristics, and the relative proportions of the various tissue systems are paramount.

Body Water

Body water is as crucial to the study of body composition as it is to life. As infants, humans are 70-75% water and as adults between 50% (women) and 60% (men). In the five level model of the body, water is an important component at the molecular, cellular and tissue levels (Schoeller 1996). Water, or H_2O, is a simple polar molecule. At the cellular level, water is found within the cells themselves, comprising approximately 73% of each cell, and in the extracellular compartment, which is 94% water. In body tissues, water is present in five separate areas: as intracellular water, plasma water, interstitial water, dense connective tissue water and transcellular water.

Knowing the amount of a subject's total body water (TBW) is imperative in body composition studies not only because of its huge proportion in the body, but because even small changes in TBW can result in significant changes in body weight and clinical state (Schoeller 1996).

Research Models

Although scientists are aware that all of the above-mentioned components do exist, the ability to measure each component remains limited. For this reason, models with fewer parts have been established for use in clinical practice and research.

The Two-Component Model

In this model the body is divided into fat mass (FM) and fat-free mass (FFM). The relative amounts of each are important in many clinical situations such as

diagnosing obesity since elevated body fat is a major risk factor for many diseases. Knowledge of the amount of FFM can also be extremely useful in clinical situations because it is a good index of energy and fluid requirements (Wells, Fuller et al. 1999).

The main disadvantage of this two-component model is that it relies on the assumption that FM and FFM composition are uniform throughout each individual and constant between individuals (Wells, Fuller et al. 1999). Its biggest advantage is that as the simplest model of BC, the two components are relatively easy to measure.

The Three-Component Model

Fat, water and fat-free dry matter are the components of this model. It is considered an improvement over the two-component model because the uncertainty concerning the composition of the FFM is avoided. However, it requires the assumption that there is a constant protein to mineral ratio within the body (Fuller, Jebb et al. 1992).

The Four-Component Model

This model divides the body into fat, protein, water and mineral. It is the best model currently available, but the determination of these components is quite expensive and labour-intensive, and it is still dependent upon several assumptions. In order to divide the body into these four components, one must assume that the densities of fat, protein and total body mineral are constant, and that there is a fixed ratio of osseous to non-osseous mineral (Fuller, Jebb et al. 1992).

NOTE: The two-component model was the model used in this programme of research. From this point, when body composition is referred to, it will indicate a measure of FM and FFM, unless otherwise indicated.

Measuring Fat Mass and Fat-Free Mass

The two components of the two-component model, FM and FFM, are calculated indirectly from the measurement of body water, which is present in all body tissues except adipose.

Body water can only be measured *in vivo* indirectly and is done so using the principle of dilution. This theory is based on the fact that "the volume of a compartment is equal to the amount of *tracer* added to the compartment divided by the concentration of the tracer in that compartment," and makes several assumptions about the behaviour of the tracer in the body (Schoeller 1996). The assumptions include that the tracer is distributed only and evenly to all body water compartments, that the rate of equilibrium is rapid, and that no metabolism of the tracer takes place. Urea and antipyrine were used as tracers in early dilution experiments, but results were inaccurate. In 1934 von Hevesy and Hofer proposed the use of tritium and deuterium as dilution tracers and Moore first applied their use in 1946 (Schoeller, VanSanen et al. 1980). Both are still used frequently today although tritium does pose a radiation hazard and both slightly overestimate TBW since some interaction with body protein does occur. The stable isotope of oxygen, ^{18}O, is also used as a tracer. ^{18}O is ideal because it is non-toxic and has very little interaction with body tissues (Schoeller, VanSanen

et al. 1980). Deuterium and ^{18}O are used as tracers in the Doubly Labelled Water Technique, which is described in detail in Section 1.9.

When the amount of water in the body is determined, FFM is calculated by applying an age and sex specific hydration constant. The difference between the FFM and total body mass is then accepted to be body FM.

Normal Body Composition

In healthy children, the proportion of FM to FFM varies depending upon age and sex. In 1982, Fomon et al. published "Body Composition of reference children from birth to age 10 years" (Fomon, Haschke et al. 1982). This paper has served as a reference guide for researchers ever since. It is still considered to be the most valid reference available, but some research groups are now suggesting the need for new standards based on more recent studies of healthy children throughout the UK (Ruxton, Reilly et al. 1999).

Risks of Abnormal Body Composition

In nutrition research, adipose tissue (or FM) is used as the primary indicator of health status. Obesity, or the accumulation of excess body fat, is becoming one of the most serious health threats to the Western World. People who are overweight are more likely to die prematurely and at 50% over average weight there is a twofold risk of premature death (Bender 1997). A large FM relative to lean muscle mass or FFM is indicative of excess energy stores and in adults is associated with type-2 diabetes mellitus, coronary heart disease, cancer, osteoarthritis, gallstones, sleep apnoea, reproductive disorders and psychological disorders (McArdle, Katch et al. 1996; British Nutrition Foundation

1999). In paediatric populations, obesity has been linked to high blood pressure, abnormal cholesterol and triglyceride profiles, sleep disorders, high fasting insulin, and psychosocial problems (British Nutrition Foundation 1999; Higgins, Gower et al. 2001). The distribution of body fat is just as important as the absolute amount. Lipid stored predominantly in the upper body (thorax and abdomen), known as central obesity and more common in males than in females, is associated with significantly greater health risks than excess body fat stored in the lower body (Bender 1997).

An extremely low FM is associated with inadequate energy intake and possibly malnutrition, the risks of which were described in section 1.2.

Method of Expression

It is important to note that FM is usually expressed as a percentage of total body weight and called "percentage body fat" (% BF). Since "percentage" assumes a constant total of 100, FFM is also being expressed when this method is used. The danger of this is that if both components are abnormal in amount yet of normal proportion the percentage value will appear normal. For example, a child may have a low FFM relative to normal standards and therefore have a low percentage body FFM and a high percentage FM. But another child could have both low FFM and FM, resulting in normal percentage measures of each. Several researchers have recently addressed this problem and new methods of expressing body composition are being developed (Warner 2000; Wells, Mok et al. 2001).

1.6 BODY COMPOSITION IN CHILDREN WITH CEREBRAL PALSY

The BC of children with CP is significantly different from that of healthy children. It is not clear whether this difference is due to nutritional factors, ambulation difficulties or other health issues, but it is postulated that all are involved.

As discussed in Section 1.2, the weights and heights of children with CP are almost always low for the children's ages, a fact which led to the first BC studies in children with CP in the 1960s and 1970s. One of the first well known studies, Kristina Berg's "Body Composition and nutrition of school children with cerebral palsy" describes not only low weights and heights in her study population, but low Body Cell Mass (BCM), which is closely related to lean mass, and high extra-cellular water (ECW) (Berg and Isaksson 1970). Unfortunately, despite the fact that these differences have been noted for more than 40 years, very little research exists on this topic and methodologies have not been constant.

The techniques of total exchangeable potassium, bioelectrical impedance analysis, anthropometrics and doubly labelled water have been used to investigate BC in this group of children. Table 1.4 gives a brief summary of the findings on FM and FFM in disabled children.

Table 1.4 A Summary of Fat Mass and Fat-Free Mass Information in Children with Severe Neurological Disabilities

Reference	FM	FFM	Notes
(Bandini, Schoeller et al. 1991)		Lower than in controls	Adolescent group
(Shepherd, Roberts et al. 1991)	%BF higher than expected (low BCM and TBW)		Children with *meningomyocele*, normal before ambulatory age, different after 3-4
(Stallings, Cronk et al. 1995)	Lower than in controls	Lower than in controls	
(Azcue, Zello et al. 1996)	% BF not different than expected	Lower than in controls (TBW, ICW and ECW also lower than expected)	
(Chad, McKay et al. 2000)	Not lower than expected		Children were deemed nutritionally adequate

The range of results presented in this table reveals that no sound conclusion has been made about the BC of children with neurological impairment. However, the results may not as complicated as they first appear. The difficulties surrounding the expression of BC data, mentioned in the previous section, account for a large proportion of the conflicting results. It is also paramount to note that the nutritional and feeding characteristics of the various children studied were not

identical. For example, Stallings et al. reported that both FM and FFM were low in the study group as compared to controls, but that there was a significantly higher amount of FM in the group who were being fed via G-tube (Stallings, Cronk et al. 1995).

Piecing together the reports of various authors, it can be concluded that:

- FM and FFM are low in children with CP, like weight and height. They are "smaller" in all aspects when compared to normal healthy, children.
- Nutritional status, ambulation and age have an impact upon the degree on this deviation from normal.
- Using % BF to describe FM in these children may be misleading due to their abnormal FFM

Very recently, research into bone mineral density (BMD) and bone mineral content (BMC) in CP has expanded rapidly. Low BMD and BMC has been demonstrated in these children in various regions of the skeleton (Chad, McKay et al. 2000; Henderson, Lark et al. 2002) with the lowest values seen in the most immobile. Again, numerous causative factors may be involved, but non-ambulation seems to play the most significant role in this lack of bone growth and structure. Earlier work by Roberts et al. complements this finding. When Roberts examined the skeletal age of patients with hemiplegic CP, it was discovered that there was a significant delay in skeletal maturation in the affected side (Roberts, Vogtle et al. 1994). The mean difference between sides was 7.3 months, and this delay correlated most strongly with age and skeletal functioning.

1.7 ENERGY METABOLISM

"Energy" is the modern name for the "innate life force" that has been recognized for centuries as necessary to all living things. The early Greek and Roman physicians named it "vital heat". It was the search for this "vital heat" that led William Harvey to discover the pattern of blood circulation in 1628 (Kinney 1988).

Numerous physicians have contributed to our current understanding of energy metabolism. In 1614 the Italian physician Sanctorious conducted experiments to analyze "insensible perspiration", as he observed that humans did not vary in size greatly over time despite the ingestion of large quantities of food. The hypothesis of the time was, correctly, that this must be due to the weight of the food and drink being lost in the urine, faeces and "insensible perspiration" (Lusk 1928). In 1668 John Mayow stated, "The atmosphere contains 'a constituent' that supports combustion as well as animal life" and shortly after Robert Boyle illustrated life's dependence upon air. Joseph Black discovered "fixed air" (later renamed carbon dioxide) and Priestly "found" oxygen in 1754 (Lusk 1928). Antoine Lavoisier, sometimes called the father of modern chemistry, realized in 1790 that respiration is a slow form of combustion. He demonstrated with a guinea pig that oxygen is utilized to produce carbon dioxide and heat while the temperature of the animal remains constant. He also noted that animals use more oxygen during digestion and movement than at rest, a phenomenon important to nutrition (Stokes 1991).

The first calorimeters were constructed by Black and Lavoisier to determine the exact relationship among oxygen, carbon dioxide and heat. The early 1800s saw

the determination of the chemical composition of carbohydrate, fat and protein, and eventually it became clear that oxidation and heat production occurred within *all* body tissues, not one specific organ. Before 1900, it was determined that the energy requirements of an animal are determined by basal metabolic rate, plus the thermic effect of food and energy expended during physical activity, an equation that holds true today (Kinney 1988).

Basal Metabolic Rate

The largest component of a human's total energy expenditure (TEE) is basal metabolic rate (BMR). BMR is "the minimum rate of energy expenditure in an awake, relaxed person lying on a bed in a thermoneutral environment after an overnight fast," or can also be described as a person's sleeping metabolic rate plus the energy cost of arousal (Ravussin and Bogardus 1989). Resting Metabolic Rate (RMR) or Resting Energy Expenditure (REE) is often measured. RMR/REE is similar to BMR, but usually the person is in a post-absorptive rather than fasting state. Often, this measurement is used in paediatric populations due to the difficulties involved in persuading children to fast.

BMR comprises 60-80% of an individual's TEE and is extremely individualized. Many researchers have attempted to find a single characteristic that correlates with BMR in an attempt to create prediction equations, however it is now hypothesized that the factors contributing to an individual's BMR are numerous.

Early investigations in metabolism led to the creation of Rubner's law in 1902, which states that the metabolism of an animal is proportional to its surface area (Lusk 1928). However, in 1913, Rubner himself discovered that the "evenness of heat production per unit of body surface was not due to any relation between the area of body surface and the area of cell surface within the organism." Benedict and Voit both stated that metabolism was determined by "the mass of active protoplasmic tissue" of an organism and *not* proportional to the organism's body surface, yet both were stumped by the task of measuring this mass (Lusk 1928).

In 1950, Grande et al. suggested that variations in BMR were eliminated when one's BMR was expressed in terms of FFM (Kinney 1988). It is now evident that although FFM is the best predictor of BMR, they do not correlate perfectly. A 1993 study by Maffies et al. found that FFM, weight, height, body mass index (BMI) and FM were all correlated to BMR in children (Maffeis, Schultz et al. 1993) and this was again validated in 1994 when Goran et al. stated that the factors contributing to individual variation in BMR were FFM, FM, gender, physical fitness, skeletal muscle metabolism and sympathetic nervous system (SNS) activity (Goran, Kaskoun et al. 1994). Genetics play a small role in BMR variation and age also contributes, with a trend of decreasing BMR with increasing age in adults (Ravussin and Bogardus 1989). Other studies have implicated body surface area, body cell mass and athletic status as determinants of BMR (Kinney 1988; Ravussin and Bogardus 1989).

Over the years, many of the above factors have been used to "normalize" metabolic rate in order to compare the BMR of individuals of different BC and

size. Since FFM has proven to be the best predictor of BMR, the ratio of BMR: FFM is frequently used to evaluate and compare the energy metabolism of people of different sizes and FFM. However, Weinsier has cautioned against this practice because the relationship between FFM and BMR is not linear. He suggests that alternative methods be used for comparisons when individuals/groups have significantly different FFM (Weinsier, Schultz et al. 1992).

Diet Induced Thermogenesis

In a letter to Black dated 1790, Lavoisier wrote this observation of a guinea pig feeding: "the quantity of oxygen gas consumed, or converted into carbonic acid, increased during the time of digestion" (Stokes 1991). This quote defines Diet Induced Thermogenesis (DIT), also known as the Thermic Effect of Food (TEF). DIT is the increase in BMR after the ingestion of a meal and accounts for 3-10% of an individual's TEE (Reed and Hill 1996).

Despite its relatively small contribution to TEE, DIT has been the focus of many recent studies as some researchers believe it may play an important role in obesity (Reed and Hill 1996).

DIT occurs because of the body's need to expend energy in order to process ingested food. There are two components: obligatory thermogenesis (previously known as specific dynamic action) and facultative thermogenesis. Obligatory thermogenesis is the energy used to initiate metabolic pathways such as digestion, absorption and nutrient assimilation. Facultative thermogenesis is

related to the activation of the SNS when food stimulates metabolism (McArdle, Katch et al. 1996).

The type of food consumed affects DIT. High protein meals, for example, will result in higher DIT than meals high in fat (Westerterp-Plantenga, Fredrix et al. 1994). Measured thermic effects (as a percent of the energy value of the food itself) for the major nutrients are 0-3% for fat, 5-10% for carbohydrate and 20-30% for protein (Tappy 1996). Since most meals are mixed, DIT is rarely constant. Furthermore, it has been observed that intra-individual DIT variability is very high (Tataranni, Larson et al. 1995).

Physical Activity

The component of TEE over which people have the most control is the energy expended during physical activity. The energy costs of different activities are often expressed as multiples of BMR. Table 1.5 below gives examples of both low and high energy expending activities.

Table 1.5 Examples of Multiples of Basal Metabolic Rate for Various Activities

X BMR	ACTIVITY
1.0 - 1.4	Lying, sitting or standing at rest. Example: watching TV
1.9 – 2.4	Standing with little effort. Example: cooking
3.4 – 4.4	Standing with movement. Examples: gardening, golfing, walking
6.0 – 7.9	Purposeful exercise. Examples: jogging, cycling, swimming

(Bender 1997)

1.8 MEASURING ENERGY EXPENDITURE

Basal Metabolic Rate

BMR can be determined directly with a calorimeter or indirectly by measured gas exchange. Calorimetry is the science of measuring heat flow, and a calorimeter is a thermally insulated device that encloses a subject and measures the heat produced. The most common types of calorimeters are surrounded by water and the subject's heat production is calculated by measuring the increase in temperature of the surrounding water (Bender 1997). Disadvantages of direct calorimetry are that whole body calorimeters are very costly and often uncomfortable, plus measurement time and the subject's "normal" activity are severely restricted.

Indirect calorimetry is much more frequently used to measure BMR. With this technique, energy expenditure is determined from the rate of oxygen consumption of the subject. Twenty kilojoules of energy are expended for every litre of oxygen consumed, so by accurately measuring how much oxygen a subject uses over a period of time, the energy output of that time period can be calculated (Bender 1997). However, as the substrate being oxidized by the tissues influences how much oxygen is used, the substrate mixture must also be determined. Simultaneously measuring carbon dioxide production allows this determination and is the preferred method. Estimation from the diet is the alternative (Black, Prentice et al. 1986).

Just as the mixture of substrate being oxidized influences the rate of oxygen utilization, carbon dioxide production (and removal from the body) depends on the substrate mixture and the metabolic activity of the tissues. Theoretically, the ratio between carbon dioxide production (VCO_2) and oxygen consumption (VO_2) is called the respiratory quotient (RQ) and is determined at the cellular level.

$RQ = (VCO_2) / (VO_2)$

However, because the measured RQ is only identical to the actual metabolic RQ when body O_2 and CO_2 pools are in steady-state, steady-state conditions are always assumed and the calculated ratio of VCO_2/VO_2 is taken to be the real RQ.

BMR is frequently predicted in clinical practice and research, as accurate measurement is often not feasible. BMR prediction equations based on physical characteristics have been published by numerous groups. The Harris and Benedict equations, published in 1919, shown below, are the best known and they are still in use today.

The Harris and Benedict Equations (1919)

(kcal per 24 hours)

BMR = 655.1 + 9.56W + 1.85H – 4.68A (women)

BMR = 66.47 + 13.75W + 5.0H – 6.76A (men)

where W= weight (kg), H= height (cm), and A= age (years)

(Harris and Benedict 1919)

As mentioned in Section 1.7, the best predictor of BMR is FFM. This is true for men and women as well as children, however many variations and variables persist. Researchers have attempted to explain the variations by investigating the actual properties FFM, notably total body water and both extra and intracellular water, but it has been shown that with increasing age there is a decrease in the BMR of lean tissue that cannot be explained by body water changes and distribution (Fukagawa, Bandini et al. 1996).

It is becoming increasingly common for research groups to create their own prediction equations after accurately measuring BMR in a number of individuals with similar characteristics. This is especially popular for groups with specific diseases since the prediction equations developed for the general population are often inaccurate, especially if the disease affects FFM.

The Schofield BMR prediction equations are perhaps the most widely known and accepted for use in children. Table 1.6 lists these equations.

Table 1.6 The Schofield Prediction Equations for BMR in Children

Sex	Age	BMR (kcal/24 hours) =
Male	0-3	0.167W + 15.147H – 617.6
	3-10	19.59W + 1.303H + 414.9
	10-18	16.25W + 1.004H +515.5
Female	0-3	16.25W + 10.232H – 413.5
	3-10	16.969W +1.618H +371.2
	10-18	8.365W + 4.65H +200
Where W=weight (kg) and H=height (cm)		

(Schofield 1985)

The BMR of hospitalized or ill children is generally accepted to be lower than that of healthy children since physical activity is usually reduced and growth (anabolism) is often slowed or stopped if the illness is catabolic. If children are being fed parentally, requirements may be even lower due to the minimization of the thermic effect of food and obligatory gastrointestinal losses of nutrients (Duggan 2000).

Total Energy Expenditure

Total energy expenditure (TEE) is the sum of all the components of energy metabolism. Its measurement is very challenging because the technique must allow the subject to remain in normal living conditions for the measurement to be valid and useful.

Doubly Labelled Water

The doubly labelled water technique (DLW) is the gold standard for measuring TEE. It is actually a creative extension of indirect calorimetry, since it measures total carbon dioxide production over a set period of time. In using DLW, two

stable isotopes, ^{2}H and ^{18}O, are administered orally to a subject. The ^{2}H disperses throughout the subject's water pool and is eliminated at the same rate as normal body water. The ^{18}O is distributed throughout the body's water pool and its bicarbonate pool. By analyzing samples of a body fluid with mass spectrometry, the difference in the disappearance rates of the two isotopes can be determined and total carbon dioxide production can be calculated. Total carbon dioxide production is then converted into TEE (Westerterp-Plantenga, Fredrix et al. 1994).

Heart Rate Monitoring

Heart rate (HR) monitoring is another method used in children to estimate TEE. This method requires minute-by-minute recording of HR after the relationship between HR and oxygen consumption has been determined at different workloads and at rest. HR monitoring has been validated with whole body calorimetry and DLW. Although it is not as robust as DLW on an individual basis, it is considered valid for estimating the energy expenditure of groups of children (Kalkwarf, Haas et al. 1989; Livingstone, Coward et al. 1992; IDECG 1994).

Time-Motion Techniques

Time-motion or activity diary techniques are not as reliable as DLW or HR monitoring, but are much easier to perform. This method of estimating TEE requires a subject to keep an accurate, time-allocated diary of motion and activity over a given time period. The energy costs of the activities recorded (either measured or estimated from published values) are then applied (IDECG 1994).

Multiples of Basal Metabolic Rate

The simplest method of TEE estimation is assigning every activity an energy cost that is expressed as a multiple of BMR (xBMR) or physical activity level (PAL). This technique can be used to calculate energy usage over a set period of time by adding up the xBMR of the various activities undertaken by an individual, or more simply, by estimating a general xBMR. For example, TEEs of 1.55, 1.78 and 2.10 xBMR were proposed for men with light, moderate and heavy occupational activities by the Food and Agriculture Organization/ World Health Organization/ United Nations University (FAO/WHO/UNU) in 1985 (IDECG 1994).

Physical Activity Energy Expenditure (PAEE)

As stated in Section 1.7, the energy expenditure associated with different physical activities is often expressed as multiples of BMR. However, it is often necessary to know the total amount of energy being used for voluntary physical activities. By measuring both TEE and BMR this amount of energy can be estimated by subtracting BMR from TEE.

TEE (kcal/24 hours) – BMR (kcal/24 hours) = PAEE

1.9 THE DOUBLY LABELLED WATER METHOD

History

Professor Nathan Lifson of the University of Minnesota outlined and developed the doubly labelled water method in the late 1940s and early 1950s. Lifson's discovery that the oxygen (O_2) in exhaled carbon dioxide (CO_2) is in equilibrium with the O_2 in body water created the basis for this now widely accepted method. The first studies were conduced using rats and mice, due to the fact that human trials were not economically feasible. Since then, analytical advances have allowed the amount of DLW required for studies to be reduced. Dale Schoeller and Edward van Santen conducted the first human study in 1982 (Prentice 1990).

Benefits of this Method

As no other method has been able to do, the DLW allows one to "sum the costs of basal metabolism, dietary thermogenesis, tissue synthesis and physical activity (Wells 1998). Its beauty lies in its "simple requirements" of needing to know:

1. The volume of DLW given to a subject
2. When pre and post samples are collected (and the isotopic enrichments of those samples)
3. The composition of the diet (Ritz and Coward 1995).

In addition, DLW is non-invasive and applicable to subjects in free living conditions.

The Isotopes

DLW uses the isotopes ^{2}H (deuterium) and ^{18}O. Early dilution trials experimented with various water-soluble tracers such as urea and antipyrene. To yield accurate results, the tracer must not bind to body proteins, nor be excreted rapidly, nor be metabolized, nor distribute unevenly through body water compartments. For dilution experiments to determine TBW it was concluded that tritium (^{3}H) and ^{2}H were the best tracers to use. Tritium, however, is a radioactive isotope and hence many are extremely wary of its use in live subjects. Deuterium is considered harmless but in 1963 Thomsen observed changes in the behaviour and metabolism of small animals when it was in excess of 10% of the body's hydrogen (Thomson 1963). In terms of accuracy, the only negative factor to be associated with either ^{3}H or ^{2}H is that they overestimate the body water pool, as the labelled H will interact with the H of body protein (Schoeller, Van Sanen et al. 1980).

A second label - ^{18}O - is also used in DLW. ^{18}O has not been associated with any harmful effects in either animals or humans yet its outrageous expense has prevented its widespread use. It is however, non-toxic, non-radioactive and tends to interact less with non-aqueous body constituents than H, making it an ideal tracer (Schoeller, Van Sanen et al. 1980).

Dosing

DLW was not used in human subjects for many years after its developmenet mainly because of the high cost involved in dosing an animal the size of a human. Even now, cost must be weighed against the need to make an

adequately long measurement and the higher precision obtained with higher doses in figuring dosage (Schoeller 1983).

The dose must be large enough to ensure that enrichment levels of 100 ppm for ^{2}H and 200 ppm for ^{18}O are established (Prentice 1990). It is necessary that the enrichment be detectable above baseline natural abundances and that it can be easily measured. Precision is poor for both short and long sampling periods. Short periods lead to enrichment changes too small to measure accurately and long periods result in the isotope concentration of final samples being too low to measure. Maximum precision has been determined at 2 to 3 half-lives of the isotope. This corresponds to approximately 14 days in adults and 5-8 days in infants and children (Schoeller 1983). Recently, Coward, Roberts and Cole stated that both precision and accuracy decrease significantly when study length is shortened (Coward, Roberts et al. 1988).

The ratio of ^{2}H to ^{18}O must also be considered in dosing. The aim is to take advantage of the natural covariance between these two isotopes in human body water-background enrichment. Adult doses are recommended at 0.05g ^{2}H /kg body weight and 0.15g ^{18}O /kg as this ratio will minimize the effects of fluctuations in the background enrichment (Prentice 1990). Roberts et al. claimed that the optimal dose ratio for children and infants should be slightly higher, as the rates of CO_2 production per kg are greater in the younger population. However, more recently Wells has stated that "children require lower doses as water turnover decreases with increasing body size" (Roberts, Fjeld et al. 1990; Wells 1998).

Routes of Isotope Loss

After ^{2}H and ^{18}O are administered, they quickly and evenly equilibrate throughout body water. ^{2}H is subsequently lost (as with all H in the body due to natural water turnover) via excretions, secretions and evaporation from the lungs and skin. The ^{2}H is also diluted as the study progresses by any new H entering the body (primarily in the form of H_2O from food and drink.) Therefore, over time, the concentration of ^{2}H in the body decreases and the rate constant for this decline is equal to the water flux of the body.

^{18}O is lost by the same routes as H, but is also lost as CO_2. The enzyme carbonic anhydrase, present in many of the body's cells, catalyses the reaction:

$$H_2O + CO_2 \leftrightarrow H_2CO_3$$

This enzyme allows the CO_2 in body fluids to equilibrate throughout the body

DLW for Total Energy Expenditure

Since ^{18}O is lost both as H_2O and CO_2, ^{18}O has a quicker disappearance rate than of ^{2}H, which is only lost via water turnover. The difference between these two rates represents the total CO_2 production of the subject. This value can then be used to calculate TEE, as outlined in the data analysis section.

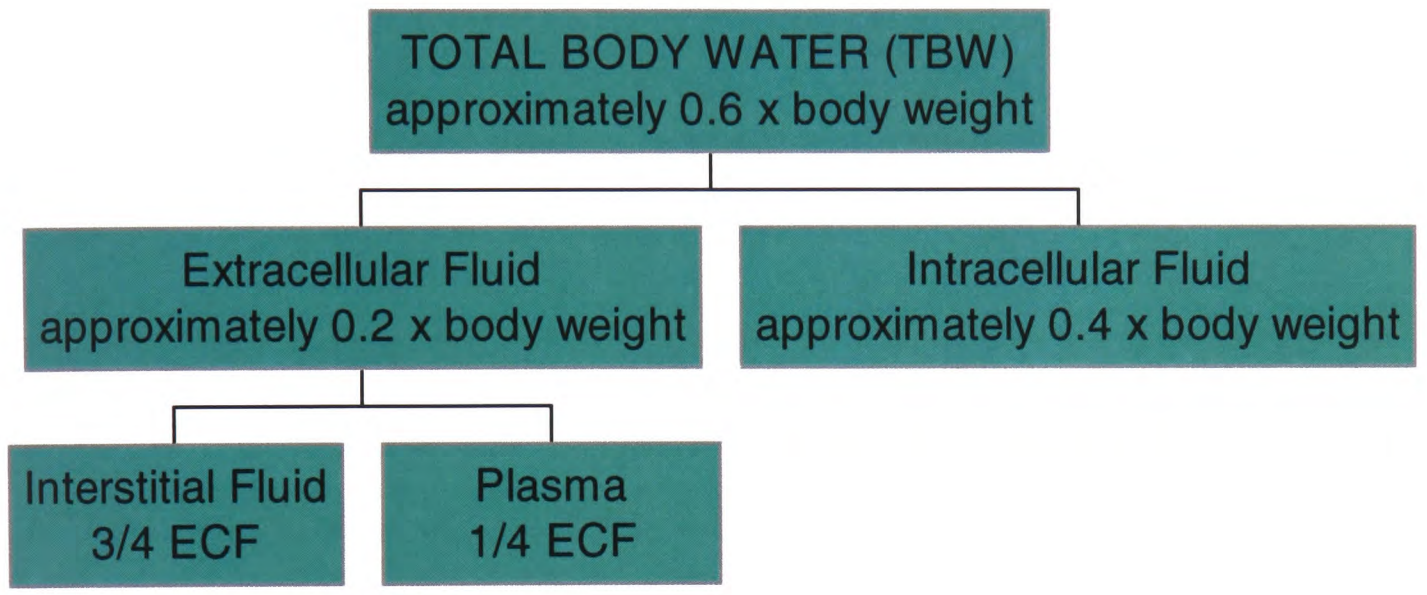
DLW for Body Composition: The Dilution Theory

Water is the most abundant component of the human body. In healthy adult males, the average amount of water (by weight) in the body is approximately 60%. In women, the percentage is about 51 due to a higher proportion of

adipose tissue. Infants, who have very little body fat, are approximately 75% water. In both male and female adults, the amount of water in lean body tissue has been determined to equal approximately 73%, but this is still debated. This body fluid is divided into two major compartments: the intracellular and extracellular. The extracellular fluid is further subdivided into interstitial fluid and plasma (Berne and Levy 2000). See figure 1.1.

Figure 1.1 The Distribution of Human Body Fluid

A Model of the Major Body Fluid Compartments



(Berne and Levy 2000)

Knowing the size of the TBW pool of the subject, called N, is crucial to the calculation of CO_2 production. Though the body is in reality composed of many small pools (as illustrated above), to use DLW one must assume that N is one large pool comprising the TBW.

Exponential decay rate equations are used to calculate the size of this pool. In this single pool, the concentration of tracer is dependent upon the rate at which the tracer is lost (and of course the amount originally administered as well as the pool size.) In equation form:

$Q_t = Q_o e^{-kt}$ where Q = tracer, k = rate constant, and t = time.

Recall that the aim of this method is to determine the pool size. The amount of tracer given is known and the rate of its disappearance determined by taking samples over time.

If we assume that the body pool (N) is a constant size, then: $Q_t/N=Q_oe^{-kt}/N$

Which equals: $C_t = C_oe^{-kt}$ where C = tracer concentration.

It is important to note that N can be calculated by either the disappearance of ^2H or of ^{18}O. Lifson's original experiments concluded that N_D (deuterium derived) = 1.03 N_O but N_O was (and still is) accepted as a truer value since O has less interaction than H with non-aqueous body components.

Physiological variation does exist with respect to this ratio. One hypothesis for this variation is that different proportions of fat, protein and water in the body (body composition) will lead to different degrees of ^2H exchange with the H in these components and therefore alter the value of N obtained. A second hypothesis is that the variation is due to analytical error.

If both values (N_D & N_O) are measured, then it is suggested that individual ratios be utilized in CO_2 calculations as long as the ratio falls between 1.015 and 1.060, which is the range accepted by the International Dietary Energy Consultancy Group (IDECG) as being physiologically feasible (Prentice 1990).

Choices in Methodology

Two different methodologies have been developed since the advent of DLW. They are known as the Plateau or Two-Point Method and the Intercept-Slope or Multi-Point Method. Each has its benefits and drawbacks.

The Two-Point Method

In this method, DLW is administered and samples are taken twice: when the isotopes have reached their peak concentration within the body's water pool - known as equilibrium establishment - and at the end of the measurement period. The requirement of few samples is the major benefit of this method, as fewer samples results in a simpler protocol and a considerably reduced analysis cost. However, there are several disadvantages to this method. The point of equilibration is often hard to estimate and errors in sampling time may result in erroneous data. Equilibration in adults ranges from 3 to 10 hours depending on the subject and the protocol of the specific experiment. Van Marken Lichtenbelt et al examined several different protocols for isotope dilution in 1994 and concluded that despite the possibility of underestimation, a 10 hour equilibration time is preferable to the more commonly used 4 or 6 (VanMarkenLichtenbelt, Westerterp et al. 1994). The most significant drawback of the two-point method is that the results are not as accurate or precise as with the multi-point method. An examination of basic calculus will reveal that many lines can be fit between the two points generated from this method, and hence the true picture of isotope elimination may not be illustrated. In 1988 Coward, Roberts and Cole determined that when the number of data points used in DLW studies is decreased (but the duration of the study remains the same) the precision is

lessened (Coward, Roberts et al. 1988). In 1992, Cole and Coward calculated the multipoint method to be 1/3 more precise than the two-point method (Cole and Coward 1992).

The Multi-Point Method

In contrast to the two-point method, in the multi-point method samples are taken regularly throughout the duration of the study. It should be noted that the basic principles behind these two techniques differ, as the two-point method uses an actual sample to determine the maximum enrichment and therefore total body water, whereas in the multi-point method, the sample values are plotted against time and the line created is extrapolated backwards to determine the maximum enrichment. The disadvantages of this method are the added cost and work of dealing with multiple samples. The advantages, as stated above, are improved precision and accuracy. As well, Dr. Jonathan Wells claims that the multi-point method is "much more appropriate (for children) because in young age groups there is a high rate of water turnover (which) leads to a significant difference in the dilution spaces obtained between the two methods" (Wells 1998). A study by Davies and Wells, conducted in 1994, found that the values obtained with the multi-point method corresponded more closely to the TBW values obtained from other techniques than those from the two-point method (Davies and Wells 1994). A final advantage is that this method is more suitable to free-living condition experiments, as day to day elimination rates may change dramatically depending on the daily activity of the subject (Salazar, Infante et al. 1994).

The choice of method can also have a great impact on the determination of N. The two methods will only result in identical values for N when the rate constant

(k) is zero. The two-point method is most accurate when all isotope losses during the equilibration period are accounted for and subtracted, which is an extremely difficult task. However, with caution and corrections, the error can usually be reduced to less than 1%. The result of these small errors is an over-estimation of the TBW volume because the dose remaining in the body at equilibration is over-estimated. The multi-point method is more correct if the mixing (of isotope with body water) is instantaneous and the rate of output (k) is constant. Although neither of these assumptions is true, the variations are usually random and error less than 1%. This method tends to overestimate the initial concentration of tracer as mixing time is not accounted for, and therefore underestimate the TBW volume (Coward 1990).

Choices in Sampling

In theory, any body fluid can be utilized for analysis, but urine, saliva and plasma are most the common. Crucially, the same fluid must be used throughout the experiment for each subject. Plasma is obviously is not the preferred method due to the invasiveness of sample collection. Urine is most commonly used in adult studies, the major disadvantage being that urine is stored in the bladder for an undetermined amount of time before voiding and therefore samples may not accurately represent the concentration of tracer in the body when the sample is actually collected (Prentice 1990). For this reason, and because of the difficulty involved in obtaining urine samples on demand, saliva is often utilized in studies involving children and infants. Schoeller cautions that different degrees of fractionation may be present in saliva at different sampling times, but Wells supports the use of saliva samples in children, claiming that "urine samples may

not accurately reflect isotopic enrichment of body water at the time the sample is given" (Wells 1998).

Assumptions made when using DLW

In order to utilize DLW to obtain values of total energy expenditure, one must assume that:

1. The volume of the body water pool remains constant throughout the measurement period.
2. The rates of water influx, and water and CO_2 efflux are constant throughout the measurement period.
3. The isotopes label only the H_2O and CO_2 in the body.
4. The isotopes leave the body only in the forms of H_2O and CO_2.
5. The concentrations of the isotopes in H_2O and CO_2 leaving the body are the same as those in body water at that time (there is no isotopic fractionation).
6. No H_2O and CO_2 that have left the body re-enter the body.
7. The natural abundance, or "background" levels of the isotopes remain constant during the measurement interval.

Unfortunately, not all these assumption are true. Appendix A describes the problems with these assumptions and lists various correction factors that have been developed.

Analysis of Samples

Gas-isotope-ratio mass spectrometry (GIRMS) is the best analytical technique available for the accurate and precise detection of ^{2}H and ^{18}O in physiological fluid samples.

Precise results are paramount to DLW studies because it is the change in isotope concentration that is used in TEE calculations. For optimal results, all the samples from a subject (including baseline and diluted dose samples) should be analysed on the same machine, on the same day, with the machine calibration kept constant. The degree of precision required depends of the dose of isotope, the isotope elimination rate, the metabolic period (length), and the number of samples taken. For the two-point method, the precision must be at least 1/600 of the initial enrichment. This corresponds to 0.16‰ for ^{18}O and 1.1‰ for ^{2}H if the error is to be less than 5% for periods between 1 and 3 half-lives of ^{18}O. When using the multi-point method, a decrease in precision proportional to the square root of total data points (samples) is accepted, but the baseline sample must be as precise as for the two-point method (Prentice 1990).

1.10 ENERGY EXPENDITURE IN DISABLED CHILDREN

Age, sex and body composition play a large role in determining the energy expenditure of an individual. In children with disabilities, additional confounding variables include ambulatory status, and the presence or absence of osteopenia, spasticity and dyskinesia (Schwarz 2002).

Indirect calorimetry has been used in numerous studies to measure the BMR of children with neurological disabilities. Although study methods and results vary slightly, the agreed conclusion is that children with CP have significantly lower BMRs than those predicted by the accepted equations (Wakoh, Hillman et al. 1965; Bandini, Puelzl-Quinn et al. 1995; VandenBerg-Emons, Saris et al. 1995; Stallings, Zemel et al. 1996; Dickerson, Brown et al. 1999).

Interestingly, results conflict when BMR is adjusted for FFM. Stallings et al. reported that resting energy expenditure (equated here to BMR) adjusted for FFM was lower in children with CP than in controls, and significantly lower in the CP children with low fat stores than those with adequate reserves (Stallings, Zemel et al. 1996). A study by Johnson et al. however, noted that adult CP subjects had a 14% higher BMR adjusted for FFM than controls (Johnson, Goran et al. 1995).

The undisputed fact that BMR prediction equations routinely overestimate the energy expenditure of this group has led researchers to search for some physical characteristic that closely correlates to BMR. As in the normal population, FFM has proven to be the best predictor to date; however, very little work has been done in children (Johnson, Goran et al. 1995; Dickerson, Brown et al. 1999). The validity of existing BMR prediction equations has also been studied in this group and new equations to better suit these children's specific needs are being developed (Krick, Murphy et al. 1992; Dickerson, Brown et al. 2002).

Not surprisingly, since BMR is the greatest contributor to TEE, TEE has been found to be significantly lower in children with CP than in controls. Physical activity levels (determined as TEE/BMR) were also lower than normal (Bandini, Schoeller et al. 1991; VandenBerg-Emons, Saris et al. 1995; Stallings, Zemel et al. 1996).

The majority of studies in children with CP have been with those with spastic quadriplegia, most of whom were non-ambulatory. Unfortunately, little work has been done to analyze the effect of type of CP on energy expenditure. Johnson et al. reported that the presence of athetosis significantly increased BMR in adults with CP, yet no similar studies have been conducted with children (Johnson, Goran et al. 1995).

1.11 ENERGY BALANCE: A LINK BETWEEN ENERGY EXPENDITURE AND BODY COMPOSITION

Photograph 1.3 A boy with Cerebral Palsy who has been fed via Gastrostomy-tube and has gained considerable amounts of body fat

Energy In = Energy Out + Energy Stored

This is the energy balance equation. Energy taken into the body in the form of nutrition will either be used by the body for metabolic processes or stored. This equation is the link between energy expenditure and BC. If more energy is taken into the body than is expended, energy stores in the form of body fat will accumulate.

FFM has been determined as the best predictor of BMR but unfortunately, FFM does not account for all the variability observed. It has been pointed out that the relationship between FFM and BMR is not linear and so cautions must be taken when expressing BMR in terms of FFM, especially when looking at groups with significantly different amounts of FFM (Weinsier, Schultz et al. 1992). Therefore, equations that predict energy expenditure based on the metabolic contribution of both FM and FFM, such as the one below, have been developed.

$EE = k_1 x FM + k_2 x FFM$

(Garby, Garrow et al. 1988)

K_1 and k_2 are the specific energy expenditures of FM and FFM. Garby et al. have determined numerical constants for both men and women, but individual variation still exists (Garby, Garrow et al. 1988). A similar model developed by Nelson and colleagues supports this idea that both FM and FFM should be taken into account when looking at variations in BMR. Taking it one level deeper, he

suggests that FFM be divided into organ mass and skeletal muscle mass (Nelson, Weinsier et al. 1992).

The most thoroughly studied aspect of the energy balance equation has been the effect of energy intake on energy metabolism. The "Minnesota Starvation Experiments" of the 1950s demonstrated that by restricting the energy intake of healthy men for a period of 2-3 weeks, BMR was significantly decreased (Keys and Brozek 1950; Grande, Anderson et al. 1958). The decrease in BMR was seen even when BMR was normalized for gross body weight, unit of body surface, and body weight to the power 0.73 (a scaling factor or power function).

Earlier studies also showed a decrease in BMR with restricted food intake. Benedict concluded that while on a reduced diet "men underwent profound metabolic changes, which were not indicated simply by the losses in weight but also by alterations in pulse-rate, in blood pressure, to a slight extent in respiration rate, and more especially in the gaseous metabolism" (Benedict, Miles et al. 1919). The two hypotheses of the time were that the metabolic depression observed was due to a lowered protein intake (a hypothesis quickly dismissed after nitrogen excretion studies), and that there was a "very considerable decrease in the active *cell-substance*" (Benedict, Miles et al. 1919).

Today, clinical research with patients suffering from anorexia nervosa and undernutrition shows the similar results. A study of undernourished adult men revealed that BMRs were significantly lower than normal (Soares and Shetty 1991). However, when adjusted for FFM, the BMR appeared to be *higher* than

expected. The authors propose that this observation was due to a greater contribution of viscera to FFM than skeletal muscle, a statement which supports Nelson's suggestion to examine the contribution of organ and muscle to FFM (Soares and Shetty 1991). When the same data was re-analyzed using an analysis of covariance, it was concluded that the BMR of the undernourished individuals was lower than expected and "metabolic economy" or "suppression of thermogenesis" was the hypothesis given.

Since the reduction in BMR with food restriction and weight loss is greater than can explained by the loss of active tissue (Luke and Schoeller 1992), energy partitioning has been examined to investigate these metabolic adaptations. The P ratio is defined as: protein energy stored (or mobilized) / total energy stored (or mobilized) and can be determined by: $1 / (1 + \alpha R_m)$ where R_m is Δ FM / Δ FFM (Dulloo, Jacquet et al. 1996). A re-examination of past studies (including the Minnesota Starvation Experiments) has revealed that this p ratio varies greatly among individuals, yet is very constant within an individual, which helps explain the different responses of individuals to dietary restriction, as well as to weight gain. It was found that this p value is maintained even during refeeding (Dulloo, Jacquet et al. 1996; Dulloo 1997).

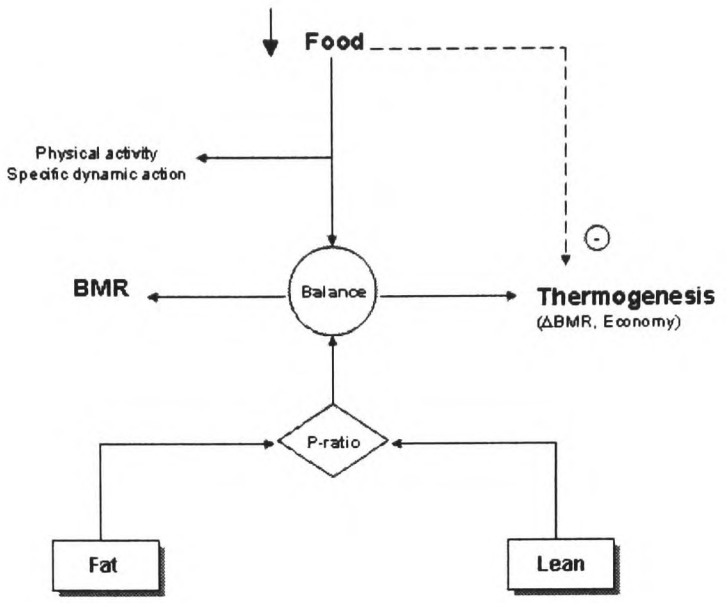
"Metabolic economy" is hypothesized to explain the high fat storage and slower protein growth seen during refeeding studies. Although the theory has not yet been fully explored in humans, it has been investigated in animals and direct evidence for increased metabolic efficiency under conditions of low energy intake has been found (Dulloo and Girardier 1990). In rats that were underfed for

various lengths of time, a 10% reduction in energy expenditure was found upon refeeding. After body composition analysis, it was discovered that all the energy saved was deposited as fat rather than as protein. When the energy cost of the fat deposition was accounted for, there was still a 15% net decrease in energy expenditure in these rats during refeeding (Dulloo and Girardier 1990). This disproportionate gain of fat upon refeeding after low nutrient intake has been reported in children and adults recovering from undernutrition as well as anorexia nervosa (Ashworth 1969; Reeds, Jackson et al. 1978; MacLean and Graham 1980; Mitchell and Truswell 1987). Dulloo et al. found in re-examining data from the Minnesota Starvation Experiments that the higher the initial body fat of an individual, the lower the proportion of energy mobilized as protein during starvation, and hence the greater propensity to mobilize fat and subsequently to re-deposit fat during refeeding (Dulloo, Jacquet et al. 1996). Furthermore, the measured decrease in BMR was found to be inversely proportional to the degree of fat recovery, but unrelated to the degree of FFM gain.

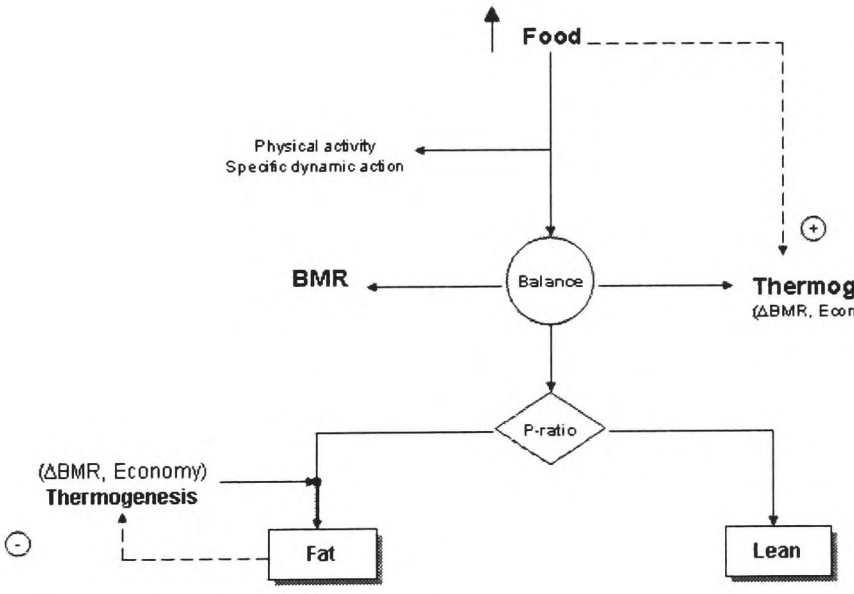
Dulloo's model of this autoregulation of thermogenesis is illustrated below.

Figure 1.2 A Model of Autoregulation of Thermogenesis; Semi-Starvation and Refeeding

SEMI - STARVATION



REFEEDING



((Dulloo and Jacquet 1998)

He proposes a biphasic response to energy deprivation. Firstly, a non-specific, immediate response to the reduction in food energy intake that is seen as a reduction in thermogenesis (BMR) and secondly, a fat-specific response. This

second response also reduces BMR, but does so based on the amount of fat stores in the body (Dulloo and Jacquet 1998). Obviously, this information is of significance not only when refeeding patients after illness, but also in the obese.

The effect of inactivity on BC is thought to be a relevant factor in the observed reduction in BMR as well. Unfortunately, as Ritz and Elia point out, "the specific effects of inactivity on metabolism and physiological functions, including appetite and energy homeostasis, are difficult to separate from those arising from the disease, its complications, and its treatment" (Ritz and Elia 1999). Bed-rest studies have confirmed that TEE, BMR and FFM all decrease after periods of prolonged inactivity. The change observed in fat mass varies and depends on the energy intake of the subject (Ritz and Elia 1999).

Energy Balance in Children with CP

The energy balance equation is complex in healthy individuals, and even more so in those affected by disease. In children with CP, energy intake may be affected by oral-motor and gut dysfunction, physical activity altered by ambulation difficulties and metabolism itself influenced by changes in hormones, sympathetic nervous system stimulation and body temperature (Stallings and Zemel 1996).

Although all the elements of the energy balance equation have been studied in disabled children, this is the first study to examine the effect of manipulating energy intake on body composition (energy storage) and energy metabolism.

Bandini et al. measured energy balance in a group of disabled children in 1995, but recommended adjusting energy intakes after long-term evaluation of weight changes, not based on measured energy expenditure. They found that RMR was significantly reduced in the study population and that there was a poor corrlelation between RMR and body weight, which they attributed to variations in BC in the group (Bandini, Puelzl-Quinn et al. 1995). The same group studied both energy expenditure and body composition in adolescents with CP in 1991. Low FFM, high % body fat, low RMR and low activity levels were detected (Bandini, Schoeller et al. 1991).

Azcue et al. hypothesized after their 1996 study that CNS damage was the primary reason behind the low RMR measurements found in children with SQCP. They also stated that they believed "individual energy expenditures should be measured to provide optimal nutritional care", however, no further studies doing this have emerged until this one (Azcue, Zello et al. 1996).

Finally, Stallings reported that in a group of children with SQCP PAL (TEE/RMR) was lower in those children deemed "better nourished" than those who were "poorly nourished" (as determined by body fat from skinfold thicknesses). It was concluded that the growth failure and abnormal RMR measurements seen in this group were related to low energy intakes (Stallings, Zemel et al. 1996).

1.12 GROSS MOTOR FUNCTION

Impairment to the voluntary muscle system is the hallmark feature of CP. The degree of impairment seen in children with CP ranges widely, depending on the extent and exact location of the damage to the brain. Of course, the more severe the motor impairment, the more severe the oral-motor dysfunction and the poorer the nutritional status (Krick and VanDuyn 1984; Thommessen, Kase et al. 1991; Sullivan, Lambert et al. 2000; Troughton and Hill 2001; Fung, Samson-Fang et al. 2002). The disability type may also have an impact upon nutritional status and energy balance.

Spasticity

The most common type of CP is spastic, characterized by an abnormal increase in muscle contraction, often caused by damage to the central motor pathways that control voluntary movement. Spasticity manifests itself clinically as increased stretch reflexes, tendon jerks and high resistance that appears as muscle tone (O'Brian 2002). The earliest studies on the pathology of spastic muscle reported varying degrees of atrophy and of hypertrophy both in type I and type II muscle fibres, increased fat and connective tissue, and increased internal nuclei and fibre splitting (Castle, Reyman et al. 1979). The authors noted that the abnormalities observed were not consistent with those of simple upper motor neuron lesions. They postulated that some of the findings were a result of the chronic nature of the condition. More recent pathology studies confirm these early findings and note increased variability in the size between type I and type II fibres and an abnormal predominance of either type I or type II muscle fibres

(Rose, Haskell et al. 1994). These findings were associated with gait abnormalities and decreased mechanical efficiency. Booth et al. found accumulations of collagen I in the endomysium of spastic muscles, plus fibrotic regions with sparse muscle fibres. The amount of collagen was positively correlated to the degree of spasticity of the child as measured by the Ashworth scale (Booth, Cortina-Borja et al. 2001).

Children's growth, as well as their functional status, is greatly affected by spasticity. In an animal model of spasticity, muscle growth was found to be 45% less in spastic muscles than in non-spastic ones and gave rise to joint contractures (fixed high resistance). The bones attached to the spastic muscles also grew more slowly. The researchers hypothesized that contractures form because of poor/slow muscle growth (Ziv, Blackburn et al. 1984).

Loss of function is the greatest concern in regard to muscle spasticity. However, even when contractures have not yet developed, spasticity may have a significant detrimental role in a child's functional status. Children with spastic CP are less efficient than their peers; that is, they expend more energy to do a set amount of muscular work (Jones and McLaughlin 1993; Rose, Haskell et al. 1993; Rose, Haskell et al. 1994). Other groups feel that muscular co-contraction, rather than spasticity, is the cause of poor motor performance, yet they confirm that children with CP have a higher energy cost for muscular activities such as walking (Unnithan, Dowling et al. 1996; Damiano, Martellotta et al. 2000).

The actual amount of this muscular inefficiency has proven extremely difficult to measure. One fascinating case report quantifies the amount of energy used by spastic muscles in terms of dietary intake. After a 13-year-old boy was treated for spasticity by the insertion of an intrathecal baclofen pump, his spasticity decreased by 30-40%. Concurrently, his energy needs decreased by 34% (calculated by the weight gain that followed pump insertion and the amount of dietary energy cut to achieve a stable weight). This is the first report on the energy requirements of spastic muscles as they affect the child as a whole (Hemingway, McGrogan et al. 2001).

Treatments to Improve Motor Function

The majority of treatments for impaired motor function in children with CP focus on relieving spasticity. The most common treatments for this condition are oral medications, botulinum toxin injections, intrathecal baclofen therapy and selective rhizotomy.

The most frequently prescribed oral medications for spasticity in children with CP are benzodiasepines (e.g. Diazepam). This drug reduces spasticity by depressing the CNS, specifically, by increasing the presynaptic effect of the inhibitory neurotransmitter gamma-amino-butyric-acid (Russman 2003). Side effects include sedation, weakness, ataxia, and memory disturbances. Dantrolene sodium is also frequently used for spasticity resulting from CP. This medication decreases nerve cell excitation (and hence muscle contraction) by inhibiting the release of calcium ions from the sarcoplasmic reticulum.

Weakness, drowsiness, lethargy, nausea and diarrhoea have been reported as side effects (Russman 2003).

Botulinum toxins are produced by *Clostridum botulinum* and work to relieve spasticity by blocking the release of synaptic vesicles at cholinergic nerve terminals after being taken up by endocytosis (Cosgrove, Corry et al. 1994). The toxin is delivered by intramuscular injection. Spasticity in both upper and lower limb muscles of children with CP decreases after this treatment, resulting in improved movement patterns and fine motor function (Cosgrove, Corry et al. 1994; O'Brian 2002; Yang, Fu et al. 2003).

Intrathecal baclofen therapy has been reported to reduce spasticity effectively in both upper and lower limbs of children with CP (Campbell, Ferrel et al. 2002; Murphy, Irwin et al. 2002). Complication rates are very low and caregiver satisfaction with the treatment is high. Caregivers have reported a reduction in the use of oral medications for spasticity and improvements in the comfort and function of the child (Campbell, Ferrel et al. 2002). Baclofen is an analogue of gamma-amino-butyric acid and functions by binding to gamma-butyric acid B receptors to decrease the influx of calcium into presynaptic terminals and to decrease the activity of the muscle fibres (Russman 2003). The pump is surgically implanted into the intrathecal space, approximately 2 cm below the skin near the waistline of the patient. Baclofen can then be delivered to the spinal fluid continuously at the rate required by the individual (Center 2003).

Surgical treatment of spasticity has been aimed at the brain, the spinal cord, the peripheral nerves and the muscle, but each approach has its strengths and weaknesses and none completely eliminates spasticity (Chambers 1997). The most common surgical treatment of spasticity in children with CP is selective rhizotomy, in which a nerve or part of a nerve is severed (Pittsburgh 2003). Surgery is usually performed on the motor nerves affecting the lower limbs. Short and long-term follow-up has revealed that rhizotomy may permanently alleviate lower-limb spasticity and augment motor function (Engsberg, Ross et al. 2002; Mittal, Farmer et al. 2002).

Treatments for improving whole body motor function include physical and occupational therapies. Physical therapy uses exercises and activities to improve muscle function and overcome functional limitations, whereas occupational therapy addresses self-care and mobility (Center 2003). Intensive physiotherapy as well as strength training has been associated with improved motor function in children with CP, even after rest periods from therapy (Damiano and Abel 1998; Trahan and Malouin 2002). Equine (or hippo-) therapy is being explored in the treatment of CP as it is thought to improve balance, posture, mobility and function by harnessing the movement of the horse (McGibbon, Andrade et al. 1998). Improvements in motor function (as measured by the Gross Motor Function Measure) after equine therapy have been reported by several groups (McGibbon, Andrade et al. 1998; Sterba, Rogers et al. 2002).

Measuring Gross Motor Function

Obviously, to evaluate the motor function of children with CP a reliable and valid measurement system is imperative. The Gross Motor Function Measure (GMFM) was developed in 1989 by Dianne Russell and colleagues at McMaster University, Ontario, Canada (Russell, Rosenbaum et al. 1989). The GMFM has undergone significant validation and reliability testing since then and is considered the most appropriate measure of gross motor function in disabled children today (Nordmark, Hagglund et al. 1997; Palisano, Rosenbaum et al. 1997; Ketelarr, Vermeer et al. 1998; Nordmark, Jarnlo et al. 2000; Palisano, Hanna et al. 2000; Palisano, Hanna et al. 2000; Russell, Avery et al. 2000; Russell, Rosenbaum et al. 2002). In a recent systematic review of available assessment measures of functional motor abilities in children, it was concluded that only the GMFM and the Pediatric Evaluation of Disability Inventory (PEDI) were satisfactorily reliable and valid with respect to responsiveness to change (Ketelarr, Vermeer et al. 1998).

The GMFM was designed for use by trained physical therapists and requires 45 to 60 minutes to complete (Russell, Rosenbaum et al. 2002). Five dimensions (Lying & Rolling, Sitting, Crawling & Kneeling, Standing, and Walking, Running & Jumping) are evaluated and each item is scored on a four point system. Scores are calculated for each dimension as percentages, and for the total GMFM.

The Gross Motor Function Classification System (GMCS) for Cerebral Palsy is a five level classification system based on self-initiated movement with emphasis on sitting and walking (Palisano, Rosenbaum et al. 1997). This system was

developed to meet the need for a reliable and valid classification method easily applied to clinical practice and research. GMFM and GMCS scores have been found to be highly correlated, indicating that it is indeed a useful system in situations where the GMFM is not feasible (Palisano, Hanna et al. 2000).

Measuring the degree of spasticity in children with CP is also of importance. Two common measures are the Modified Ashworth Scale, a numerical classification of spasticity developed in 1964, and the Wartenberg pendulum test, first described in 1951 (Bohannon and Smith 1987; Nordmark and Andersson 2002). The Ashworth scale shows high agreement with isokinetic dynamometer measurements of spasticity, especially at the extremes (Damiano, Quinlivan et al. 2002) and the Wartenberg pendulum test has been deemed an objective and sensitive method for quantifying spasticity, even in young patients (Nordmark and Andersson 2002). One technique to measure spasticity still being developed is evaluation of the stretch reflex threshold in affected muscles. Early studies have been promising (Jobin and Levin 2000).

1.13 QUALITY OF LIFE

Quality of Life

Quality of Life (QoL) has been recognized as an important aspect of health since the WHO included "physical, mental and social well-being" in their definition of health in 1948. Despite the official recognition of its importance, a 1998 bibliographic study revealed that less than 5% of studies on the Cochrane Controlled Trials Register reported on QoL (Sanders, Egger et al. 1998). Studying QoL is difficult because it is an "abstract and ill defined" concept, but Lindstrom points out that because of its broad application it is an excellent field for interdisciplinary study (Lindstrom 1994). Christine Eiser agrees, and lists the reasons why QoL should be studied: it is useful for comparing treatments, has potential as a screening tool, is a useful adjunct to survival/intervention data; and it is one measure that incorporates many aspects (Eiser 1997). Jenney adds that is an excellent additional measure when considering resource allocation (Jenney and Campbell 1997).

Health Related Quality of Life (HRQoL) is described as a "measurement of perceived wellbeing in relation to functional status" (Lindstrom 1994). This concept was created in an attempt to narrow the broader concept of QoL and excludes the religious beliefs and practices included in the traditional definition (McLaughlin and Bjornson 1998). It is most often HRQoL that is measured in medical trials, even if not explicitly stated.

A concept emerging in QoL research is that HRQoL is best defined by the individual whose life quality is in question (McLaughlin and Bjornson 1998). This subjectivity creates many barriers to measuring QoL accurately, especially in children. Since children's perceptions of themselves and health differ greatly from those of adults, and children's perceptions change as they age, it has been suggested that parents or caregivers rate the QoL of their children. However, Eiser warns that parents' and children's ratings will not be significantly correlated because they have vastly different understandings of health, the causes of illness and how medications work (Eiser 1997).

Quality of Life in Those with Disabilities

The QoL of people with disabilities is a prime focus for the many advocacy and charity groups established for and by those with disabilities. The mission statement of the United Cerebral Palsy (UCP) is "to advance the independence, productivity and full citizenship of people with cerebral palsy and other disabilities" (UCP 2003). SCOPE states that their aim "is that disabled people achieve equality: a society in which they are as valued and have the same human and civil rights as everyone else" (SCOPE 2003). Both groups also offer advice and services to the families and carers of those with disabilities. They recognize that the QoL of the primary caregivers of disabled children is often greatly compromised due to the high level of care required by the children and the stress of providing this care.

Research supports this recognition of high stress in carers of disabled children. A 1985 study by Blaylock Johnson and Crosetto Deitz measured the amount of

time mothers of disabled and non-disabled preschool children spent on feeding, personal care for their child and transportation. In all three areas, the mothers of the disabled children spent significantly more time (Blaylock Johnson and Crosetto Deitz 1985). Furthermore, it has been shown that mothers of children with feeding disabilities, and especially the mothers of those who required feeding tubes, experienced significantly greater stress than mothers of children who did not have feeding problems and were also at risk for depression (Adams, Gordon et al. 1999; Manual, Naughton et al. 2003).

In many children with disabilities, measuring QoL directly is impossible. If the neurological damage is severe enough to prevent communication then it is not possible to obtain an accurate picture of the child's perspective on life or even to know if he or she has a sufficient awareness to form a perspective. For this reason, as in this study, the QoL of the children's carers is often evaluated.

1.14 THE ETHICAL ISSUES OF TUBE FEEDING AND CARING FOR CHILDREN WITH SEVERE DISABILITIES

The scope of this thesis does not allow for an in depth examination of the ethical and philosophical arguments surrounding tube feeding and caring for disabled children. However, it would not be complete without an acknowledgement of these complex issues.

The rapid advancement of medical technology has resulted in a dramatic increase in the number of children surviving aggressive intervention as infants (Mims and Chrisham 1996). As these infants develop, medical problems often continue, and ethical questions about the initial intervention and the care to be provided arise. A 1999 survey of paediatric neurosurgeons revealed that respondents felt disabled children should receive the same level of medical care as normally developing children, but that the provision of care should be influenced by cost (Mori and Basauri 1999). The surgeons also felt that cardiopulmonary resuscitation should not be used "if a child is not retrievable". Vehmas argues that "intellectual disability is not a sufficient reason for withholding life-saving treatment", but also that human well-being "is a result of the individual's relation to other people" (Vehmas 1999).

Parents and carers of children born with severe disabilities frequently struggle with the ethical decisions they are forced to make. A study examining the lives of parents of severely disabled children revealed that the parents have "an

extremely tough life" (Brinchmann 1999). Relationships between parents and children have been described as "somewhat ambivalent", due to the "love-hate" relationship that results from total dependency on the part of the child and lack of rest and sleep for the parents. Teresa Savage notes that the primary concern of parents of disabled children is the welfare of the child, although concerns about the cost of caring for their child and the effect on the rest of the family are also frequently voiced (Savage 1998).

Society tends to view children with severe/profound disabilities as "tragedies, mistakes, or a harm to personhood" (Savage 1998). Savage asks if the tragedy is the child's, the parent's or society's, and answers that individuals' responses reflect society's impression of its obligations to the child.

Ethical issues surrounding tube feeding have been explored to date mainly in the elderly. Dr. Christopher Pennington states firmly that "not all patients benefit from PEG feeding. The aim must be an improvement in the quality of life, not a prolongation of terminal disease" (Pennington 2002). The issue grows even more complex when dealing with children with severe disabilities, as measuring QoL in a group of children, most of whom can not even communicate on a basic level is extremely difficult. The authors of *The Handbook for Mortals* explain that since offering food has long signalled caring and hospitality, the inability to feed loved ones is often perceived as an inability to "care" (Lynn and Harrold 1999). Traditionally, the provision of food has been the responsibility of the mother and many mothers of disabled children report feelings of "maternal failure" when their

children's feeding difficulties are severe enough that tube feeding is suggested (Thorne, Radford et al. 1997).

Marianne Rogoff, who gave birth to a severely brain damaged daughter in 1988 and later wrote the book *Silvie's Life* chronicling her family's struggle says, "What may be morally clear to others (who speak hypothetically) is unclear to family members who live the real life with the real patient," and, "The real challenge of dealing with an infant is that an infant cannot speak for him/herself" (Rogoff 2001). In outlining the many difficult decisions she was forced to make during her daughter's short life, she states, "What I know is that every case is different, individual, complex, personal, profound and decisions have to be made on the basis of that personal complexity. Not black or white, wrong or right, good or bad, no or yes" (Rogoff 2001).

SECTION TWO: PROGRAMME OF STUDY

2.1 STUDY OBJECTIVES

The general aims of this programme of research were to

- Assess the nutritional status of children with severe neurological disabilities and feeding problems according to several different measures: growth, body composition, general health and energy metabolism
- To examine the effect of the intervention of gastrostomy tube feeding on nutritional status.

2.2 STUDY DESIGN

The research was conducted in the three major studies: The Gastrostomy Study - a Prospective Longitudinal Study of the Impact of Gastrostomy Placement, The Energy Balance and Body Composition Study - an examination of the Energy Balance and Body Composition in a group of disabled children, and The 12 Month Energy Metabolism Study - a study of the changes in body composition and energy balance in a group of these children over one year. The Oxfordshire Clinical Research Ethics Committee granted ethical consent for each study. The carers of the children enrolled provided informed, written consent in advance of data collection.

2.2.1 THE GASTROSTOMY STUDY

Study Aim

This study aimed to investigate the impact of gastrostomy tube feeding on the growth, general health, and nutritional status of children with severe neurological disabilities and feeding problems. It also measured the Quality of Life of the children's primary caregivers.

Hypothesis One: It is predicted that significant improvements will be seen in the growth, nutritional status, general health status and nutritional intake after gastrostomy placement in a group of disabled children.

Hypothesis Two: The Quality of Life of the carers of the children in the Gastrostomy Study will increase because the stress associated with trying to feed their disabled children will decrease.

Set up

Although a randomized control trial of gastrostomy tube feeding would have been ideal, statisticians concluded that the number of children required to conduct such a study was 950. Since recruiting this number of children was unrealistic, it was decided that a longitudinal, prospective study with each child acting as his/her own control was the best option.

The Gastrostomy Study (GS) began in 1998 under the supervision of Dr. Peter Sullivan and the management of Bridget Lambert (RD). Dr. Adrian Thomas (Booth Hall Children's Hospital, Manchester) and Dr. Eltumi Muftah (Watford General Hospital) were involved in the initial study design and agreed to recruit patients when possible.

Data Collection Personnel

Bridget Lambert (RD) was responsible for the questionnaire design used in this study. She acted as the primary dietician for many of the children enrolled and was trained extensively in nutritional assessment.

Liz MacLean (RD) was based in Watford and conducted the nutritional assessments of the children required at Watford General Hospital.

Allison M E Bachlet became involved in the GS in October 2000. Bridget Lambert left the study in January 2001, after training Allison in nutritional assessment and handing over the management of the study.

Recruitment

Children were recruited into the study after being seen by a specialist multi-disciplinary feeding team and the decision to have a gastrostomy placed was made. Inclusion criteria also included being between 0 and 18 years of age and having feeding difficulties as a result of neurological disability. The majority of the children were recruited from the Oxford Feeding Clinic in the John Radcliffe

Hospital, where the assessment team consists of a paediatric gastroenterologist, a clinical nurse specialist, a dietician and a speech/language therapist.

Data Collection

Each child was seen three times over a period of 12 months.

Visit One

The first visit took place before the G-tube was placed to establish the health history and current feeding habits of the child. The data collected included:

1. Patient Details (age, sex, ethnicity, etc.)
2. History
    a. Aetiology and timing of disability
    b. Severity of disability
    c. Other disabilities (vision/hearing/epilepsy)
    d. Behavioural problems
    e. Current medications (for feeding/bowels/other)
    f. Feeding behaviour
    g. Bowel habits
    h. Chest infections
    i. Orthopaedic problems/history
3. Feeding assessment
    a. History
    b. Current methods
    c. Child's feeding ability
    d. Carers perspectives of feeding problems
    e. Previous input and help for feeding difficulties

f. Usual feeder and feeding regime (e.g. length of time to feed)

g. Modification to food and drink

4. Physical Examination (chest abnormalities/anaemia/other)
5. Nutritional Assessment (wasting/stunting/skin and hair condition/subcutaneous fat stores/rickets etc.)
6. Oral Motor Function (tongue thrust/tonic jaw/palate/lip closure)
7. Anthropometry
    a. Weight
    b. Length (where possible)
    c. Lower leg length and upper arm length
    d. Mid upper arm circumference
    e. Triceps, biceps, suprailiac and subscapular skinfolds
    f. Head circumference
8. Dietary Intake (with a three day dietary diary)

The second and third visits occurred six and twelve months post G-tube insertion. On each of these visits the data collected included:

1. Gastrostomy details (type, date of insertion/revision to button/problems or complications)
2. Current medications
3. Chest infections
4. Physical/Feeding Problems/Symptoms (coughing/choking/vomiting/gas/bloating/diarrhoea/constipation)
5. Nutritional assessment (wasting/stunting/skin and hair condition/subcutaneous fat stores/rickets etc.)

6. Gastrostomy feeding Details (feed and volume used/regime/problems)
7. Dietary Intake (with a three day dietary diary)

Please see Appendix B for an example of the data collection forms used.

Quality of Life Questionnaire Design

It was decided that two separate methods of evaluating the carers' Quality of Life would be necessary. First, a respected and validated measurement tool was selected: the Short Form 36 (SF-36), which was developed in 1990 by the Rand Corporation. Second, a questionnaire to measure the issues specific to carers of disabled children was developed and piloted.

The questions on this second questionnaire were created after focus group sessions with carers of disabled children in Manchester under the direction of Dr. Adrian Thomas. The main topics of concern were evaluated and a list of questions generated. Statistical analysis was then used to reduce the number of questions to 28.

It was also decided that free form comment sheets would be beneficial to reveal any unusual advantages or disadvantages of gastrostomy feeding.

At visits one, two, and three the two-part questionnaire containing the SF-36 and Cerebral Palsy Specific Questionnaire was given to the carers. At visits two and three, a free form comment sheet was also provided. Please see Appendix C for a copy of this questionnaire.

Data Entry

All data entry and dietary analysis was done in Oxford to ensure continuity. For children recruited in Watford or Manchester, interviews and anthropometric measurements were conducted on site and the data collection sheets, QoL questionnaire and dietary diary immediately sent to Oxford. NOTE: Only anthropometric measurements taken by the same person on each of the three visits were taken into account during data analysis.

2.2.2 THE ENERGY BALANCE AND BODY COMPOSITION STUDY

Preliminary findings from The GS along with the previous epidemiological work of this group (Sullivan, Lambert et al. 2000; Sullivan, Juszczak et al. 2002) revealed that although feeding difficulties may be reduced with the introduction of G-tube feeding, the overall health implications of this intervention and the actual energy needs of this group of children were still unknown.

Study Aim

The goals of this study were to:

- Examine the impact of G-tube feeding on the body composition of disabled children
- Measure the energy needs (via energy expenditure) of this population (both G-tube and orally fed) and compare to reference standards
- Investigate the energy balance equation (energy input = energy expended + energy stored)

Hypothesis One: Children who are fed via G-tube will be heavier and have more fat storage than children who are orally fed.

Hypothesis Two: This difference in body composition will be linked to energy balance; the children who are gastrostomy-fed will be in a more positive state of energy balance in order to account for increased fat stores.

Set Up and Personnel

Allison M E Bachlet was the primary organizer and manager of this study, under the supervision of Dr. Peter Sullivan. The study began in January 2001 and data collection in March 2001. Angharad Vernon-Roberts (Paediatric Research Nurse) joined the study in September 2001 and Lyn Stirling (RD) in October 2002.

Recruitment

Children were recruited into the study in several ways . The majority were asked to take part after they presented in either the Oxford John Radcliffe Hospital Feeding Clinic or Paediatric Gastroenterology Clinic. Others were referred by community nurses or local children's hospices. Inclusion criteria were a diagnosis of cerebral palsy (or severe neurological disability), and an age of 0-18 years. Children with evidence of genetic, metabolic neurodegenerative disease were excluded, as were those receiving corticosteroids or growth hormone.

Data Collection

Data collected included:

1. Patient Details

2. Health history
3. Temperatures of the skin of the hand, foot, and axilla
4. Anthropometry
    a. Weight
    b. Length
    c. Lower leg length and upper arm length
    d. Mid upper arm circumference
    e. Triceps, biceps, suprailiac and subscapular skinfolds
    f. Head and thigh circumference
    g. Waist and hip circumference
5. Resting Metabolic Rate with Indirect Calorimetry
6. Total Energy Expenditure with Doubly Labelled Water
7. Body Composition with ^{18}O dilution
8. Dietary intake (with weighed three day dietary diary)
9. Gross Motor Classification System (GMCS) Rating
10. Gross Motor Function Measure
11. Activity Level (measured with activity diary)
12. Degree of Spasticity (measured with the Modified Ashworth Scale)

2.3 BODY COMPOSITION AND ENERGY METABOLISM CHANGES OVER TWELVE MONTHS

Study Aim

This study was a continuation of the Energy Balance Study (EBS). All children who participated in the EBS were encouraged to attend follow-up appointments for one year. Dietetic advice was provided based on the results of the energy balance measures taken at the first visit. After one year, all the above measurements were repeated.

The goal of this section was to evaluate the changes in body composition and energy metabolism in children with severe neurological disabilities who were receiving moderate nutritional intervention and compare the changes between those children who were fed via gastrostomy-tube and those who were oral feeders.

Hypothesis One: Children who are fed via gastrostomy-tube will continue to gain weight, primarily as fat, whereas orally fed children will gain both fat and fat-free mass.

Hypothesis Two: Energy metabolism measures will reflect changes in body composition; primarily gaining fat will not increase energy expenditure

significantly, but gaining both fat and lean tissue will increase energy expenditure.

The following elements were studied for significant change:

1. Growth
2. Nutritional Intake
3. Resting Metabolic Rate
4. Body Composition
5. Total Energy Expenditure
6. Energy Balance

SECTION THREE: METHODS

For each of the below methods utilized in this programme of research, the following will be addressed:

- A brief background of the chosen methodology and the reasons for its selection.
- The study protocol and data collection.

3.1 ANTHROPOMETRY

Classic anthropometry was used to evaluate growth and nutritional status in the GS and growth and body composition in the EBS.

3.1.1 GROWTH

Measurements taken for the GS include:

- Weight
- Height/length (where possible)
- Lower leg length
- Upper arm length
- Triceps skinfold
- Biceps skinfold
- Sub-scapular skinfold
- Supra-iliac skinfold

- Mid-upper arm circumference (MUAC)
- Occipito-frontal circumference

Measurements taken for the EBS:

- Weight
- Height (length)- where possible
- Lower leg length
- Heel to knee length
- Upper arm length
- Triceps skinfold
- Biceps skinfold
- Sub-scapular skinfold
- Supra-iliac skinfold
- Mid-upper arm circumference (MUAC)
- Occipito-frontal circumference
- Waist circumference
- Hip circumference
- Thigh circumference

Specific Measurement Methodology

- Body weight was taken using seated electronic weighing scales (the same at each visit where possible). If the child could not sit by him or herself, the carer was weighed separately and then holding the child. The child's weight was determined by the difference between the two measurements.

- Height/Length was measured with a stadiometer if the child could stand. If the child could not stand, but could lie flat on a bed, a cloth tape measure was used to measure from the heel (with foot flexed) to the top of the head. In the Energy Balance Study, height was critical for body composition analysis. If height was not measured at the first visit, the height taken at the subsequent visit was used as the initial visit measurement.
- Lower leg length, upper arm length and heel to knee length were determined using a Harpenden Anthropometer (Child Growth Foundation, London). Measurements were taken on the left side as according to Stevenson (Stevenson 1995).
- Skinfolds (triceps, biceps, subscapular and suprailiac) were taken using a Holtain calliper according the method of Cameron (Cameron 1984).
- Occipito-frontal, waist, hip and thigh circumference were measured with a Harpenden Anthropometric tape using the method of Cameron (Cameron 1984).

Bridget Lambert, Allison Bachlet or Liz McLean, all of who were trained in anthropometry, took measurements for the GS. Allison Bachlet took all the measurements for the EBS.

Each measurement was taken in triplicate and an average calculated. When it was not possible to attain a valid measurement due to a participant's physical state or behaviour no value was recorded.

To analyze the weight, height, BMI, and head circumference values, Z scores were calculated using the data of Freeman et al (Freeman, Cole et al. 1995). In the GS, growth was also evaluated by calculating rate of change of body weight, the weight gain in kg between two consecutive visits divided by the time in decimal years between those two visits.

Nutritional Status

Triceps skinfold thickness was used as an indicator of nutritional status in the GS. Although Sutphen cautions that a single skinfold measurement may not adequately reflect the entire mass of subcutaneous fat, triceps skinfold values are routinely used as markers of nutritional status in healthy and disabled children (Sutphen 1985; Stallings, Charney et al. 1993; Reilly, Hassan et al. 1996).

Triceps skinfolds were taken on the left side of the body in triplicate as according to Cameron (Cameron 1984) and an average was calculated.

Tricep skinfold Z scores were calculated according to the method of Davies et al (Davies, Day et al. 1993).

3.1.2 BODY COMPOSITION

Body composition (percentage of body fat by weight) was calculated from skinfold measurements using the equations of Brook (Brook 1971) and Slaughter (Slaughter, Lohman et al. 1988), depending on the age of the child and the

available skinfold measurements. Where possible, both equations were used and the values compared.

Brook

Brook's method of % BF calculation uses the 1956 equation of Siri:

Body fat % (of weight) = {(4.95/body density) – 4.5} x 100

Brook determined the density of both boys and girls 1-11 years of age with Total Body Water (using deuterium oxide dilution).

For Boys, Density = 1.1690 – 0.0788 x log sum of skinfolds at 4 sites (triceps, biceps, subscapular and suprailiac)

For Girls, Density = 1.2063 – 0.0999 x log sum of skinfolds at 4 sites

Slaughter

The equations derived by Slaughter et al. use only the triceps and subscapular skinfold measurements and are valid for children aged 8-18. The equations are as follows:

Males:

Prepubescent white

$\%\ BF = 1.21(\text{triceps} + \text{subscapular}) - 0.008(\text{triceps} + \text{subscapular})^2 - 1.7$

Prepubescent black

$$\% \text{ BF} = 1.21(\text{triceps} + \text{subscapular}) - 0.008(\text{triceps} + \text{subscapular})^2 - 3.2$$

Pubescent white

$$\% \text{ BF} = 1.21(\text{triceps} + \text{subscapular}) - 0.008(\text{triceps} + \text{subscapular})^2 - 3.4$$

Pubescent black

$$\% \text{ BF} = 1.21(\text{triceps} + \text{subscapular}) - 0.008(\text{triceps} + \text{subscapular})^2 - 5.2$$

Postpubescent white

$$\% \text{ BF} = 1.21(\text{triceps} + \text{subscapular}) - 0.008(\text{triceps} + \text{subscapular})^2 - 5.5$$

Postpubescent black

$$\% \text{ BF} = 1.21(\text{triceps} + \text{subscapular}) - 0.008(\text{triceps} + \text{subscapular})^2 - 6.8$$

All Females:

$$\% \text{ BF} = 1.33(\text{triceps} + \text{subscapular}) - 0.013(\text{triceps} + \text{subscapular})^2 - 2.5$$

These equations were derived from multiple regression analysis that determined which skinfold measurements most accurately predicted body fat as measured with body density, water (deuterium oxide dilution) and bone density (photon absorptiometry) in 310 subjects, 8-29 years.

Trends over time were evaluated with paired t-tests and differences between groups with independent t-tests

3.2 GENERAL HEALTH STATUS

General health status was investigated in the GS during the carer interview. Interviews were conducted when and where it was most convenient for the child's carer. Most often, interviews took place in the John Radcliffe Hospital, before or after a clinic appointment. When this was not possible, home visits were arranged. Appendix B shows a copy of the interview forms used at Baseline and 6 and 12 Months after G-tube placement.

In order to estimate the general health status of the participants, the carers of the child were asked how many chest infections he/she had had in the 6 months prior to the visit that required either antibiotics or hospital admission. Clarification was requested when answers were unclear and responses were recorded numerically. Data was transferred to an SPSS database after the carer interview. Statistical analysis involved calculating the mean number of chest infections requiring antibiotics or hospital admission at each visit and comparing the results between visits. Paired and independent t-tests were used to determine significant changes over time and between groups.

3.3 DIETARY INTAKE

In both the GS and the EBS, a three-day diet diary was used to collect dietary intake information.

Basiotis and colleagues have stated that between 31 and 433 days are required in order to determine accurately the usual nutrient intakes of an individual, and between 3 to 41 for the intakes of a group (Basiotis, Welsh et al. 1987). Energy and macronutrients require the fewest number of days, and Vitamin A the most. As it was not feasible to ask carers of the study participants to record dietary intake for an extended period of time, a three-day diary was requested. Reports indicate that this method is more accurate than using food frequency questionnaires (Bergman, Boyungs et al. 1990).

Many of the difficulties commonly encountered in studies using diet diaries were not relevant to this study. For example, habitual underestimation of dietary intake has been demonstrated in studies that used total energy expenditure to validate energy intake (Black, Prentice et al. 1993). Psychological studies have revealed that the degree of underreporting increases in proportion to the degree of attention directed to food intake and that this underestimation increases with increasing age (Mertz 1992). Since the participants' carers kept the dietary records used in this study, unconscious underestimation was not a problem. *Overestimation* of children's diets has been detected by several groups when parents were asked to recall the food intake of their children (Eck, Klesges et al.

1989; Olinto, Victora et al. 1995). Of particular concern was Olinto's finding that this overestimation was more marked for malnourished children than for those who were well nourished. These studies provided additional support for the decision to employ three-diet diaries as opposed to food recall methods.

The actual compositions of the participant's diets provide a final reason why three-day diet diaries were deemed sufficient for this study. Seasonal variation and person choice have been proposed as reasons why three-day dietary diets are not particularly accurate in determining usual nutrient intakes (Nutrition-Reviews 1991). Disabled children with oral-motor dysfunction often have extremely unvaried diets due to their feeding difficulties. Items such as baby food and yoghurt (provided in standard sized containers) often provided the bulk of a participant's diet. In addition, those who were tube fed received only standardized commercial feeds in pre-measured amounts.

THE GASTROSTOMY STUDY

Appendix D shows an example of the diary used in The GS.

Carers were given verbal and written instructions on how to complete the diary. It was emphasized that the amount actually consumed by the child be recorded; a column to record the amount eaten/spilled was included. Also included in the diary was a brief questionnaire about commonly used proprietary products, portion size, and the type of drinking vessel used by the child.

The carers were given a diary at each visit and asked to record three typical days of their child's intake. The three days were to be random days and include two weekdays and one weekend day as Larkin et al. found that random day sampling was preferable to consecutive day sampling for calculating the intake of individuals (Larkin, Metzner et al. 1991). All diaries were returned to the John Radcliffe Hospital, Oxford, in a pre-stamped envelope and either Bridget Lambert or Allison Bachlet completed the dietary analysis using DietPlan 5 (Forestfield Software 2000). If the diary was not complete or entries were unclear, follow-up phone calls were made. In a few very difficult cases, the child's dietary intake was recorded after verbal recall from the carer.

At 6 and 12 Months post G-tube placement, if the child took nothing orally dietary analysis was performed based on the gastrostomy feeding routine as given by the carer in the general interview.

An average daily intake was calculated for each child at each visit using DietPlan 5 and intake values were transferred to an SPSS database. The participants' usual intakes for macro- and micronutrients were compared at each visit and also to the RNI for the age and sex of the child.

3.3.2 THE ENERGY BALANCE STUDY

As in the GS Study, three-day diet diaries were used to record the dietary intake of each child. However, due to the extreme precision required for the energy

balance portion of this study, food-weighing scales were used for all children who ate orally. An example of The EBS diary is shown as Appendix E.

Carers were given verbal and written instructions on how to use the diary and food weighing scale. Again, it was emphasized that the actual amount *eaten* by the child be recorded, not the amount offered. A subtraction method was suggested to those with food scales; the meal plus plate/bowl was measured at the start of the meal and then again at the end. For mixed meals, the masses of each portion were requested. Diaries were sent home at the end of each visit and carers were asked to complete the diary within 10 days of the visit. The diaries were then collected along with the saliva/urine samples that were taken for the energy expenditure portion of the study.

For children who ate at school, school diaries were sent to the school directly or via the carer. The diary asked the school to record everything consumed by the child for three days and return the diary to either Allison M E Bachlet or the child's carer.

Dietary analysis was completed using DietPlan 5. Allison M E Bachlet performed all the dietary analysis to ensure continuity. The average dietary intake of each child was transferred to an SPSS database.

In the statistical analysis, energy intake was compared to the Estimated Average Requirements (EAR) for UK children as outlined by the Department of Health, 1991 (Thomas 1994). As the EAR are age stratified, a specific recommendation

for each year of childhood was calculated by taking the difference in energy requirements between age groups and distributing the kcal evenly between the years. This was done for both male and female recommendations.

3.4 RESTING METABOLIC RATE

Photograph 3.1 *A girl with Cerebral Palsy having her RMR Measured with the Deltatrac II*

For the measurement of RMR in the EBS, indirect calorimetry was used. As mentioned in the introduction, indirect calorimetry is the most common method of measuring RMR in humans and energy expenditure is determined from the rate of oxygen consumption and the rate of carbon dioxide production of the subject (Bender 1997).

Many different commercial devices for measuring RMR are now available for use in clinical and research settings. A Deltatrac II MBM 200 was the machine used in this study. The Deltatrac II was purchased in March 2001 from Datex Ohmeda, Hatfield, UK. A certified Deltatrac technician performed regular testing and maintenance as recommended by the manufacturer.

A 1998 study by Wells and Fuller concluded that the Deltratrac Mk I is a very precise and accurate monitor (Wells and Fuller 1998). Personal communication has confirmed that the newer model (the Deltratrac II) is also an excellent machine.

Study protocol for the EBS included the following:

- The Deltatrac II was turned on prior to each participant's visit to allow for the minimum "warm-up" period of 30 minutes.
- The child was brought to the scheduled appointment by his/her carer in a fasting state.
- Upon arrival, the weight and height of the child was taken and the subject was then placed upon a hospital bed in a quiet area.
- The Deltratrac II was programmed with the subject's personal data (height, weight, sex, date of birth) and gas calibration was performed.
- When the child had settled and was resting comfortably, the hood of the Deltratrac II was placed over his/her head.
- Measurement was started and continued for 30 minutes.

- The hood was removed and a printout of the measurement period was obtained.
- After the participant visit was complete, the data from the Deltratrac II printout was entered into an SPSS database.

The Weir equation was also used to calculate an average resting energy expenditure from the measured average CO_2 production and O_2 consumption per minute (Weir 1949). Weir's equation was developed to reduce the error associated with the effect of protein metabolism on indirect calorimetry and is valid if the dietary intake of protein lies between 10 and 14% of the total kcal intake.

EQUATION: total kcal/minute = 3.9 (L O_2 used) + 1.1 (L CO_2 produced)

The above protocol was slightly altered on several occasions due to logistical problems or the health requirements of individual participants.

- The measurement was sometimes performed with the participant in a post-prandial rather than fasting state if it was not possible to see the participant until late in the day or if the child usually had over-night tube feeds. Also, it was necessary to give some of the participants a small volume of juice or milk with their regular medications before the measurement.
- Infrequently, a participant became agitated while the measurement was being done and the measurement was stopped. If the child calmed

sufficiently the measurement was attempted again. If not, average CO_2 production and O_2 consumption were calculated from the collected measurement.

The time of the last food/drink consumed as well the participant's level of relaxation was noted and recorded at each visit. These comments were recorded in the SPSS database and a scoring system was devised to avoid using invalid measurements of RMR in statistical analyses. The coding system was:

Level 1 - child was fasting (last eaten 7+ hours prior), totally relaxed

Level 2 - child had last eaten 4-7 hours prior, totally relaxed

Level 3 - child was relaxed but had eaten within 4 hours prior to the measurement OR child had not eaten within 4 hours prior but was not totally relaxed (small movements, obvious awareness of environment)

Level 4 - child was not at all relaxed

To compare and evaluate RMR between these four levels, re-coding and regression was used.

First, the average RMR/kg FFM was calculated for each coded group. As there was no statistical difference between the RMR/kg FFM of the children in Level 1 and Level 2, all these entries were re-coded as "0". Level 3s were re-coded as "1" and Level 4s were discarded. A regression equation revealed that the difference between Level "0" and Level "1" was a constant of 164 kcal. (See equation below). 164 kcal/24 hours was subtracted from each measurement coded Level "1" so that all remaining RMR measurements could be compared.

This adjustment resulted in no significant difference in RMR/kg FFM between groups.

Model Equation: $RMR = k_1(FFM) - k_2\ (RMR\ status) - k_3$

Derived Regression Equation: RMR = 42.1 (FFM) + 164 (RMR status) + 150

3.5 THE DOUBLY LABELLED WATER TECHNIQUE

Doubly labelled water (DLW) was used in the EBS to calculate total body water (TBW) for body composition analysis and total energy expenditure (TEE). The history and background of this method was provided in Section 1.9.

Prior to this study's commencement, numerous studies were reviewed and the most successful elements of each were combined to create the following protocol. The health and abilities of the children participating in this study were kept in mind at all times. Carers were given the choice of collecting either saliva or urine due to the fact that the children involved were not able to produce urine on demand and some, but not all, drooled profusely. Once a sample method was selected, the same sample type was collected for the duration of the child's participation.The neurological disabilities of the participants contributed several additional problems. For example, many of children had severe oral motor difficulties and could not swallow the sample dose easily. If the child had a gastrostomy, then this was used to administer the dose to ensure that no losses occurred. Lack of reference data on body composition and hydration state in disabled children also added complications during the analysis stage.

Dosing

1. 10% $H_2{}^{18}O$ (99.9% pure) and 99.9% $H^2{}_2O$ (98.0% pure) were purchased from Cambridge Isotope Laboratories, Andover, Massachusetts, USA.
2. The mass of the child was determined from his/her last recorded weighing.

3. Amount of each isotope required was calculated based on 0.125g ^{18}O /kg body weight.
4. The grams $H_2{}^{18}O$ of required were measured out using a pipette (estimating one mL equals one gram) and placed into the dose bottle.
5. Step 4 was repeated for the ^{2}H (dosage 0.05g/kg body weight).
6. The $H_2{}^{18}O$ and $^{2}H_2O$ were mixed by vigorous shaking.
7. 0.5mL of the dose was removed and frozen.
8. The dose was stored in the refrigerator until it was administered to the subject.

Dose Administration

1. The mass of the bottle (with lid) and dose was taken to three decimal places on a weighing scale (Sartorius ISO 9001).
2. The dose was given to the child, usually via a gastrostomy tube using either gravity or a syringe.
3. The dose bottle was rinsed with water and this water was also administered to the subject. NOTE: If the child did not have a gastrostomy tube then they were encouraged to drink the water from a cup into which the water was poured, along with water for rinsing. A straw often facilitated complete consumption.
4. The time of dosing was noted and recorded.
5. The mass of the empty bottle and lid was taken to three decimal places.
6. The mass of isotope-enriched water received by the subject was calculated.

Sample Collection

Saliva

1. Before the administration of the dose, a saliva sample was collected into a disposable plastic cup and then immediately transferred to a small tube with an airtight cap using a disposable pipette.
2. The carers were instructed on how to take the saliva samples and were requested to take samples on days 1-10 at home, ensuring that nothing had been in their child's mouth for at least 30 minutes prior. They were also requested to record the exact time that the sample was taken and to freeze the samples immediately after they were taken.
3. The samples were kept frozen until collection by Angharad Vernon-Roberts and transported on ice to the John Radcliffe Hospital where they were placed in a –20 °C freezer.

Urine

1. Before the administration of the dose, carers were asked to put a disposable urine pad in the child's nappy. Once the pad was saturated, the urine was transferred to a sterile, small, air-tight container and frozen.
2. Carers were requested to take urine samples on days 1-10 at home during the day to ensure that the sample was not the first void of the day and that the pad was not contaminated with faeces. They were also requested to record the exact time that the sample was taken and to freeze the samples immediately after they were taken.

3. Samples were kept in the freezer until collection by Angharad Vernon-Roberts and transported on ice to the John Radcliffe Hospital where they were placed in a –20 °C freezer.

Sample Analysis

Sample analysis was done at Iso-Analytical Limited, Unit 2 Zan Industrial Park, Sandbach, Cheshire, CW11 4QD U.K. The subject's samples were shipped on dry ice to Iso-Analytical Ltd. by RM Couriers, UK.

As received from Dr. Steven Brookes (Iso-Analytical Ltd) analysis protocol was as follows:

Deuterium

A sample size of 0.3mL was pipetted into septum sealed vials (in duplicate) along with the catalyst Platinum (5%) on Alumina in Chromacol insert vials. The vials were sealed and the headspace flushed with pure hydrogen. Reference waters (including a quality control standard) were prepared in the same manner. Once all vials were flushed, they were left to equilibrate for a period of four days to ensure complete equilibration. The samples and references were then analysed by continuous flow using an ANCA-GSL and Geo 20-20 IRMS.

Oxygen-18

After deuterium analysis, the vials were flushed with pure CO_2 and left to equilibrate for over 24 hours. Reference waters (including a quality control standard) were prepared in the same manner. The samples and references

were then analysed by continuous flow using an ANCA-GSL and Geo 20-20 IRMS.

Data Analysis

Dr. Jonathan Wells of the Institute of Child Health, London, completed all data analysis. Analysis was performed using a programme created by Dr. Andrew Coward, MRC Dunn Nutrition Unit, Cambridge University.

A summary and explanation of the calculations performed by the program is as follows:

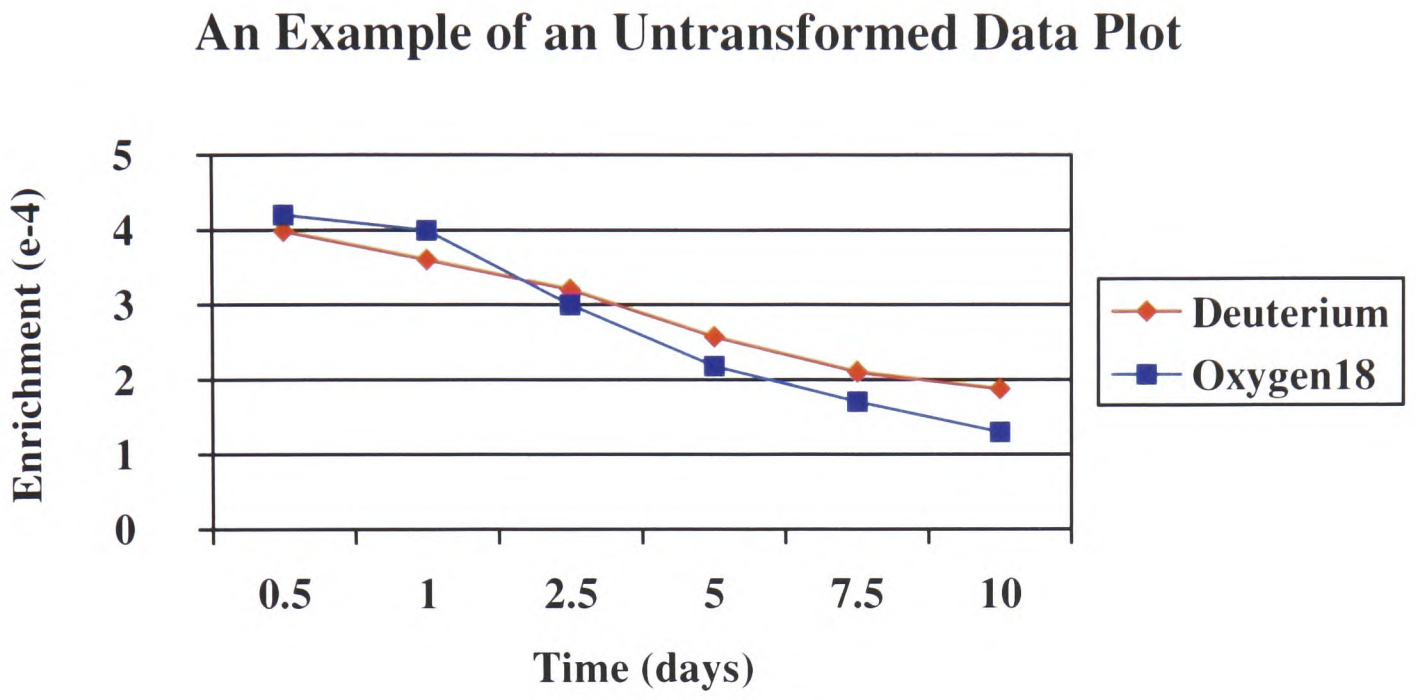
First, the spectroscopic reading for each sample is converted to represent a fraction of the initial dose using the formula:

$$X = \frac{(\delta_s - \delta_p)}{(\delta_a - \delta_t)} \times \frac{18.02a}{WA}$$

Note: δ is enrichment, δ_s enrichment of the sample, δ_p of pre-dose baseline, δ_a of the dose and δ_t of the tap water used to dilute the dose (if diluted). Measured in grams are: a, the amount of dose diluted for analysis; W, the amount of water used to dilute the dose; and A, the amount of dose given. 18.02 converts grams into moles.

These values are then plotted against time. See Figure 3.1.

Figure 3.1 A Line Graph Demonstrating Enrichment Values for Deuterium and Oxygen 18 against Time



(Prentice 1990)

In the plotted version of the data, the pool sizes can be calculated as the reciprocal of the intercept. (N_D from the ^2H line and N_O from the ^{18}O line respectively.) Also, the intercept of the δ_O/δ_D plot is the ratio of N_D/ N_O. Mathematically, the pool space can be calculated with the equation:

$$N \text{ (moles)} = \frac{WA}{18.02a} \times \frac{(\delta_a - \delta_t)f}{(\delta_s - \delta_p)}$$

There are then several methods of transforming the data, the curve fitting method, log transformation, exponential fit and Poisson fit. With clean data sets each model will yield very similar results. The log transformation method was utilized for this study.

The slopes of the regression lines represent the rate constants k_D and k_O.

Recalling the assumptions paramount to DLW, the uncorrected production of CO_2 is calculated:

$$r'_{CO2} = N(k_O - k_D) / 2$$

However, recalling that the pool size of TBW is estimated differently with ^2H and ^{18}O, the equation can then be further modified to:

$$r'_{CO2} = N_O(k_O - 1.03k_D) / 2$$

Note: this equation is used because if an individual ratio for the difference in pool sizes was not determined, N_O is considered to be more accurate than N_D. However, individual ratios were calculated in this study and hence used in place of 1.03.

The fractionation correction for r'_{CO2} is then calculated.

Three different isotope fractionations have been defined by convention:

$$f_1 = \frac{(^2H^1HO/^1H_2O) \text{ vapour}}{(^2H^1HO/^1H_2O) \text{ liquid}}$$

$$f_2 = \frac{(H_2{}^{18}O/\ H_2{}^{16}O)\ \text{vapour}}{(H_2{}^{18}O/\ H_2{}^{16}O)\ \text{liquid}}$$

$$f_3 = \frac{(C^{18}O^{16}O/C^{16}O_2)}{(H_2{}^{18}O/\ H_2{}^{16}O)}$$

The original correction assumed that a constant proportion of water output (x) was fractionated and the resulting equation as:

$$r_{CO2} = k_O N_O - k_D N_D(\ 1 + \{f_2 - f_1\}x)$$

$$r_{CO2} = \frac{k_O N_O - k_D N_D - 27\{f_2 - f_1\}}{2f_3 + 1.1\{f_2 - f_1\}}$$

Finally, EE can be calculated.

$$Eeq_{CO2\ [body]} = \frac{\text{Total energy expenditure}}{\text{Total } CO_2 \text{ produced}}$$

Note: $Eeq_{CO2\ [body]}$ is the energy equivalent of carbon dioxide for a subject. The total CO_2 produced is dependent on the amount of CO_2 produced from the oxidation of each fuel source in the diet (protein, fat, carbohydrate and alcohol.)

If each component of the diet is known accurately, then:

$$Eeq_{CO2\,[body]} = 100 / \{(\%pr/23.33) + (\%f/27.46) + (\%cho/21.12) + (\%al/30.49)\} kJ/L$$

If an estimated RQ value is to be used, then:

$$Eeq_{CO2\,[body]} = \frac{15.48}{RQ} + 5.55\ kJ/L$$

EE therefore equals $Eeq_{CO2\,[body]}$ multiplied by the total CO_2 produced.

In this study, individualized RQ values were obtained via indirect calonimetry. (See section 3.4 on Resting Metabolic Rate)

Body Composition

As mentioned above, TBW was used to determine body composition.

Age and sex specific hydration factors were recorded for each child from published standards (Fomon, Haschke et al. 1982; Lohman 1989). Lean body mass was calculated by dividing the child's TBW by this hydration factor. When both Fomon and Lohman references were available for a given child, both were calculated and an average taken. Fat mass was determined by subtracting lean body mass from total weight. Percentage fat mass and percentage lean mass were determined by dividing the fat mass and lean mass by total body weight. Several other methods of expressing body composition data were also employed. Fat Free Mass Index (FFMI) and Fat Mass Index (FMI) were calculated according to the equations:

$$FFMI = (\text{fat free mass in kg}) / \text{height in meters}^2$$

FMI = (fat mass in kg) / height in meters^2

Total Energy Expenditure

TEE was calculated directly by the programme created by Dr. Andrew Coward.

3.6 GROSS MOTOR FUNCTION

It was imperative to get an accurate measurement of the physical abilities of the children involved in the EBS in order to assess whether or not their disabilities had an effect on their energy expenditure and requirements. Four methods of assessment were used:

1. The GMFM
2. The GMCS
3. The Modified Ashworth Scale of Spasticity
4. An Activity diary

The Gross Motor Function Measure

The Gross Motor Function Measure (GMFM) was designed for use by trained physical therapists. Allison M E Bachlet and Angharad Vernon-Roberts conducted the assessments for this study since there was no physical therapist available to participate in the research. The GMFM incorporates five dimensions (Lying & Rolling, Sitting, Crawling & Kneeling, Standing, and Walking, Running & Jumping), but the majority of the children in the study needed evaluation only in the Lying & Rolling and Sitting domains due to the extent of their disability. Testing was conducted at the first visit. When children were uncooperative during the testing, or unable to comprehend what was desired of them in terms of movement, carers were asked whether or not their child could perform certain actions. Scores were recorded on the GMFM evaluation sheets (Appendix F) and percentage scores for each dimension and total GMFM were calculated.

The Gross Motor Classification System

Although the GMFM and Gross Motor Classification System (GMCS) have been found to be highly correlative, both were utilized in this study (Palisano, Hanna et al. 2000). At the final study visit, both Allison M E Bachlet and Angharad Vernon-Roberts assigned each child a GMCS score based on their observations of the child's physical abilities as seen over the duration of the study. There were no discrepancies between the assignments of scores. The rating scores, I – V, are detailed in Appendix G.

The Modified Ashworth Scale of Spasticity

This scale rates the spasticity of the muscles around a given joint from 0 to 4. The elbow joint was selected for assessment in this study for its accessibility. The child's forearm was moved from an extended to flexed position and back again, while resistance was noted. This test was performed by both Allison M E Bachlet and Angharad Vernon-Roberts and the scores compared. The test was repeated if any discrepancies were found. Appendix H shows the rating scale.

For these three measures, scores were recorded in the participant's file and transferred to an SPSS database for later analysis.

Activity Diary

Participant's carers were requested to complete an activity diary in order to ascertain whether or not the values obtained via DLW and indirect calorimetry were "logical" and to better evaluate each child's physical abilities. The diary contained simple questions regarding the children's daily functioning including how many hours per day they usually slept and whether they spent the majority

of their day lying down, in a chair or unsupported. The second portion of the dairy asked carers to record any physical activity undertaken by their child such as swimming or active therapy. An example of the diary can be found in Appendix I. Data was transferred to an SPSS database.

3.7 CARER PERCEPTIONS OF THE CHILD'S HEALTH

In the GS, the primary carer's perception of his or her child's heath was evaluated because most of the children involved in this study were unable to communicate their feelings and thoughts concerning G-tube feeding. The carers were asked to comment on their observations of how G-tube feeding affected the child, as well as how it affected *their* life. Questions included:

- Do carers think their child is: the right size / too small / too thin / too big?
- Are carers concerned about their child's nutritional status?
- Have carers had to buy bigger clothes/shoes for their child?
- Has the GS improved the ease of drug administration?
- Has the GS reduced the amount of time spent feeding the child?

See Appendix B for the complete interview questions for visits one, two and three.

3.8 CARER QUALITY OF LIFE

The Quality of Life (QoL) of the primary caregiver of each child enrolled in the GS was evaluated at Visits One, Two and Three.

Three measures of QoL were utilized: the SF-36; a questionnaire designed for this study; and a comment form. Appendix C contains an example of the questionnaire. Several data collection tools were utilized in order to obtain a full picture of the QoL status of the care-giver, and to provide a standardized method of evaluation (SF-36) on which to compare the created questionnaire

Methods of Evaluation

The SF-36 (Short Form 36) was developed by The Rand Corporation and John Ware in 1990 for use as a generic indicator of health status. It is considered a valid and reliable indicator of QoL and has been used in many different test populations. The UK SF-36 version II was introduced in 1999 with improved reliability, wording enhancements, and a reduction of the floor/ceiling effect (Jenkinson, Stewart-Brown et al. 1999). The UK SF-36 version II measures eight domains of health: physical functioning; social functioning; role limitations due to physical problems; role limitations due to emotional problems; mental health; energy/vitality; pain; and general health perception. This measurement tool was selected for its reputation as an excellent indicator of QoL, its ease of administration and because there were normalized scores available for the local area

In order to test whether or not the placement of a gastrostomy had an impact upon the concerns specific to carers of disabled children, a specialized questionnaire was developed. Ideas for the types of questions to be included were generated in focus group discussions with carers of severely disabled children, coordinated by Dr. Adrian Thomas at Booth Hall Children's Hospital, Manchester. The focus group discussions were transcribed and themes noted. A list of general areas of concern was created and from that a list of questions generated. The questions were then classified according to theme and the number reduced to 28. A Likert-type scale was used to code the responses of each question for ease in tabulation.

As it was recognized that many carers had concerns or comments that were not addressed with either the SF-36 or the disability specific questionnaire, a free-form comment sheet was provided to the carers at visits two and three. Carers were asked the following questions:

- What are the advantages/best things about gastrostomy feeding?
- What are the disadvantages/worst things about gastrostomy feeding?
- Do you have an extra time now that your child is fed with a gastrostomy? What do you do with this time?
- Do you have less time? If so, why do you think this is the case?

Data Collection

The carer was asked to complete the two-part questionnaire (containing the SF-36 and the Disability Specific Questionnaire as described in section II) during the child's physical assessment, or was sent home with a pre-addressed stamped envelope for quick return. If the questionnaire was not received within two weeks of the appointment, a follow-up phone call was made. In a few cases, the questionnaire was read aloud to the carer and the answers recorded by the GS data collector. At visits two and three, the free-form comment sheet was also provided.

The quantitative data (SF-36 and disability specific questionnaire) was recorded in an SPSS database (specifically for QoL data) as soon as the questionnaires were received from the carers. The comment forms were retained for later analysis.

Analysis

Total score and scores for each domain of the SF-36 were calculated as according to Jenkinson et al. (Jenkinson, Stewart-Brown et al. 1999). Comparisons of the scores between visits and between the study population and the normative data set were completed. Paired tt tests were used to evaluate changes in score over time and independent tt tests to compare the study and normative groups.

A "total score" was tabulated for each carer on each visit from the quantitative data of the disability specific questionnaire. Paired t-tests revealed whether or not a significant change had occurred with time.

The comment forms were analyzed following the recommendations of Oppenheim (Oppenheim 1992) for dealing with questionnaires containing open ended response questions. Based on some of the most frequently noted responses, a coding system was developed for each question. The comment forms were then re-read carefully and the codes applied. A numerical tabulation of how often each code/theme was mentioned by various participants was then performed.

3.9 STATISTICAL ANALYSIS

All statistical analysis was conducted with "Statistics Package for the Social Sciences" (SPSS) version 10.0.

Data were described according to mean, median, range and standard deviation (SD) to provide several interpretations of the data. As noted in the previous sections, paired t-tests were used to compare scores and changes across time. Independent t-tests were used to compare groups of children, usually gastrostomy and non-gastrostomy fed. Age, sex and the use of nasogastric tube prior to G-tube placement were also often evaluated.

2 scores were calculated for certain variables in order to compare individual measurements to the population norm for age and sex. A 2 scores is defined statistically as a measure of the distance is standard deviations of the sample from the mean.

When the data was not normally distributed, non-parametric tests (Mann-Whitney U or Wilcoxon) were used to evaluate changes between groups or over time. These scores are reported where indicated.

Graphs and scatter plots of data were created and are included where appropriate. Pearson correlations were used to compare different methods of evaluating the same measurement. Linear regression was used to control for various factors (e.g. eliminating the effect of FFM in RMR and TEE).

Longitudinal data was evaluated with tt tests to maintain continuity, however the limitations of this multiple testing were considered.

SECTION FOUR: RESULTS AND DISCUSSION- GASTROSTOMY PLACEMENT

Aim of Section Four

The goal of this study was to evaluate the changes in growth, nutritional status, general health status and nutritional intake in a group of children with severe neurological disabilities after gastrostomy-tube placement.

Hypothesis One: It is predicted that significant improvements will be seen in the growth, nutritional status, general health status and nutritional intake after gastrostomy placement in a group of disabled children.

Abbreviations used in Section Four

% BF	Percentage Body Fat (by Weight)
BC	Body Composition
BMI	Body Mass Index
RNI	Recommended Nutrient Intake
FFM	Fat-free Mass
FM	Fat Mass
GS	Gastrostomy Study
G-tube	Gastrostomy-tube
HC	Head Circumference
kcal	Kilo-calories
NG-tube	Naso-gastric tube

OBW	Original Body Weight
OLLL	Original Lower Leg Length
OUAL	Original Upper Arm Length
PC	Pearson Correlation
PEG	Percutaneous Endoscopic Gastrostomy
SD	Standard Deviation

Table Layout

Several tables accompany each sub-section of the following Results to fully illustrate the data. Each table is laid out as follows:

Title

Statistic	List of the statistics used to evaluate the data
NG-tube?	Indication of NG-tube fed prior to G-tube placement
N	Number of children in the group for which the data applies
Mean (SD)	Mean Value and Standard Deviation
Median	Median Value
Range	Range of the Data

Independent t-tests: When the table is referring to differences between NG-tube and non NG-tube fed children, results will apply to the mean differences between groups.

Paired t-tests: these results always apply to the testing of individuals' values from Baseline to 6 months, Baseline to 12 months, and 6 months to 12 months. (When Feeding Groups are tested separately, this is indicated.)

Results Outline

4.1 Participant Details

4.2 Intervention Details

4.3 Anthropometry

4.3.1 Growth

4.3.2 Nutritional Status

4.3.3 Body Composition

4.4 General Health Status

4.5 Nutritional Intake

4.6 Problems Encountered

4.7 Discussion

RESULTS

4.1 PARTICIPANT DETAILS

57 children (28 female and 29 male) were enrolled in the study. The median age was 4.62 years (mean = 5.98) with a range of 0.439 to 17.3 years.

BASELINE CHARACTERISTICS

Disability Level

Three quarters of the children enrolled (43/57) had spastic quadriplegic cerebral palsy. Two children were classified as having left hemiplegia, one ataxic cerebral palsy and the remainder with mixed disabilities. Their motor impairment was of a severe degree: only 12.3% could sit independently and 5.3% could walk unaided. 93.0% of the children could not use their hands to feed themselves and 77.2% were unable to grasp any object. In addition to motor disabilities, 77.2% exhibited profound/severe global developmental delay and learning difficulties and 67.3% had some degree of visual impairment.

Clinical Evaluation:

Epilepsy was a problem in 31/55 (56.4%) of the study population. 66.7% of the children had microcephaly; scoliosis was present in 35.1%, hip dislocation in 29.8%, and 50.9% had at least one chest infection requiring antibiotics in the six months prior to the first visit.

Feeding Ability:

Nearly half the children (49.1%, 28/57) had had feeding difficulties since birth. 25/54 (46.3%) of the children had significant tongue thrust and 35.2% tonic jaw biting. Common problematic feeding behaviours included "turns head away" (22/55-40.0%), "easily distracted whilst feeding" (13/55-23.6%) and "food refusal" (24/55-43.6%.) Possibly dangerous feeding behaviours were also reported, with 27/57 (47.4%) of children "always coughing" with food and drink and 25/57 (43.9%) frequently choking; these factors are associated with failure to protect the airway during swallowing.

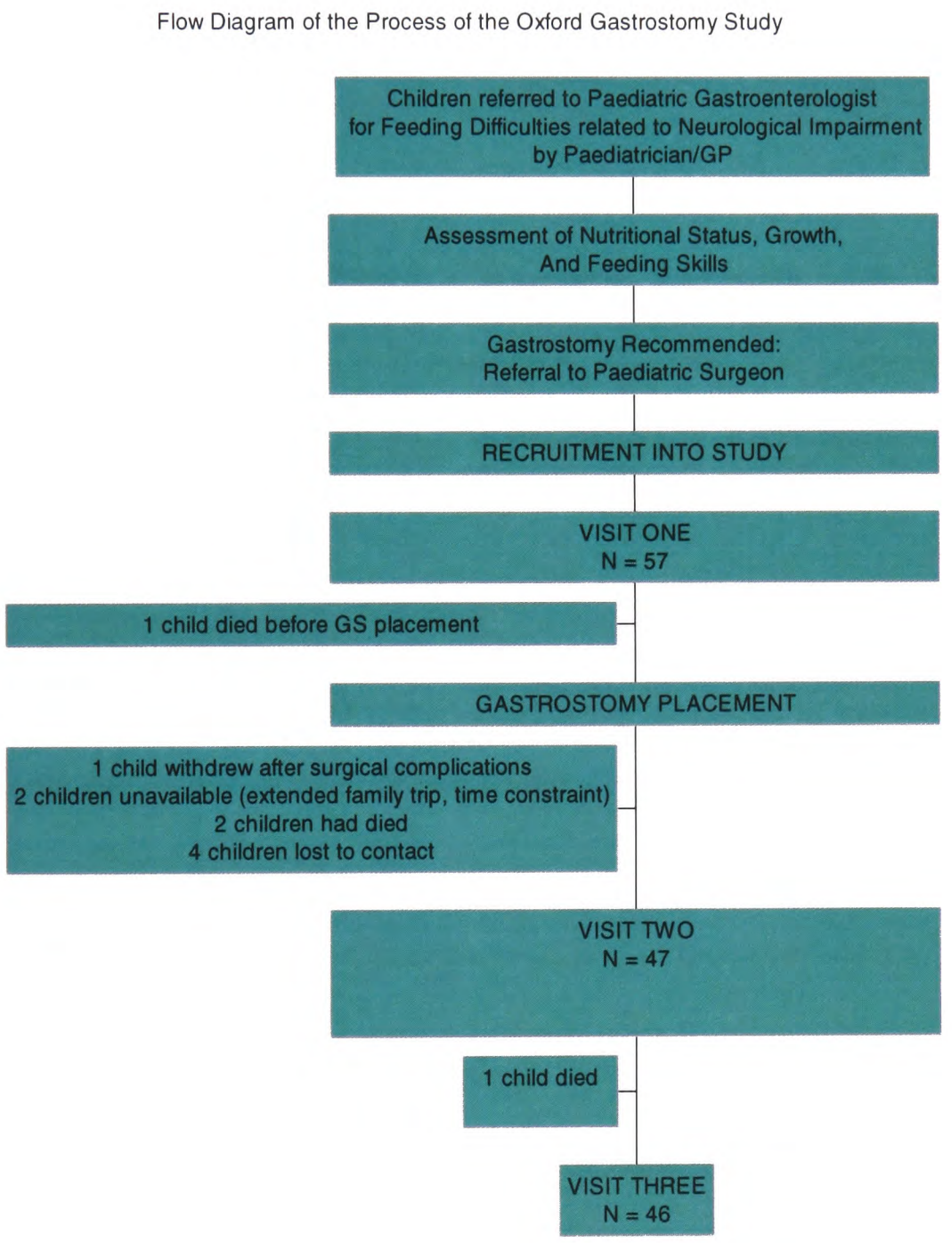
Nasogastric Tube Feeding:

Two thirds (38/57) of study participants had used a naso-gastric feeding tube (NG-tube) for a period in infancy (median length of time 1.70 months, range 0.50 to 36.1 months).

The same proportion of children (66.7%) had an NG-tube in place at enrolment. The median length of time that the NG-tube had been in place prior to G-tube placement was 8.00 months (range 0.87 to 36.1). The median age of the NG-tube fed group was 3.00 years (mean = 4.94, range 0.439 to 17.3) and the orally fed group 7.33 years (mean 8.07, range 1.41 to 16.0). The age difference between these two groups was statistically significant (p=0.013).

4.2 INTERVENTION DETAILS

Figure 4.1 A Consort Diagram for the Gastrostomy Study



Gastrostomy Placement

One child died before gastrostomy placement. Fifty-two children had Percutaneous Endoscopic Gastrostomies (PEGs) placed, while 2 had Stamm gastrostomies and 2 had open gastrostomies. Eighteen had a simultaneous Nissen's fundoplication following demonstration of significant gastroesophageal reflux. There were no reported complications during gastrostomy placement. Only one child experienced serious post-surgical complications: one week after his open gastrostomy, laparoscopic fundoplication and bilateral orchidopexy, he was readmitted with gastric leakage, erythema, excoriation and skin ulceration. As these complications were not medically resolved the gastrostomy site was closed and he was fed via NG-tube until a Stamm gastrostomy was placed 18 months later.

At the second visit (6 months post gastrostomy placement) 51.1% (24/47) of children had had their PEGs changed to a skin-flush button device (Mickey button™).

By 12 months post gastrostomy insertion 73.9% (34/46) had had a button placed.

Complications of Gastrostomy Feeding

Table 4.1 lists the complications of G-tube feeding as reported by caregivers in the year following G-tube insertion. Although minor complications such as site infections and granulation tissue were extremely frequent, major complications were rare.

Table 4.1 Complications of G-tube Feeding in the 12 Months Following G-tube Placement

Complication	Number of Children (of 47)	Percentage
Site infection	27	57.45
Granulation tissue	20	42.55
Leakage	14	29.79
Tube blockages	9	19.15
Tube migration	2	4.26
Peritonitis	1	2.13
Child pulled tube out	2	4.26

4.3 ANTHROPOMETRY

4.3.1 GROWTH

Weight

Z scores, based on normative data from the British Growth Foundation, (Freeman, Cole et al. 1995) were calculated for each child at each visit and are displayed in table 4.2. Paired t-tests of the body weight Z scores revealed a significant difference between the Baseline and 6 Month values ($p<0.001$), the Baseline and 12 Month values ($p<0.001$) and between the 6 and 12 Month values ($p=0.002$).

Weights at time points before G-tube placement were available for a subgroup of children. The Z scores of the data collected retrospectively are included in table 4.2. Paired t-tests indicate that there was no significant difference in the Z scores of Approximately 12 to 6 Months Pre G-tube ($p=0.462$) or Approximately 6 Months Pre G-tube to Baseline ($p=0.133$).

Table 4.2 Weight Z Scores for All Children Before and After G-tube Placement

	Approx 12 Months Pre G-tube	Approx 6 Months Pre G-tube	Baseline	6 Months	12 Months
N	11	37	53	54	44
Mean (SD)	-4.67 (4.48)	-3.27 (3.18)	-3.48 (3.04)	-2.58 (2.51)	-2.17 (2.62)
Median	-3.0	-3.36	-3.03	-2.23	-1.64
Range	-15.7 to 0.83	-13.6 to 2.80	-14.5 to 2.05	- 12.0 to 1.32	-11.7 to 2.32

Paired t-tests: 12 – 6 months Pre G-tube p=0.462, 6 Months Pre G-tube-Baseline p=0.133, Baseline -6 Months p=0<0.001, 6 – 12 Months p=0.002

Table 4.3 reveals the rates of change of body weight before and after G-tube placement. P values, (from paired t-tests), reveal that the only significant difference in the rates of change of body weight was between 6 Months Pre G-tube Baseline to Baseline – 6 months (p=0.01). The P value for 12 - 6 Months Pre G-tube to 6 Months pre-G - Baseline was 0.62, and 0.19 for Baseline - 6 Months to 6-12 Months.

Table 4.3 Rate of Change of Body Weight for all Children Before and After G-tube Placement

	Rate of Change of BW (kg/year) 12-6 Months pre G-tube	Rate of Change of BW (kg/year) 6 Months pre G-tube to Baseline	Rate of Change of BW (kg/year) Baseline to 6 Months	Rate of Change of BW (kg/year) 6-12 Months
N	11	36	45	42
Mean (SD)	-1.45 (6.80)	0.83 (4.87)	4.37 (4.15)	3.24 (3.67)
Median	-0.24	0.80	3.54	2.72
Range	-17.5 to 8.00	-10.4 to 11.3	-0.66 to 22.3	-5.85 to 12.1

Paired t-tests: 12-6 Months Pre G-tube to 6 months Pre G-tube-Baseline: p=0.618, 6 months Pre G-tube-Baseline to Baseline-6 months: p=0.012, Baseline-6 months to 6-12 months: p=0.194

In order to examine whether NG-tube feeding prior to G-tube placement had an effect on these changes in Z scores, weight Z scores and rate of change of body weight were also examined after dividing the children into feeding groups: those who had had an NG-tube prior to G-tube placement and those who had not. Independent t-tests revealed that the only time period where a difference in Z scores was apparent was at Baseline, where the NG-tube fed children had a significantly higher mean weight Z score. In terms of rate of change of body weight, the rate of change for 6 months Pre G-tube – Baseline was nearly significant with a P value of 0.057. Here again, the NG-tube fed children exhibited a larger rate of weight gain.

Table 4.3 Body Weight Z Scores Before and After G-tube Placement by NG-tube fed and Non NG-tube fed sub-groups

	Approx 12 Months Pre G-tube		Approx 6 Months Pre G-tube		Baseline		6 Months		12 Months	
	NG N=7	NonNG N=4	NG N=26	NonNG N=11	NG N=35	NonNG N=18	NG N=31	NonNG N=14	NG N=28	NonNG N=16
Mean (SD)	-4.2 (5.3)	-5.4 (3.0)	-2.7 (3.2)	-4.7 (2.9)	-2.7 (2.8)	-4.9 (3.0)	-2.2 (2.6)	-3.5 (2.1)	-1.7 (2.7)	-3.0 (2.3)
Median	-3.3	-4.2	-2.8	-4.5	-2.4	-4.8	-1.9	-3.3	-1.0	-3.4
Range	-15.7 to 0.8	-9.9 to –3.5	-13.6 to 2.8	-10.3 to 0.6	-14.5 to 2.1	-13.7 to –1.5	-12.0 to 1.3	-7.3 to –0.9	-11.7 to 2.3	-7.9 to 0.4

Independent t-tests: 12 Months Pre G-tube p=0.688, 6 Months Pre G-tube p=0.073, Baseline p=0.012, 6 Months p=0.095, 12 Months p=0.114

Table 4.4 Rate of Change of Body Weight Before and After Gastrostomy Placement by NG-tube fed and Non NG-tube fed sub-groups

	Rate of Change of BW (kg/year) 12-6 Months pre G-tube		Rate of Change of BW (kg/year) 6 Months pre G-tube to Baseline		Rate of Change of BW (kg/year) Baseline to 6 Months		Rate of Change of BW (kg/year) 6-12 Months	
NG tube?	NG	No NG	NG	No NG	NG	No NG	NG	No NG
N	7	4	25	11	31	14	27	13
Mean (SD)	-3.2 (8.0)	1.7 (2.4)	1.8 (5.2)	-1.5 (3.3)	4.5 (4.8)	4.1 (2.1)	3.5 (3.6)	2.8 (3.9)
Median	-3.5	0.8	2.4	-0.4	3.4	3.8	3.1	1.8
Range	-17.5 to 8.0	-0.2 to 5.2	-10.4 to 11.3	-8.1 to 2.7	-0.7 to 22.3	1.7 to 7.6	-5.9 to 11.8	-1.6 to 12.1

Independent t-tests: 12-6 months Pre G-tube p=0.273, 6 months Pre G-tube -Baseline p=0.057, Baseline -6 months p=0.771, 6-12 months p=0.595

The significant changes in weight Z scores and rate of change of body weight reveal significant weight gain after G-tube placement. Although weight gain is expected as a normal part of children's growth, significant changes in Z score and in the *rate* of growth are not.

Head Circumference

Z scores for head circumference (HC) were calculated based on the British Growth Foundation normative data (Freeman, Cole et al. 1995). Significant changes in Z score were again seen in the 12 Months after intervention.

Table 4.5 Head Circumference Z Scores for All Children At Baseline and After G-tube Placement

	Baseline	6 Months	12 Months
N	50	43	41
Mean (SD)	-3.67 (2.26)	-3.64 (2.13)	-3.35 (1.89)
Median	-3.40	-3.76	-3.33
Range	-9.45 to 1.02	-8.67 to 0.80	-6.96 to 0.51

Paired t-tests: Baseline -6 Months p=0.024, 6-12 Months p=0.266, Baseline- 12 Months p=0.004

Independent t-tests were used to determine if there were any significant differences in HC Z scores between feeding groups. The P values, which revealed no significant differences were: Baseline p=0.052, 6 Months p=0.393, 12 Months p=0.176. However, the value at baseline is almost significant, similar to the increased rate of weight gain seen in the NG-tube fed children in the section above.

Linear Growth

Linear length Z scores are presented in Table 4.6. Evaluations of the Z scores reveal that the change in linear Z score was not as significant as the change seen in weight or HC Z scores. Only by 12 Months did paired t-tests reveal significance change from Baseline.

Table 4.6 Height Z Scores for All Children At Baseline and After G-tube Placement

	Baseline	6 Months post-G	12 Months post-G
N	22	24	24
Mean (SD)	-2.88 (2.28)	-2.61 (2.36)	-2.50 (1.92)
Median	-2.47	-2.31	-2.08
Range	-9.63 to 0.03	-8.51 to 2.00	-8.37 to –0.08

Paired t-tests: Baseline -6 Months p=0.479, 6-12 Months p=0.133, Baseline -12 Months p=0.049

Independent t-tests were again used to test for differences between the feeding groups. P values at Visit One p=0.592, Visit Two p=0.325, Visit Three p=0.431 indicating no differences in height Z scores between those children who were fed via NG-tube prior to G-tube placement and those who were not.

Comparison of Weight and Length Changes

Table 4.7 compares the changes in weight and linear lengths as a percentage of the baseline measure. Since total length (height) is very difficult to measure in disabled children alternative measures of linear growth were taken over the course of this study. Lower leg and upper arm length were used in the following comparison. The table shows growth in both the lower legs and upper arms of the children who participated in the study. Since growth is expected with increasing age, it is difficult to know whether the placement of the G-tube had a large role in the growth seen. However, it is evident that the linear and ponderal growth were not equal after G-tube placement. Paired t-tests reveal that at 6 Months after intervention the growth seen in linear and ponderal measures was

significantly different, with the gain in weight being greater than the gains seen in length. However, when two different measures of linear growth were compared (lower leg and upper arm) there were no significant differences detected.

Table 4.7 Percentage of Original Body Weight (OBW), Lower Leg Length (OLLL) and Upper Arm Length (OUAL) Gained in 6 and 12 Months after Gastrostomy Placement

	Six Months			Twelve Months		
Statistic	% Change in OBW	% Change in OLLL	% Change in OUAL	% Change in OBW	% Change in OLLL	% Change in OUAL
N	45	41	41	46	35	35
Mean (SD)	18.9 (14.8)	7.79 (5.67)	10.1 (11.2)	37.2 (24.0)	16.9 (10.1)	15.5 (14.9)
Median	17.5	7.50	6.58	32.0	14.7	13.0
Range	-1.82 to 65.2	0.00 to 20.8	-2.15 to 62.2	4.10 to 137	1.88 to 40.9	-1.79 to 87.8

6 MONTHS Paired t-tests: OBW – OLLL $p<0.001$, OBW – OUAL $p=0.004$, OLLL – OUAL $p=0.213$

12 MONTHS Paired t-tests: OBW – OLLL $p<0.001$, OBW – OUAL $p<0.001$, OLLL – OUAL $p=0.404$

Body Mass Index (BMI) is the most commonly used indicator of weight for height. BMI Z scores were calculated according to Freeman et al (Freeman, Cole et al. 1995). In support of the above data that found greater gains of weight than of linear growth, changes in BMI Z scores indicated that there was a significant increase in weight for height in the year following G-tube placement.

Table 4.8a Body Mass Index (BMI) Z Scores for All Children At Baseline and After G-tube Placement

	Baseline	6 Months post-G	12 Months post-G
N	22	24	24
Mean (SD)	-2.46 (2.14)	-0.93 (2.05)	-0.79 (2.00)
Median	-1.90	-1.14	-0.61
Range	-7.03 to 1.44	-4.72 to 2.26	-4.28 to 2.84

Paired t-tests: Baseline-6 Months: p=0.021, Baseline-12 Months: p=0.004, 6-12 Months: p=0.459

When BMI Z scores were evaluated by feeding group to test whether the presence of an NG-tube prior to G-tube placement had an impact upon these weight and length trends no significant differences were found. This lack of significant difference is shown in Table 4.8b.

Table 4.8b Body Mass Index (BMI) Z Scores At Baseline and After G-tube Placement by NG-tube fed and Non NG-tube fed sub-groups

Statistic	Baseline		6 Months		12 Months	
NG-tube?	NG-tube	No NG-tube	NG-tube	No NG-tube	NG-tube	No NG-tube
N	10	12	16	8	13	11
Mean (SD)	-1.93 (1.87)	-2.91 (2.33)	-0.95 (2.27)	-0.91 (1.64)	-0.69 (2.30)	-0.90 (1.69)
Median	-1.59	-2.94	-1.14	-0.77	-0.33	-0.90
Range	-5.35 to 0.71	-7.03 to 1.44	-4.72 to2.26	-3.16 to 1.06	-4.28 to 2.84	-3.90 to1.41

Independent t tests: Baseline p=0.292, 6 Months p=0.968, 12 Months p=0.812

4.3.2 NUTRITIONAL STATUS

Table 4.9a, below, contains the data for triceps skinfold measurements taken over the three visits. Significant paired t-test values indicate that significant fat storage occurred in the upper arm, especially in the first six months after G-tube placement.

Table 4.9a Triceps Skinfold Measurements in All Children at Baseline and After G-tube Placement

Statistic	Baseline (mm)	6 Months (mm)	12 Months (mm)
N	53	45	45
Mean (SD)	7.7 (3.7)	8.8 (4.1)	9.1 (4.2)
Median	7.4	8.7	8.2
Range	2.0 to 20.0	2.3 to 21.7	3.0 to 22.0

Paired t-tests: Baseline-6 Months p=0.001, Baseline-12 Months p=0.001, 6-12 Months p=0.19

Table 4.9b shows the triceps skinfold measurements by feeding group. It was apparent that the NG-tube fed children had higher triceps fat stores than those children who were not NG-tube fed both immediately prior to G-tube placement and 6 months after. However, the significance of the difference was lost by 12 months.

Table 4.9b Triceps Skinfold Measurements at Baseline and After G-tube Placement by NG-tube fed and Non NG-tube fed sub-groups

Statistic	Baseline (mm)		6 Months (mm)		12 Months (mm)	
NG-tube?	NG-tube	No NG-tube	NG-tube	No NG-tube	NG-tube	No NG-tube
N	35	18	30	15	29	16
Mean (SD)	8.54 (3.13)	5.93 (4.10)	9.65 (3.55)	7.11 (4.65)	9.87 (4.00)	7.62 (4.40)
Median	8.60	5.25	9.50	6.20	8.80	6.40
Range	3.00 to 20.0	2.00 to 19.8	3.80 to 21.0	2.30 to 21.7	4.40 to 22.0	3.00 to 20.5

Independent t-test scores:

Baseline p=0.013, 6 Months p=0.048, 12 Months p=0.088

Triceps Z scores were calculated according to Davies et al. (Davies, Day et al. 1993) and re-illustrate the results of the triceps skinfold measures (see table 4.10a). A significant increase in Z score was detected in the first 6 months after G-tube placement but gain slowed in the following six months. The children fed via NG-tube had higher Z scores just prior to and at 6 months post G-tube placement, but again, this difference was lost by 12 months, as shown in Table 4.10b.

Table 4.10a Triceps Z Scores for All Children at Baseline and After G-tube Placement

Statistic	Baseline	6 Months	12 Months
N	49	44	45
Mean (SD)	-1.51 (1.67)	-0.88 (1.56)	-0.76 (1.43)
Median	-1.17	-0.67	-0.92
Range	-5.68 to 1.62	-6.11 to 2.35	-3.54 to 2.33

Paired t-tests: Baseline – 6 Months p=0.003, Baseline – 12 Months p<0.001, 6-12 Months p=0.173

Table 4.10b Triceps Z Scores at Baseline and After G-tube Placement by NG-tube fed and Non NG-tube fed sub-groups

Statistic	Baseline		6 Months		12 Months	
NG-tube?	NG-tube	No NG-tube	NG-tube	No NG-tube	NG-tube	No NG-tube
N	31	18	29	15	29	16
Mean (SD)	-0.95 (1.20)	-2.47 (1.93)	-0.52 (1.30)	-1.57 (1.86)	-0.50 (1.34)	-1.25 (1.48)
Median	-0.90	-2.06	-0.48	-1.36	-0.55	-1.44
Range	-4.17 to 1.62	-5.68 to 1.22	-3.17 to 2.35	1.40 to 1.86	-3.02 to 2.33	-3.54 to 1.74

Independent t-test: Baseline p=0.006, 6 Months p=0.092

4.3.3 BODY COMPOSITION

Similar to Nutritional Status, body composition as Percentage Body Fat (% BF) can be estimated from skinfold measurements. (See Table 4.11a.)

Using either the Brook or Slaughter equation, (dependent upon the age of the child) a significant increase in body fat was seen over the course of the year. As seen in the triceps skinfold measurements, the gain was dramatic in the first six months after G-tube placement, but slowed in the second half of the year. Although the number of children who could be analyzed with both equations was low, the correlation between the Slaughter and Brook equations was high at each visit. (Baseline: n=8, PC=0.839, p=0.009. 6 Months: n=6, PC=0.978, p=0.001. 12 Months: n=7, PC=0.983, P<0.001.

Table 4.11a Percentage Body Fat as Determined from Skinfold Measurements for All Children at Baseline and After G-tube Placement

Statistic	Baseline		6 Months		12 Months	
Equation Used	Brook	Slaughter	Brook	Slaughter	Brook	Slaughter
N	34	13	28	12	29	11
Mean (SD)	13.7 (4.88)	9.70 (3.89)	17.0 (6.95)	14.2 (6.04)	17.2 (7.76)	16.6 (6.55)
Median	13.5	9.07	15.9	14.1	15.5	15.7
Range	6.54 to 23.4	3.46 to 15.8	6.33 to 34.6	6.30 to 28.4	6.36 to 33.5	6.38 to 26.8

BROOK Paired t-tests: Baseline – 6 Months p=0.032, Baseline – 12 Months p=0.336, 6-12 Months p=0.010

SLAUGHTER Paired t-tests: Baseline – 6 Months p=0.008, Baseline – 12 Months p=0.158, 6-12 Months p=0.009

When Independent t-tests were used to compare the % BF of children who had been fed via NG-tube prior to intervention with those who had not, scores revealed that with either the Brook or Slaughter equation, NG-tube fed children had significantly higher % BF at Baseline. However, by 6 Months, the difference was not significant.

Table 4.11b Percentage Body Fat as Determined from Skinfold Measurements at Baseline and After G-tube Placement by NG-tube fed and Non NG-tube fed sub-groups

Statistic	Baseline				6 Months				12 Months			
Equation Used	Brook		Slaughter		Brook		Slaughter		Brook		Slaughter	
NG-tube?	NG	No-NG	NG	No-NG	NG	No-NG	NG	No-NG	NG	No-NG	NG	No-NG
N	23	11	7	6	21	7	7	5	19	10	6	5
Mean	15.2	10.6	12.6	6.32	18.3	13.1	16.8	10.4	19.9	12.0	18.3	14.4
SD	4.91	3.05	2.20	2.23	7.35	3.61	6.21	3.56	7.41	5.58	7.25	5.58
Median	16.2	9.00	12.6	6.06	16.9	14.2	17.1	8.86	17.7	11.1	18.8	13.6

BROOK Independent t-tests: Baseline p=0.007, 6 Months p=0.083, 12 Months p=0.006

SLAUGHTER Independent t-tests: Baseline p<0.001, 6 Months p=0.067, 12 Months p=0.350

4.4 GENERAL HEALTH STATUS

Chest infections were selected to act as a marker of general health in the children who participated in the study. Table 4.12 shows the number of chest infections requiring antibiotics or hospital visits as reported by the child's primary caregiver in the six months prior to G-tube placement and in the year following intervention. The only statistically significant change was in the number of chest infections requiring hospitalization from Baseline to 12 Months after G-tube placement. However, the number of chest infections requiring antibiotics from Baseline to 6 Months was almost significant as well, with a p value of 0.055.

Table 4.12 Number of Chest Infections Requiring Antibiotics or Hospital Admission in the Six Months Prior to Baseline Visit and Visits 6 and 12 Months After G-tube Placement

Statistic	Chest Infections- Antibiotics			Chest Infections- Hospital Admissions		
	Baseline	6 Months	12 Months	Baseline	6 Months	12 Months
N	57	47	45	57	47	45
Mean (SD)	1.79 (2.66)	1.02 (1.82)	0.93 (1.68)	0.47 (0.98)	0.28 (0.71)	0.09 (0.36)
Median	1.00	0.00	0.00	0.00	0.00	0.00
Range	0.00 to 12.0	0.00 to 10.0	0.00 to 8.00	0.00 to 5.00	0.00 to 3.00	0.00 to 2.00

ANTIBIOTICS Paired t-tests: Baseline – 6 Months p=0.055, Baseline – 12 Months p=0.248, 6-12 Months p=0.065

ADMISSIONS Paired t-tests: Baseline – 6 Months p=0.302, Baseline – 12 Months p=0.038, 6-12 Months p=0.095

Table 4.13 shows the difference in the number of chest infections requiring either antibiotics or hospital admission between the children who were fed via NG-tube prior to G-tube placement and those who were not. The children without NG-tubes had significantly fewer chest infections requiring antibiotics in the 6 months prior to the Baseline visit.

Table 4.13 Number of Chest Infections Requiring Antibiotics or Hospital Admission in the Six Months Prior to Baseline Visit by NG-tube fed and Non NG-tube fed sub-groups

	Baseline Chest Infections- Antibiotics		Baseline Chest Infections- Hospital Admissions	
NG-tube	NG-tube	No NG-tube	NG-tube	No NG-tube
N	38	19	38	19
Mean (SD)	2.24 (2.98)	0.89 (1.56)	0.55 (1.11)	0.32 (0.67)
Median	1.00	0.00	0.00	0.00
Range	0.00 to 12.0	0.00 to 6.00	0.00 to 5.00	0.00 to 2.00

Independent t-tests: Antibiotics p=0.030, Admissions p=0.396

(Note: Non-parametric tests revealed the same significance values)

4.5 NUTRITIONAL INTAKE

Because of the varying ages of children in the study, dietary intake was analyzed by comparing each child's daily intake to the Dietary Reference Values (RNI) for that child's age and sex. Data was therefore expressed as a percentage of the RNI (% RNI) and permitted valid comparisons between children of differing age and sex.

Macro-Nutrient Intake

The % RNI intakes for Energy, Protein, Carbohydrate and Fat from Baseline and 6 and 12 Month visits are presented in Table 4.14. Paired t-tests revealed that there were no significant differences in % RNI intake between visits for individuals.

Table 4.14 Energy and Macronutrient Intakes (by % RNI) for All Children at Baseline and After G-tube Placement

Visit	Statistic	% RNI for Energy	% RNI for Protein	% RNI for Carbohydrate	% RNI for Fat
BASELINE N= 49	Mean	66.3	142.7	53.4	73.0
	SD	25.3	67.2	22.3	29.8
	Median	63.0	130.0	50.0	72.0
	Range	22.0 to 148	37.0 to 273	14.0 to 134	20.0 to 141
6 MONTHS N= 43	Mean	73.6	164.3	57.0	83.7
	SD	29.6	80.0	25.5	34.3
	Median	67.1	145.0	49.3	78.7
	Range	39.0 to 198	51.0 to 388	28.0 to 171	15.0 to 213
12 MONTHS N= 38	Mean	71.2	163.4	54.1	84.8
	SD	19.8	57.8	14.8	29.1
	Median	68.5	153.5	53.0	82.5
	Range	33.0 to 116	64.0 to 307	23.0 to 92	37.0 to 147

ENERGY Paired t-tests: Baseline – 6 Months p=0.204, 6-12 Months p=0.576, Baseline – 12 Months p=0.778

PROTEIN Paired t-tests: Baseline – 6 Months p=0.088, 6-12 Months p=0.671, Baseline – 12 Months p=0.286

CARB. Paired t-tests: Baseline – 6 Months p=0.479, 6-12 Months p=0.575, Baseline – 12 Months p=0.738

FAT Paired t-tests: Baseline – 6 Months p=0.101, 6-12 Months p=0.853, Baseline – 12 Months p=0.271

To compare whether or not the presence of a NG-tube prior to Baseline had an effect of the % RNI intake of energy and the macronutrients, % RNI intakes at Baseline were also evaluated by feeding group. Table 14.15 reveals that there were no significant differences in % RNI intake at Baseline between these two groups, and Independent t-test scores confirm that this continued at 6 and 12 Months.

Table 14.15 Energy and Macronutrient Intakes (by %RNI) at Baseline by NG-tube fed and Non NG-tube fed sub-groups

Statistic	% RNI for Energy		% RNI for Protein		% RNI for Carbohydrate		% RNI for Fat	
NG-tube?	NG-tube	No NG-tube	NG-tube	No NG-tube	NG-tube	No NG-tube	NG-tube	No NG-tube
N	35	14	35	14	35	14	35	14
Mean	68.7	57.8	142.3	133.2	54.4	47.8	77.9	59.8
SD	26.3	19.1	59.8	64.1	23.9	16.0	29.4	26.9
Median	65.0	58.0	130.0	122.0	50.0	46.3	72.0	52.5
Range	22 to 148	32 to 86	49 to 261	37 to 273	14 to 134	25 to 80	31 to 141	20 to 101

Independent t-tests: Energy p=0.287, Protein p=0.956, Carb. p=0.631, Fat p=0.070 / 6 Months Independent t-tests: Energy p=0.253, Protein p=0.667, Carb. p=0.338, Fat p=0.169 / 12 Months Independent t-tests: Energy p=0.359, Protein p=0.604, Carb. p=0.632, Fat p=0.587

The energy intakes per kg of body weight for all children at each visit are shown in table 14.16a. No change in intake/kg was detected from Baseline to 6 Months post G-tube placement, but there was a significant *decrease* in energy intake/kg

between Baseline and the 12 Month values. Evaluated by feeding group, there were no significant differences in the energy intake/kg at any of the visits, as shown in table 14.16b.

Table 14.16a Daily Energy Intake per Kg of Body Weight for All Children at Baseline and After G-tube Placement (kcal/kg/24 hours)

Statistic	Baseline	6 Months	12 Months
N	49	43	37
Mean (SD)	75.8 (32.1)	76.7 (28.6)	72.5 (26.0)
Median	72.0	74.0	75.5
Range	21.1 to 164	31 to 174	27 to 117

Paired t-tests: Baseline – 6 Months p=0.853, 6-12 Months p=0.240, Baseline – 12 Months p=0.028

Table 14.16b Daily Energy Intake per Kg of Body Weight at Baseline and After G-tube Placement by NG-tube fed and Non NG-tube fed sub-groups (kcal/kg/24 hours)

Statistic	Baseline		6 Months		12 Months	
Ng-tube?	NG-tube	No NG-tube	NG-tube	No NG-tube	NG-tube	No NG-tube
N	35	14	29	14	25	12
Mean (SD)	72.8 (30.4)	83.3 (35.9)	76.1 (32.8)	78.0 (16.0)	70.9 (26.9)	76.0 (24.7)
Median	69.0	80.0	68.2	76.4	76.5	72.2
Range	21.1 to 145	38.2 to 164	31.3 to174	50.4 to 117	27.0 to 113	38.4 to117

Independent t-tests: Baseline p=0.305, 6 Months p=0.838, 12 Months p=0.582

Micronutrient Intake

Table 14.17 shows the mean micronutrient intake of all the children in the study at each visit. No major micronutrient deficiencies were revealed, as the table shows that nearly all mean intakes exceeded 100% of the RNI. Paired t-tests reveal that there were significant increases in the intake of magnesium (p=0.03), zinc (p=0.002) and selenium (p=0.02) between Baseline and 6 Months. Between Baseline and 12 Months there were significant increases in the intakes of iron (p=0.05), zinc (p=0.01) and selenium (p=0.009).

Table 14.17 The Mean % RNI Intake of Selected Micronutrients for All Children at Baseline and After G-tube Placement, And the Paired t-test Results of Individual Comparison of These Intakes

Nutrient	Mean % of RNI at Baseline	Mean % of RNI at 6 Months	Mean % of RNI at 12 Months	P Value Visits Baseline – 6 Months	P Value Visits Baseline – 12 Months
Sodium	70.6	73.5	76.4	0.640	0.710
Potassium	127.3	113.1	111.8	0.571	0.539
Calcium	141.4	142.9	148.1	0.900	0.362
Magnesium	109.2	128.3	127.8	0.025	0.078
Phosphorus	157.8	168.9	173.0	0.339	0.571
Iron	108.3	124.1	130.2	0.073	0.047
Copper	166.6	222.4	285.9	0.191	0.122
Zinc	122.7	144.2	151.6	0.002	0.012
Chloride	93.1	110.5	103.2	0.147	0.838
Selenium	102.6	126.7	134.3	0.020	0.009
Iodine	108.0	126.8	120.9	0.099	0.401
Vitamin B1	168.4	180.7	191.4	0.118	0.268
Vitamin B2	187.9	204.3	255.4	0.185	0.280
Niacin	98.7	109.1	110.9	0.073	0.204
Vitamin B6	362.4	368.6	379.4	0.683	0.982
Vitamin B12	387.4	408.7	428.9	0.229	0.297
Folate	147.4	157.7	167.8	0.164	0.201
Vitamin C	257.7	214.3	233.4	0.549	0.573

Table 4.18 explores whether or not NG-tube feeding prior to G-tube placement had a significant impact upon micronutrient intake at baseline. The data in table 4.18 is presented as the percentage of children, either NG-tube fed or not, who

had intakes *greater* than 100% of the RNI. Independent t-test scores reveal that the only micronutrients for which significantly more children received 100%+ of the RNI were copper, selenium, niacin and folate. The NG-tube fed group received higher amounts of those nutrients.

Table 4.18 The Percentage of Children with Intakes of 100%+ RNI at Baseline by NG-tube fed and Non NG-tube fed sub-groups for Selected Micronutrients

Nutrient	% Of NG-tube fed Children at Baseline with Intakes 100% or greater of the RNI	% Of non-NG fed Children at Baseline with Intakes 100% or greater of the RNI
Sodium	28.6	28.6
Potassium	37.1	42.9
Calcium	65.7	71.4
Magnesium	51.4	57.1
Phosphorus	60.0	85.7
Iron	54.3	42.9
Copper*	70.6	35.7
Zinc	57.1	42.9
Chloride	40.0	28.6
Selenium*	54.3	14.3
Iodine	57.1	35.7
Vitamin B1	68.6	71.4
Vitamin B2	77.1	78.6
Niacin*	45.7	14.3
Vitamin B6	94.3	100
Vitamin B12	100	92.9
Folate*	77.1	57.1
Vitamin C	80.0	71.4

*Significant Independent t-tests results: copper ($p=0.003$), selenium ($p<0.001$), niacin ($p=0.02$) and folate ($p=0.001$).

Fibre

The fibre intake of all the children in the study is reported in grams/day in Table 4.19. The mean intake was extremely low at each visit, and did not change over the course of the study.

Table 4.19 Fibre Intake in Grams of All Children at Baseline and After G-tube Placement

Statistic	Baseline	6 Months	12 Months
N	49	43	38
Mean (SD)	2.1 (2.9)	2.3 (4.0)	2.1 (3.2)
Median	0.2	0.4	0.6
Range	0 to 11	0 to 23	0 to 14.6

Investigating fibre intake just prior to G-tube placement by feeding group, the children who had an NG-tube were receiving an average of 1.3g fibre (SD=2.6), whereas the children who did not have an NG-tube received 4.2g (SD=2.8). This difference was statistically significant with a P value of 0.001.

4.6 PROBLEMS ENCOUNTERED

The two major problems encountered in this study concerned taking accurate anthropometric measurements on disabled children and scheduling follow-up visits.

Contractures, muscle spasticity and immobility made it extremely difficult to get full anthropometric measurements for all the children who participated in the study. Length was especially problematic. For this reason, alternative measures of linear length were taken routinely.

Follow-up visits were extremely difficult to obtain for a number of study participants. Home visits were offered when the family had no hospital appointments coinciding with 6 and 12 months post G-tube placement, but some carers were still not keen to have follow-up for their children. Home visits often made data collection more difficult as clinical evaluations were not as thorough as when a visit took place in a hospital setting.

Collecting dietary intake data raised two concerns. Accuracy and completeness of information was the first problem. Although carers were given detailed instructions at each visit, some food diaries were not completed to satisfaction. Phone calls helped to clarify this matter, but as with any type of study relying on diet diaries concerns about the accuracy and precision of recorded data remained. The second problem encountered with the diet diaries was in the actual receiving of the information. Carers were provided with pre-stamped

envelopes to return to diaries to Oxford, yet often carers "forgot" or did not find the time to complete the diary. Again, follow-up phone calls helped with that issue.

A final problem in this study was a lack of accurate body composition measurement. Although skinfold measures are very routinely used to estimate % BF there are concerns with this method, especially in disabled children (VandenBerg-Emons, VanBaak et al. 1998). Bioelectrical Impedance Analysis (Bodystat MD 1200) was used to measure body composition throughout the study, but the data was not included in the final analysis because of the many problems encountered. Results were continually "out of range" or totally unrealistic. Measurements were tried in various locations and the problem was taken up with the manufacturer numerous times. Even when the machine was replaced the results were not acceptable.

4.7 DISCUSSION

The Participants

The baseline characteristics of the children who took part in the GS reveal that this group was highly disabled. A validated measure of gross motor function (such as the Gross Motor Function Measure) would have been useful in this study, but was not used. This was rectified in the Energy Balance Study where objective measures of gross motor function were employed.

The Intervention

The complications of G-tube feeding reported by carers of the children who took part in this study were all relatively common but not severe. Problems associated with the site itself (infection, granulation tissue and leakage) occurred in 57, 43 and 30 percent of children respectively. Although carers were often frustrated by these problems, they were in almost all cases easily treated. Site infections were often recurrent suggesting that continual follow-up nursing care is required for all children with G-tubes.

Anthropometry- Growth

Weight Z score data clearly indicates that these disabled children were light for their age, an observation reported by many other groups studying children with severe neurological disabilities (Sterling 1960; Tobis, Saturen et al. 1961; Stevenson, Hayes et al. 1994; Krick, Murphy-Miller et al. 1996). The significant change in weight Z score seen after G-tube placement in disabled children indicates that this intervention has a significant impact upon body weight. This

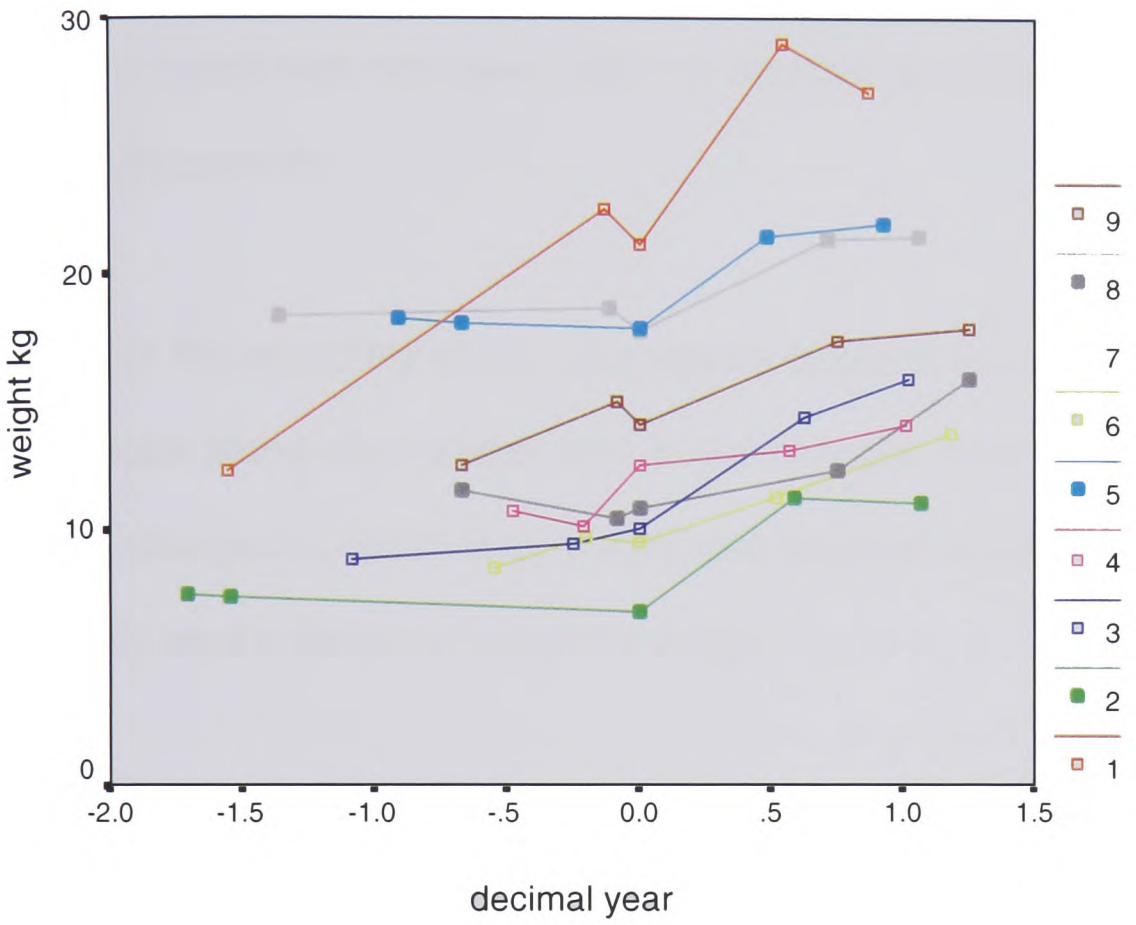
theory has also been supported by several other research groups (Rempel, Colwell et al. 1988; Sanders, Cox et al. 1990; Amundson, Sherbondy et al. 1994; SugarmanIsaacs, Georgeson et al. 1994; Corwin, Sugarman-Isaacs et al. 1996; Brant, Stanich et al. 1999).

The children without NG-tubes prior to G-tube placement routinely had lower weight Z scores than those with NG-tubes, both before and after G-tube placement. This suggests that NG-tube feeding, as expected, also has an impact upon weight. However, the difference in scores between these two groups was only significant immediately prior to G-tube placement. This suggests that although NG-tube feeding increases weight in disabled children, it is not as effective as G-tube feeding, since its effects are not sustained. After initiating G-tube feeding, both groups gained weight and this weight gain was equal by 6 months post G-tube.

Longitudinal weight data also reveals important differences between those fed by NG-tube and those without NG-tube feeding. Approximately 12 months Pre G-tube placement those children with an NG-tube at Baseline were losing weight whereas the children who did not have an NG-tube prior to G-tube placement exhibited slow weight gain. At approximately 6 months pre G-tube placement, the children without NG-tubes were losing weight and those with NG-tubes were gaining weight at a slow rate. The choice to have an NG-tube placed prior to G-tube placement may have been impacted by physician or carer preference.

The figure located below illustrates the changes in body weight from one year pre to one year post G-tube for 9 children whose data was available at each of these time points. The children represented by closed squares are those who did not have an NG-tube prior to G-tube placement. In these children, slow weight gain and in some cases weight loss is seen before G-tube intervention. In the children represented by open squares, those who had an NG-tube, significant weight gain is seen even before G-tube placement. The short and small decline in weight just prior to G placement in this group was most likely caused by the removal of the NG-tube to test whether tube feeding was necessary, was an indication that the child did not tolerate NG-tube feeding or was simply in preparation for G-tube placement.

Figure 4.2 A Line Graph of the Weight of Nine Children, Four of Whom had NG-tubes and Five of Whom did not, for One Year Before and One Year After G-tube Placement



Rate of change of body weight was calculated in addition to the evaluation of weight Z scores at each visit because it allowed for a more precise tracking of weight gain before and after G-tube placement since it used the exact number of months between each visit. The significance of the rate of change pre and post G-tube once again indicated that this intervention had a definite impact upon the weight gain of disabled children.

Examination of other forms and areas of growth allowed further study of the impact of G-tube placement. Table 4.5 showed that HC Z scores increased significantly after G-tube placement, particularly in the first 6 months. Table 4.6 illustrates linear length Z scores. The data reveal that linear length was not as affected after one year of G-tube feeding as was weight and HC. A significant change in score was only seen after 12 months, as opposed to 6 months with both weight and HC.

To explore the possibility of this discrepancy between linear and ponderal growth after G-tube placement, weight and linear changes were compared directly by using % change in original body weight and segment lengths, and BMI, the most commonly used indicator of weight for height.

Table 4.7 and its accompanying paired t-test scores revealed that there was a much larger percentage change in weight gain than in linear growth, measured either as LLL or UAL. The changes seen in BMI Z scores also indicated a disproportionate gain in weight for height increase gain due to the significant changes seen in score.

The above evaluations suggest that tube feeding (in any form) fosters significant weight gain but only moderate linear growth. If a child had an NG-tube tube prior to G-tube placement then weight gain was accelerated, however the intervention of G-tube placement was more effective since all the differences seen between the feeding groups disappeared by one year after G-tube placement.

Anthropometry- Nutritional Status

Nutritional Status is commonly evaluated in clinical settings by measuring the subcutaneous fat stores, most frequently by measuring the thickness of the triceps skinfold. The actual triceps skinfold measurements taken in this study indicated very significant increases in the fat stored in the upper arm area over time. This fat deposition was especially marked in the first 6 months after G-tube placement and slowed in the following 6 months.

Similar to the impact of the NG-tubes on weight gain, independent t-test scores suggested that the presence of an NG-tube prior to G-tube placement had a positive impact upon fat storage. However, since table 4.10b contained actual skinfold measurements, the significant difference in age between the two groups must be noted. The mean age of the children who had an NG-tube prior to G-tube placement was 4.94 years and that of the orally fed children 8.07 years.

It was therefore more appropriate to examine differences between these two groups using triceps Z scores. First, evaluating all the children, changes in Z score were statistically significant between Baseline and 6 Month visits, as well as Baseline and 12 Month visits, indicating significant subcutaneous fat storage. The rate of fat storage appeared to slow 6 months after G-tube placement, however, as the change in Z score between the 6 and 12 Month values was not significant.

Independent t-tests revealed that there was a significant difference in the triceps skinfold Z score at Baseline between those children who had an NG-tube prior to

G-tube placement and those who did not. At 6 Months, this difference was still significant, but disappeared by 12 Months.

These findings echo what was determined in the previous section: G-tube feeding fosters fat deposition in disabled children. NG-tube feeding aids the process of fat storage, but by one-year post-G-tube placement, all differences between those who had an NG-tube and those who did not prior to G-tube placement were lost.

Anthropometry- Body Composition

In support of the conclusions drawn from the data on triceps skinfold thicknesses, the data from this section emphasizes that fat gain post G-tube placement is significant, especially in the first 6 months.

At Baseline, there was a significant difference in body fat stores between children who had an NG-tube and those who had not. By 6 Months this difference was not significant; however, at 12 Months a significant difference was again determined in those children evaluated with the Brook equation. A possible explanation for this finding is the small numbers of children in the two groups being compared at 12 Months.

General Health Status

This significant decrease in the number of chest infections requiring hospital admission in the year post G-tube placement as seen in table 4.12 is an important finding. In parallel with these observations, carers reported that they

felt their children were healthier in general. Moreover, when children did become ill the illness was shorter and easier to cope with because of the ease with which medications and liquids could be delivered via the G-tube.

Interestingly, those with NG-tubes prior to G-tube placement had a significantly higher number of chest infections requiring antibiotics in the 6 months prior to Baseline. The fact that this finding disappeared by 6 Months (Independent t-test values for 6 Months were: Antibiotics p=0.219, Admissions p=0.300 and for 12 Months: Antibiotics p=0.265, Admissions p=0.772) suggests that these children were not just more prone to chest infections. The possibility of the NG-tube feeding tube contributing to the more frequent chest infections must be considered and is an area that should be investigated in more detail. A literature search revealed that very little research has been done on the relationship between NG tube feeding and chest infections. Interestingly, NG-tube feeding has been associated with an increased risk of post-operative respiratory mortality in surgical patients (Mitchell, Garrahy et al. 1982). Strauss and Kastner, who have been looking at tube feeding and mortality in children with disabilities, claim that tube feeding is related to increased mortality. However, although their studies did not distinguish between the type of tube feeding, the authors believe that up to 90% of cases were G-tube tube fed (Strauss, Kastner et al. 1997).

Nutritional Intake

The data on energy and macronutrient intake is interesting considering the significant weight gain observed in these children. The mean % RNI intake for energy, protein, fat and carbohydrate did *not* increase significantly over the

course of the study. Although the % RNI intakes at 6 Months are higher than at Baseline, they all then decreased by 12 Months. Twelve Months values were higher than those at Baseline, but not significantly so.

Possible technical explanations include relatively small study numbers and/or inaccurate dietetic assessment. An alternative explanation is that the low energy requirements of this group (see Sections 5 and 6) mean that even small increases in dietary intake caused significant changes in body weight. As for why the % RNI decreased from 6 to 12 Months, it is possible that the rapid weight gain of the first 6 months encouraged changes in the dietary regime in the second half of the year.

Energy intake was also expressed as kcal intake per kg body weight. The only significant difference in kcal/kg body weight for the whole group was between visits was a *decrease* from Baseline to 12 Months ($p=0.028$). Since the children gained a significant amount of weight over the course of the study, adequate energy intake is suggested. But since weight gain was significant and the energy intake increases were not, the ratio of energy intake to body weight would naturally have decreased. This would especially be true if the majority of weight gain was in the form of adipose tissue (see Section 6).

The differences in micronutrient intake at Baseline by feeding group indicate a possible benefit of NG-tube feeding prior to G-tube placement. Note that significantly more of the children who were NG-tube fed received 100%+ of the RNI for copper ($p=0.003$), selenium ($p<0.001$), niacin ($p=0.02$) and folate

(p=0.001). However, this benefit assumes that 100% RNI is required for all micronutrients in disabled children.

Fibre is a critical dietary component for disabled children due to the chronic problems with constipation they experience as a group and increased fibre intake has been shown to reduce constipation and laxative use in this group (Tse, Leung et al. 2000). The % RNI intake for fibre for all children at all visits was zero. The fact that the children fed via NG-tube had a significantly lower fibre intake even before G-tube placement suggests that the consumption of commercial enteral feeding products lowers fibre intake dramatically. This fact should be taken into consideration when enteral feeds are being selected.

Conclusion

This study demonstrated that the growth, nutritional status and general health status of disabled children significantly improves after G-tube placement.

- Weight, HC and BMI Z scores increased significantly in the first six months after G-tube placement
- Tricep Z Scores and % BF (from skinfold measures) also significantly increased in the first six months
- The number of chest infections requiring hospital admission decreased significantly in the year post G-tube placement

SECTION FIVE: RESULTS AND DISCUSSION-

ENERGY BALANCE AND BODY COMPOSITION

Aim of Section Five

The goal of this study was to investigate the energy balance and body composition of two groups of children with severe neurological disabilities, those who were fed via gastrostomy-tube and those who ate orally.

Hypothesis One: The children who are fed via gastrostomy-tube will be heavier and have more fat storage than the children who are orally fed.

Hypothesis Two: This difference in body composition will be linked to energy balance; the children who are gastrostomy-fed will be in a more positive state of energy balance in order to account for increased fat stores.

Abbreviations used in Section Five

%BF	Percentage Body Fat (by Weight)
BC	Body Composition
BMI	Body Mass Index
CHOL	Cholesterol
DLW	Doubly Labelled Water
RNI	Recommended Nutrient Intake
EAR	Estimated Average Requirement
EB	Energy Balance

EBS	Energy Balance Study
FFM	Fat-free Mass
FFMI	Fat-free Mass Index
FM	Fat Mass
FMI	Fat Mass Index
GMCS	Gross Motor Classification System
GMFM	Gross Motor Function Measure
G-tube	Gastrostomy-tube
kcal	Kilo-calories
MUFA	Mono-unsaturated Fatty Acids
NG-tube	Naso-gastric tube
PC	Pearson Correlation
PUFA	Poly-unsaturated Fatty Acids
RMR	Resting Metabolic Rate
SD	Standard Deviation
SFA	Saturated Fatty Acids
TEE	Total Energy Expenditure

Table Layout

Several tables accompany each sub-section of the following Results to fully illustrate the data. Each table is laid out as follows:

Title

Statistic	List of the statistics used to evaluate the data
G-tube?	Indication of G-tube or Orally Fed Feeding Group
N	Number of children in the group for which the data applies
Mean (SD)	Mean Value and Standard Deviation
Median	Median Value
Range	Range of the Data

Independent t-tests: These results always apply to the testing of G-tube vs Orally fed children

Paired t-tests: these results always apply to the testing of individuals' values from First to Final Visit. When Feeding Groups are tested separately, this is indicated.

Results Outline

5.1 Participant Details

5.2 Anthropometry

5.3 Body Composition

5.4 Nutritional Intake

5.5 Resting Metabolic Rate

5.6 Body Composition from Doubly Labelled Water

5.7 Total Energy Expenditure from Doubly Labelled Water

5.8 Energy Balance

5.9 Gross Motor Function

5.10 Problems Encountered

5.11 Discussion

RESULTS

5.1 PARTICIPANT DETAILS

Forty children participated in the Energy Balance Study (EBS). Twenty-seven were male and 13 female. The median age was 8.50 years with a range of 1.30 to 18.9 years.

Twenty-four children had a gastrostomy-tube (G-tube) upon enrolment into the study and 16 were orally fed. There was no significant difference between the ages of the children in these two groups. The mean age of the G-tube fed children was 8.33 years and of the orally fed children 8.39 years. The median length of time was 12.0 months, with a range of 4.00 to 60.0 months. Of the children who had a G-tube, 13 reportedly had a naso-gastric tube prior to the insertion of their G-tube, the median length of time being 5.00 months (range = 1.00 to 22.0).

5.2 ANTHROPOMETRY

Weight, height and Body Mass Index (BMI) Z scores are presented below in Table 5.1a. The negative scores indicate that weight, height and weight for height (BMI) are below normal standards for age and sex, a common finding among disabled children.

Table 5.1a Weight, Height and Body Mass Index Z Scores for All Children

Statistic	Weight Z Score	Height Z Score	Z score
N	40	32	32
Mean (SD)	-2.79 (2.07)	-2.11 (1.83)	-1.68 (1.95)
Median	-2.92	-2.30	-2.15
Range	-6.96 to 2.97	-6.45 to 3.03	-5.68 to 3.54

Evaluating the data for significant differences between G-tube and orally fed children was a critical element of this study. Weight, height and BMI Z score evaluation by independent t-tests revealed no significant differences between these two feeding groups, as shown in Table 5.1b.

Table 5.1b Weight, Height and Body Mass Index Z Scores Evaluated by Feeding Group

Statistic	Weight Z Score		Height Z Score		BMI	
Gastrostomy?	G-tube	Oral	G-tube	Oral	G-tube	Oral
N	23	17	17	15	17	15
Mean (SD)	-2.30 (1.83)	-3.45 (2.23)	-1.94 (2.17)	-2.30 (1.39)	-1.34 (1.72)	-2.07 (2.18)
Median	-2.78	-4.23	-2.19	-2.61	-1.79	-2.18
Range	-6.45 to 2.66	-6.96 to 2.97	-6.45 to 3.03	-4.05 to –0.05	-4.35 to 1.76	-5.68 to 3.54

Independent t-tests: Weight Z p=0.082, height Z p=0.593 and BMI Z p=0.993

Trends in weight and height with age were explored to test existing hypotheses on the worsening of height/weight deviation from normal with increasing age. Figures 5.1a and b support these hypotheses, as negative relationships are displayed. Age/Height PC=0.925, $p<0.001$. Age/Weight PC=0.672, $p<0.001$.

Figure 5.1a A Scatter Plot of Decimal Age of the Children (years) vs Weight Z Score

Figure 5.1b A Scatter Plot of Decimal Age of the Children (years) vs Height Z Score

5.3 BODY COMPOSITON FROM ANTHROPOMETRY

Percentage Body Fat (% BF) was determined from skinfold measurements according to the equations of Brook and Slaughter (Brook 1971; Slaughter, Lohman et al. 1988). Using the Brook equation, Table 5.2b reveals that the G-tube fed children displayed significantly higher levels of body fat. The children evaluated with the Slaughter equation showed no significant differences.

Table 5.2a Percentage Body Fat from Skinfold Measurements with the Brook and Slaughter Equations

Statistic	% Body Fat (Brook)	% Body Fat (Slaughter)
N	35	21
Mean (SD)	17.0 (9.33)	12.5 (8.91)
Median	13.8	8.82
Range	4.00 to 42.5	2.69 to 42.9

Table 5.2b Percentage Body Fat from Skinfold Measurements with the Brook and Slaughter Equations by Feeding Group

Statistic	% Body Fat (Brook)		% Body Fat (Slaughter)	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	19	16	10	11
Mean (SD)	21.3 (7.56)	11.9 (8.80)	14.4 (5.39)	10.8 (11.2)
Median	21.3	10.8	13.1	8.33
Range	8.67 to 34.3	3.99 to 42.5	5.48 to 21.8	2.69 to 43.9

Independent t-tests: Brook p=0.002, Slaughter p=0.365

Mann-Whitney tests: Brook p=0.003, Slaughter p=0.057

Triceps Z scores for triceps skinfolds were calculated based on the methods of Davies et al. Table 5.3b shows that the difference in scores between feeding groups was very significant ($p<0.001$) with the G-tube fed children displaying higher Z scores.

Table 5.3a Triceps Z Scores for All Children

Statistic	Triceps Z Score
N	40
Mean (SD)	-1.26 (1.55)
Median	-1.63
Range	-4.53 to 2.26

Table 5.3b Triceps Z Scores by Feeding Group

Statistic	Triceps Z Score	
Gastrostomy?	G-tube	Oral
N	23	17
Mean (SD)	-0.56 (1.23)	-2.20 (1.46)
Median	-0.62	-2.30
Range	-2.80 to 1.80	-4.53 to 2.26

Independent t-test: $p<0.001$

5.4 NUTRITIONAL INTAKE

The total kcal intake per 24 hours for each age group is represented in Table 5.4a. As expected, total energy intake increased with age. Evaluation with a Pearson Correlation test revealed a relationship of PC=0.655, $p<0.001$.

Table 5.4a Total Energy Intake by Age Group (kcal/24 hours)

Statistic	0-2 yrs	3-6 yrs	7-10 yrs	11-13 yrs	14+ yrs
N	7	9	10	5	5
Mean (SD)	807 (308)	835 (210)	1075 (291)	1346 (376)	1454 (261)
Median	750	881	1036	1305	1483
Range	380 to 1221	520 to 1200	596 to 1442	825 to 1858	1024 to 1710

Energy intakes were compared to the Estimated Average Requirement (EAR) for age and sex. EAR deficit was calculated as the child's actual energy intake – the EAR. Just as energy intake increases with age, so does EAR deficit (PC=-0.438, p=0.008). Table 5.5c shows that no significant differences in deficit were detected between feeding groups.

Table 5.5a EAR Deficit by Age Group

Statistic	0-2 yrs	3-6 yrs	7-10 yrs	11-13 yrs	14+ yrs
N	7	9	10	5	5
Mean (SD)	-510 (276)	-832 (248)	-957 (292)	-987 (431)	-1040 (483)
Median	-505	-923	-940	-997	-1139
Range	-886 to -170	-1210 to-515	-1408 to -528	-1663 to -595	-1598 to-270

Table 5.5b EAR Deficit for All Children

Statistic	EAR Deficit (Actual Intake – EAR) kcal/24 hours
N	36
Mean (SD)	-855 (362)
Median	-868
Range	-1663 to –170

Table 5.5c EAR Deficit by Feeding Group

Statistic	EAR Deficit (Actual Intake – EAR) kcal/24 hours	
Gastrostomy?	G-tube	Oral
N	20	16
Mean (SD)	-909 (304)	-786 (424)
Median	-983	-705
Range	-1408 to –281	-1663 to -170

Independent t-test: p=0.318

Energy intakes per kg and per kg FFM (see Section 5.6 for FFM values) were calculated and are presented for the group as a whole and by feeding group in Tables 5.6a and b. No significant difference in energy intake per kg FFM was

found, but the p value for energy intake per kg was *almost* significant (p=0.058) with the orally fed children displaying a much higher intake.

Table 5.6a Total Energy Intake per kg and Total Energy Intake per kg FFM for All Children

Statistic	KCAL/KG (kcal/24hours/kg)	KCAL/KG FFM (kcal/24hours/kgFFM)
N	36	36
Mean (SD)	60.4 (24.0)	83.2 (29.6)
Median	58.3	80.9
Range	21.6 to 119	36.6 to 161.8

Table 5.6a Total Energy Intake per kg and Total Energy Intake per kg FFM by Feeding Group

Statistic	KCAL/KG (kcal/24hours/kg)		KCAL/KG FFM (kcal/24hours/kgFFM)	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	20	16	20	16
Mean (SD)	53.7 (21.7)	68.9 (24.7)	80.0 (29.0)	87.1 (30.7)
Median	45.8	69.3	79.1	87.0
Range	31.3 to 119.4	21.6 to 116.3	42.8 to 161.8	36.6 to 149.7

Independent t-tests: kcal/kg p=0.058, kcal/kg FFM p= 0.486

Macronutrients

Although energy was evaluated in terms of EAR above, % RNI was also used to examine the children's energy intake and their intakes of protein, carbohydrate and fat. With the exception of protein, the % RNI intakes were low. No differences were seen between G-tube and orally fed feeding groups. See tables 5.7 a and b, below.

Table 5.7a Percentage RNI Intakes for Protein, Carbohydrate, Fat and Energy for All Children

Statistic	% RNI Protein	% RNI Carbohydrate	% RNI Fat	% RNI Energy
N	36	36	36	36
Mean (SD)	136 (46.7)	49.8 (16.3)	58.9 (24.2)	59.7 (16.4)
Median	137	48.4	55.2	59.0
Range	59.4 to 244	22.0 to 82.8	30.1 to 142	33.7 to 99.3

Table 5.7b Percentage RNI Intakes for Protein, Carbohydrate, Fat and Energy by Feeding Group

Statistic	% RNI Protein		% RNI Carbohydrate		% RNI Fat		% RNI Energy	
Gastrostomy?	G-tube	Oral	G-tube	Oral	G-tube	Oral	G-tube	Oral
N	20	16	20	16	20	16	20	16
Mean (SD)	134 (44.5)	139 (50.7)	46.6 (15.3)	53.7 (17.1)	56.5 (20.0)	64.1 (29.2)	56.1 (14.9)	64.1 (17.6)
Median	138	131	44.6	55.3	52.9	59.2	56.4	64.9
Range	59.4 to 244	74.2 to 240	22.0 to 82.8	31.9 to 82.5	31.5 to 115	30.1 to 142	33.7 to 91.2	37.2 to 99.3

Independent t-tests: Protein p=0.764, Carbo p=0.197, Fat p=0.359, Energy p=0.150

Fats

The intakes of specific fatty acids were investigated. Although the group as a whole received well below the RNI for each type of fatty acid, the orally fed children had significantly higher intakes for all types of fat. (Tables 5.8a and b.)

Table 5.8a Percentage RNI Intake of SFA, MUFA, PUFA and mg of Cholesterol for All Children

Statistic	% RNI SFA	% RNI MUFA	% RNI PUFA	CHOL (mg)
N	36	36	36	36
Mean (SD)	51.5 (41.1)	26.8 (25.6)	34.5 (36.1)	65.4 (75.1)
Median	43.9	25.8	24.1	47.0
Range	0.00 to 94.4	0.00 to 97.5	0.00 to 124	0.00 to 274

Table 5.8b Percentage RNI Intake of SFA, MUFA, PUFA and mg of Cholesterol by Feeding Group

Statistic	% RNI SFA		% RNI MUFA		% RNI PUFA		CHOL (mg)	
Gastrostomy?	G-tube	Oral	G-tube	Oral	G-tube	Oral	G-tube	Oral
N	20	16	20	16	20	16	20	16
Mean (SD)	31.8 (27.6)	76.2 (42.6)	12.1 (17.8)	45.0 (22.0)	28.9 (39.5)	41.6 (31.0)	23.1 (35.4)	118 (78.7)
Median	27.3	73.7	0.00	49.0	7.10	27.0	0.00	113
Range	0.00 to 94.4	12.7 to 184	0.00 to 59.9	12.6 to 97.5	0.00 to 124	10.6 to 104	0.00 to 102	9.00 to 274

Independent t-tests: SFA $p=0.001$, MUFA $p<0.001$, PUFA $p=0.299$, CHOL $p<0.001$

Fibre

Dietplan 5 presents the intake of grams of fibre per day according to 2 fibre evaluation methods: the Southgate and the Englyst, both of which are presented in Table 5.9a. As stated in Section 4, the commencement of G-tube feeding in disabled children appears to decrease fibre intake dramatically. The data seen in

Table 5.9b supports this statement: orally fed children had much higher fibre intakes than the G-tube fed children.

Table 5.9a Grams of Fibre Intake per 24 hours with the Southgate and Englyst Method for All Children

Statistic	Grams of Fibre (Southgate)	Grams of Fibre (Englyst)
N	36	36
Mean (SD)	5.37 (6.43)	4.43 (4.81)
Median	4.60	3.70
Range	0.00 to 22.8	0.00 to 19.0

Table 5.9b Grams of Fibre Intake per 24 hours with the Southgate and Englyst Method by Feeding Group

Statistic	Grams of Fibre (Southgate)		Grams of Fibre (Englyst)	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	20	16	20	16
Mean (SD)	1.56 (3.12)	10.1 (6.36)	2.04 (3.26)	7.42 (4.82)
Median	0.00	9.20	0.00	6.10
Range	0.00 to 10.2	1.70 to 22.8	0.00 to 10.8	2.90 to 19.0

Independent t-tests: Southgate $p<0.001$, Englyst $p<0.001$

Micronutrients

The intake of micronutrients was calculated as a % RNI so that comparisons between groups and to reference standards could be made. As Table 5.10a displays, the lowest mean micronutrient intake (for the group as a whole) was 83.2% (iodine) and only 6 of the 18 micronutrients evaluated had mean intakes below 100% of the RNI. This data supports the findings of Section 4 and reveals that micronutrient deficiencies are not common in this group.

Table 5.10a Percentage RNI of Micronutrients for All Children

Nutrient	Mean (SD)	Median	Range
Sodium	79.4 (54.4)	75.8	0.00 to 216
Potassium	84.0 (33.7)	74.8	28.8 to 180
Calcium	103 (42.8)	103	27.6 to 179
Magnesium	99.5 (45.6)	94.0	29.0 to 219
Phosphorus	145 (53.2)	140	65.0 to 278
Iron	103 (65.3)	85.1	32.3 to 383
Copper	314 (655)	120	43.8 to 3599
Zinc	113 (69.0)	97.6	28.5 to 266
Chloride	91.1 (42.1)	80.3	30.5 to 200
Selenium	97.0 (63.8)	83.3	0.00 to 233
Iodine	83.2 (36.9)	86.3	14.2 to 163
Thiamin	163 (96.4)	140	53.6 to 437
Riboflavin	168 (78.2)	163	43.4 to 366
Niacin	107 (81.4)	77.5	24.8 to 347
Vitamin B 6	336 (186)	308	98.6 to 1024
Vitamin B 12	453 (732)	283	74.0 to 4525
Folate	137 (97.1)	104	25.8 to 383
Vitamin C	237 (161)	184	36.2 to 659

NOTE: N=36

A comparison of micronutrient intake by feeding group revealed that the orally fed children had significantly higher intakes of sodium and chloride while the G-tube fed children had significantly higher intakes of iron, zinc, niacin, thiamine, selenium, Vitamin B6 and folate. See Table 5.10b for the mean and median % RNI micronutrient intakes and Table 5.10c for the p values from independent t-tests used to compare the intakes of the feeding groups.

Table 5.10b Percentage RNI of Micronutrients by Feeding Group

Nutrient	Mean (SD)		Median		Range	
Gastrostomy?	G-tube	Oral	G-tube	Oral	G-tube	Oral
Sodium	48.1 (36.0)	119 (48.0)	45.7	119	0.00 to 105	51.1 to 216
Potassium	79.3 (30.2)	89.9 (37.7)	69.6	84.8	39.0 to 143	28.8 to 180
Calcium	112 (35.7)	92.5 (49.2)	105.8	81.6	60.3 to 174	27.6 to 179
Magnesium	111 (47.7)	84.7 (39.4)	105	81.4	41.3 to 219	29.0 to 200
Phosphorus	142 (51.4)	148 (56.8)	153	148	65.0 to 278	71.9 to 253
Iron	128 (74.8)	72.9 (33.0)	106	66.5	46.8 to 383	32.3 to 144
Copper	477 (837)	96.0 (49.3)	200	71.7	43.8 to 3599	51.1 to 208
Zinc	148 (72.1)	69.0 (28.2)	126	65.4	28.5 to 266	32.1 to 124
Chloride	72.6 (28.3)	114 (45.7)	65.8	111	30.5 to 129	41.9 to 200
Selenium	120 (70.3)	67.7 (39.6)	127	54.0	0.00 to 233	25.6 to 156
Iodine	92.5 (33.4)	71.5 (38.7)	94.5	75.5	36.9 to 160	14.2 to 163
Thiamin	196 (110)	120 (54.0)	182	103	53.6 to 437	62.1 to 225
Riboflavin	189 (83.8)	142 (63.6)	197	155	67.5 to 366	43.3 to 270
Niacin	130 (100)	78.7 (34.3)	95.4	69.4	24.8 to 347	35.7 to 143
Vitamin B 6	397 (209)	260 (119)	349	211	98.6 to 1024	127 to 567

Vitamin B 12	620 (954)	244 (129)	300	227	128 to 4525	74.0 to 494
Folate	171 (115)	95.0 (44.3)	107	89.3	25.8 to 383	40.1 to 195
Vitamin C	277 (196)	186 (81.6)	210	175	64.9 to 659	36.2 to 342

NOTE: N for G=20, No-G =16

Table 5.10c Independent t-test Scores of Comparing the % RNI Intakes of Micronutrients by Feeding Group

Sodium	P<0.001
Potassium	P=0.356
Calcium	P=0.176
Magnesium	P=0.082
Phosphorus	P=0.735
Iron	P=0.010
Copper	P=0.057
Zinc	P<0.001
Chloride	P=0.004
Selenium	P=0.008
Iodine	P=0.090
Thiamin	P=0.011
Riboflavin	P=0.070
Niacin	P=0.043
Vitamin B 6	P=0.026
Vitamin B 12	P=0.128
Folate	P=0.012
Vitamin C	P=0.073

5.5 RESTING METABOLIC RATE

RMR was analyzed by age group and with normalization for kg and kg FFM. Similar to energy intake, RMR measurements increased with age, but only up until the 14+ year age group. (See Table 5.11a.) A correlation between RMR and decimal age revealed that the Pearson Correlation score was fairly high and statistically significant; RMR/Age PC=0.583, $p<0.001$. Tables 5.12a to d reveal that no significant differences were detected between feeding groups for either RMR/kg or RMR/kg FFM.

Table 5.11a Resting Metabolic Rate Measurements by Age Group (kcal/24 hours)

Age group	0-2 (yrs)	3-6 (yrs)	7-10 (yrs)	11-13 (yrs)	14+ (yrs)
N	8	8	8	5	6
Mean (SD)	435 (93.7)	603 (136)	911 (341)	943 (402)	809 (228)
Median	464	594	828	859	879
Range	283 to 553	442 to 791	633 to 1681	641 to 1640	518 to 1094

Table 5.12a Resting Metabolic Rate per Kg Body Weight for All Children

Statistic	RMR per KG (kcal/24 hours per kg)
N	35
Mean (SD)	39.1 (11.3)
Median	37.2
Range	22.2 to 60.9

Table 5.12b Resting Metabolic Rate per Kg Body Weight by Feeding Group

Statistic	RMR per KG (kcal/24 hours per kg)	
Gastrostomy?	G-tube	Oral
N	19	16
Mean (SD)	37.1 (10.2)	41.6 (12.3)
Median	35.3	41.8
Range	25.1 to 59.5	22.2 to 60.9

Independent t-test: p=0.248

Table 5.12c Resting Metabolic Rate per Kg Fat Free Mass for All Children

Statistic	RMR per KG FFM (kcal/24 hours per kg FFM)
N	34
Mean (SD)	55.7 (14.2)
Median	56.0
Range	29.0 to 82.8

Table 5.12d Resting Metabolic Rate per Kg Fat Free Mass by Feeding Group

Statistic	RMR per KG FFM (kcal/24 hours per kg FFM)	
Gastrostomy?	G-tube	Oral
N	19	15
Mean (SD)	55.7 (13.5)	55.6 (15.6)
Median	56.9	54.8
Range	33.0 to 80.6	29.0 to 82.8

Independent t-test: p=0.976

Pearson Correlation was used to evaluate the relationship between FFM and RMR and due to the high correlation found (PC=0.813, $p<0.001$), RMR values adjusted for FFM were created according to the method of Toth et al (Toth,

Goran et al. 1993). The linear regression equation yielded that RMR = 42.098(FFM) + 150.337. Table 5.13 shows that no significant differences in RMR adjusted for FFM were found between the feeding groups.

Table 5.13 Resting Metabolic Rate Adjusted for Fat-Free Mass by Feeding Group

Statistic	Adjusted RMR (kcal/24 hours)	
Gastrostomy?	G-tube	Oral
N	19	15
Mean (SD)	727 (135)	749 (234)
Median	733	783
Range	463 to 963	343 to 1148

Independent t-test: p=0.739

The Schofield prediction equation for estimating BMR in children was used to calculate a theoretical RMR for each child (Schofield 1985). Paired t-tests between the predicted and actual RMR revealed that the overestimation by the equation was significant (p=0.001). When Paired t-tests were conduced by feeding group: G-tube fed p<0.001, orally fed p=0.327. Tables 5.14a and b show the overestimation of this prediction equation for the group as a whole and by feeding group.

Table 5.14a Overestimation of RMR by Schofield Prediction Equations for All Children

Statistic	RMR Overestimation (kcal/day)
N	35
Mean (SD)	108 (182)
Median	128
Range	-450 to 486

Table 5.14a Overestimation of RMR by Schofield Prediction Equations by Feeding Group

Statistic	RMR Overestimation (kcal/day)	
Gastrostomy?	G-tube	Oral
N	19	16
Mean (SD)	152 (137)	55.3 (218)
Median	138	43.1
Range	-104 to 348	-450 to 486

Independent t-test p=0.120

5.6 BODY COMPOSITION FROM DOUBLY LABELLED WATER

Tables 5.15a and c present Fat-Free Mass Index (FFMI) and Fat Mass Index (FMI) for the study group as a whole and by feeding group. Both FMI and FFMI were significantly different from reference (Fomon) (see Table 5.15b) with the children exhibiting significantly higher than normal FMI and significantly lower FFMI.

Table 5.15a Fat-Free Mass Index and Fat Mass Index (kg/m^2) For All Children

Statistic	Fat Free Mass Index	Fat Mass Index
N	38	38
Mean (SD)	10.7 (1.61)	4.18 (2.98)
Median	10.3	3.91
Range	8.44 to 15.9	-0.50 to 17.9

Table 5.15b Fat-Free Mass Index and Fat Mass Index Compared to Reference Values For All Children

Statistic	Ref FFMI – Actual FFMI	Ref FMI – Actual FMI
N	26	26
Mean (SD)	2.82 (1.68)	-1.45 (3.31)
Median	3.07	-0.82
Range	-2.17 to 5.75	-14.57 to 3.44

Paired t-tests: FFMI $p<0.001$ and FMI $p=0.035$.

When FMI and FFMI were evaluated by feeding group, the difference in FFMI was apparent. Table 5.15c shows that although the G-tube fed and orally fed children do not differ significantly in terms of FMI, they do in terms of FFMI.

Table 5.15d shows the results of comparing measured FMI and FFMI to reference standards by feeding group. Neither group differed significantly from reference in terms of FMI, but a difference between groups was detected (by independent t test) for FFMI and the orally fed children's scores showed much less deviation from reference.

Table 5.15c Fat-Free Mass Index and Fat Mass Index (kg/m^2) by Feeding Group

Statistic	Fat Free Mass Index		Fat Mass Index	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	21	17	21	17
Mean (SD)	10.2 (1.32)	11.5 (1.67)	4.61 (1.80)	3.64 (4.00)
Median	9.70	11.0	4.23	2.83
Range	8.44 to 12.7	9.14 to 15.9	0.07 to 8.32	-0.50 to 17.9

Independent t-tests: FFMI p =0.010, FMI p =0.327

Table 5.15d Fat-Free Mass Index and Fat Mass Index Compared to Reference Values by Feeding Group

Statistic	Ref FFMI – Actual FFMI		Ref FMI – Actual FMI	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	15	11	15	11
Mean (SD)	3.48 (1.32)	1.93 (1.76)	-1.59 (2.16)	-1.27 (4.56)
Median	3.61	2.57	-1.56	0.10
Range	0.84 to 5.75	-2.17 to 3.70	-5.81 to 3.44	-14.57 to 2.44

Independent t-tests: FFMI p =0.017, FMI p =0.814

Absolute fat mass and fat as a percentage of body weight were also examined. Table 5.16b shows that absolute fat mass is not different between groups, but % BF *is*.

Table 5.16a Fat Mass and Percentage Body Fat for All Children

Statistic	Fat Mass (kg)	% Body Fat
N	39	39
Mean (SD)	5.70 (5.77)	27.2 (11.8)
Median	4.37	26.9
Range	-0.67 to 34.5	-3.90 to 52.9

Table 5.16b Fat Mass and Percentage Body Fat by Feeding Group

Statistic	Fat Mass (kg)		% Body Fat	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	22	17	22	17
Mean (SD)	5.99 (3.18)	5.32 (8.09)	32.1 (8.51)	21.0 (12.7)
Median	5.40	2.70	32.0	21.4
Range	0.07 to 12.8	-0.67 to 34.5	18.4 to 49.5	-3.90 to 52.9

Independent t-tests: Fat mass p=0.721, Fat % p=0.002

For clinical and practical purposes, Pearson Correlations were used to evaluate the relationship between % BF as determined from DLW and from anthropometrics. The relationship was positive with both the Slaughter and Brook equation. For Brook, n=34, PC=0.741 and p<0.001. For Slaughter, n=21, PC=0.802, and p<0.001.

The actual FM and FFM determined from total body water calculations were compared to the reference values for FM and FFM for children of the same age

and sex (Fomon, Haschke et al. 1982). Tables 5.17a and b show the deviation from reference for the entire group of children and reveal that their measured FM is higher than reference, although not significantly so. FFM however, is lower than expected for age and sex, and this deviation is significant.

Table 5.17a Fat and Fat-Free Mass Compared to Reference Values for All Children

Statistic	FAT MASS Ref – Actual (kg)	FF MASS Ref – Actual (kg)
N	27	27
Mean (SD)	-1.78 (5.61)	5.10 (4.43)
Median	-0.04	3.94
Range	-28.2 to 2.31	-4.45 to 13.25

Table 5.17b Paired t-test Results of a Comparison of Measured Fat and Fat Free Mass to Reference Values for All Children

Paired t-test	FAT MASS First Visit Ref – Actual	FF MASS First Visit Ref – Actual
P value	0.111	<0.001

Tables 5.17c, d and e show this comparison of FM and FFM to reference standards by feeding group. Conducting the paired t tests (measured to reference values) by feeding group it becomes evident that whereas orally fed children are not significantly different from reference in terms of FM, the G-tube fed children actually have *higher* amounts than normal. And although both

groups have less FFM than the reference child, this is more pronounced in the G-tube fed children.

Table 5.17c Fat Mass Compared to Reference Values by Feeding Group

Statistic	FAT MASS Ref – Actual (kg)	
Gastrostomy?	G-tube	Oral
N	16	11
Mean (SD)	-1.44 (2.07)	-2.27 (8.66)
Median	-1.41	0.26
Range	-4.84 to 2.31	-28.2 to 2.22

Independent t-test p=0.717

Table 5.17d Fat-Free Mass Compared to Reference Values by Feeding Group

Statistic	FF MASS Ref – Actual (kg)	
Gastrostomy?	G-tube	Oral
N	16	11
Mean (SD)	6.33 (4.43)	3.33 (3.96)
Median	5.27	2.73
Range	-0.71 to 13.3	-4.45 to 8.79

Independent t-test p=0.083

Table 5.17e Paired t-test Results of a Comparison of Measured Fat and Fat-Free Mass to Reference Values by Feeding Group

Paired T test	FAT MASS Ref – Actual		FF MASS Ref – Actual	
Gastrostomy?	G	No-G	G	No-G
P value	0.014	0.406	<0.001	0.019

5.7 TOTAL ENERGY EXPENDITURE FROM DOUBLY LABELLED WATER

The mean and median TEE for each age group of children are presented in the Table 5.18. The trend of increased TEE with age until 14+ years (as seen with the RMR data) is again seen here. (PC=0.559, p<0.001)

Table 5.18 Total Energy Expenditure by Age Group (kcal/24 hours)

Statistic	0-2 yrs	3-6 yrs	7-10 yrs	11-13 yrs	14+ yrs
N	8	9	9	6	6
Mean (SD)	650 (187)	803 (272)	1129 (392)	1339 (483)	1076 (278)
Median	694	746	1064	1308	1094
Range	383 to 875	328 to 1253	830 to 2110	722 to 2061	677 to 1416

As with RMR, TEE per kg and per kg FFM was investigated as a total population and by feeding group and the results are displayed in Tables 5.19a to d. The only significant difference between feeding groups observed was for TEE/kg where values were significantly higher in the orally fed children. (See Table 5.19b.)

Table 5.19a Energy Expenditure per Kg Body Weight for All Children

Statistic	TEE/KG (kcal/24hours/kg)
N	38
Mean (SD)	55.2 (21.1)
Median	54.3
Range	20.9 to 94.1

Table 5.19b Energy Expenditure per Kg Body Weight by Feeding Group

Statistic	TEE/KG (kcal/24hours/kg)	
Gastrostomy?	G-tube	Oral
N	21	17
Mean (SD)	49.1 (20.0)	62.7 (20.4)
Median	43.7	62.8
Range	20.9 to 94.1	22.7 to 93.6

Independent t-test p=0.046

Table 5.19c Energy Expenditure per Kg Fat-Free Mass for All Children

Statistic	TEE/KG FFM (kcal/24hours/kgFFM)
N	38
Mean (SD)	75.0 (23.7)
Median	73.3
Range	32.1 to 128

Table 5.19d Energy Expenditure per Kg Fat-Free Mass by Feeding Group

Statistic	TEE/KG FFM (kcal/24hours/kgFFM)	
Gastrostomy?	G-tube	Oral
N	21	17
Mean (SD)	71.9 (25.7)	78.7 (21.0)
Median	65.8	80.4
Range	40.4 to 128	32.1 to 113

Independent t-test p=0.388

As for RMR, due to the significant relationship between TEE and FFM (TEE/RMR PC=0.844, $p<0.001$), TEE was adjusted to control for the effect of FFM. The linear regression equation stated: TEE = 48.497(FFM) + 304.180. kcal/day Table 5.20b shows that there was no significant difference in between the feeding groups.

Table 5.20a Total Energy Expenditure Adjusted for Fat-Free Mass for All Children

Statistic	TEE (kcal/24hours)
N	38
Mean (SD)	980 (259)
Median	969
Range	306 to 1495

Table 5.20b Total Energy Expenditure Adjusted for Fat-Free Mass by Feeding Group

Statistic	TEE (kcal/24hours)	
Gastrostomy?	G-tube	Oral
N	21	17
Mean (SD)	933 (234)	1039 (282)
Median	935	1079
Range	577 to 1450	306 to 1495

Independent t-test p=0.213

5.8 ENERGY BALANCE

Energy balance (EB) was calculated as Energy Intake (total dietary intake) minus Energy Output (measured TEE). EB values by age and feeding group are displayed in Tables 5.21a and c. Table 5.21b shows that the energy balance of the group as a whole was positive (+92 kcal/24 hours) and 5.21c reveals that there was no difference in energy balance between the G-tube and orally fed children.

Table 5.21a Energy Balance by Age Group (kcal/24 hours)

Statistic	0-2 yrs	3-6 yrs	7-10 yrs	11-13 yrs	14+ yrs
N	7	9	9	5	5
Mean (SD)	183 (228)	32.0 (243)	-18.1 (328)	66.4 (252)	299 (255)
Median	122	-57.0	110	103	345
Range	-15.0 to 648	-336 to 520	-699 to 378	-203 to 359	-56.0 to 630

Table 5.21b Energy Balance for All Children

Statistic	Energy Balance (kcal/24 hours)
N	35
Mean (SD)	92.3 (275)
Median	115
Range	-699 to 648

Table 5.21c Energy Balance by Feeding Group

Statistic	Energy Balance (kcal/24 hours)	
Gastrostomy?	G-tube	Oral
N	19	16
Mean (SD)	99.4 (216)	83.8 (340)
Median	115	111
Range	-336 to 520	-699 to 648

Independent t-test p=0.871

Correlations between EE and BC were also examined in this section. It was determined that both FM and FFM had a positive relationship with TEE. For FM, PC=0.515, p=0.001 and for FFM, PC=0.757, p<0.001. However, there were also significant correlations detected between age, height and weight. (Age PC=0.559, Height PC=0.699, Weight PC=0.682 and all p<0.001.)

Similar findings were found for RMR. RMR was significantly correlated to age, height, weight, FM and FFM. (Age PC=0.583, p<0.001, Height PC=0.790, p<0.001, Weight PC=0.814, p<0.001, FM PC=0.706, p<0.001 and FFM PC=0.813, P<0.001).

5.9 GROSS MOTOR FUNCTION

Physical Activity Level (PAL) was calculated as TEE/RMR and Table 5.22 holds the mean PAL calculated for all the children in the study.

Table 5.22 Physical Activity Level for All Children

Statistic	PAL
N	34
Mean (SD)	1.35 (0.38)
Median	1.26
Range	0.69 to 2.32

Independent t-test between feeding groups p=0.317

An adjusted PAL was calculated (using TEE and RMR adjusted for FFM) and is shown in Table 5.23.

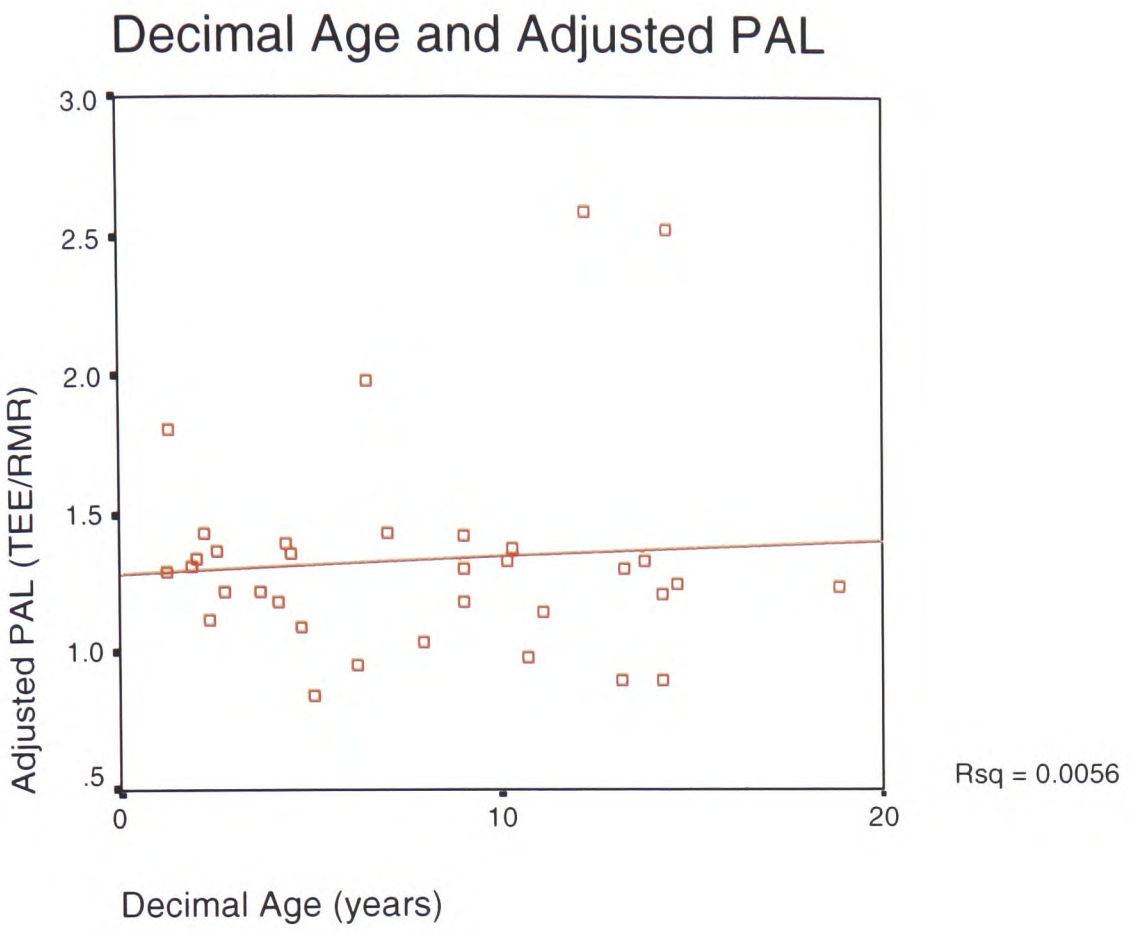
Table 5.23 Adjusted Physical Activity Level for All Children

Statistic	ADJUSTED PAL
N	34
Mean (SD)	1.33 (0.39)
Median	1.29
Range	0.84 to 2.58

Independent t-test between feeding groups p=0.240

In order to assess whether age had any impact upon this adjusted PAL, decimal age was plotted against adjusted PAL. No significant relationship was revealed (PC=0.075, p=0.240).

Figure 5.2 A Scatter Plot of Decimal Age vs Adjusted Physical Activity Level



However, adjusted PAL was correlated to several aspects of BC. The significant P values shown in Table 5.24 indicate a negative relationship between activity level and body fat, independent of FFM.

Table 5.24 Pearson Correlation Values Between Adjusted PAL and FMI, BMI Z Score and % Body Fat for All Children

Relationship Between:		Pearson Correlation	P value
Adjusted PAL and	FMI	-0.382	0.026
	BMI Z score	-0.459	0.016
	% Body Fat	-0.590	<0.001

Several measures of gross motor function including the GMCS, the GMFM and the Modified Ashworth Spasticity Measure were used to evaluate the more specific abilities and activities of the children in the EBS. Table 5.25b indicates that no difference in Spasticity was found between the feeding groups, but that the G-tube fed children displayed significantly higher GMCS scores and lower GMFM scores than the orally fed children.

Table 5.25a Gross Motor Classification System, Gross Motor Function Measure and the Modified Ashworth Test of Spasticity Scores for All Children

Statistic	GMCS	GMFM	Ash. Spasticity
N	37	37	37
Mean (SD)	4.76 (0.60)	12.9 (18.3)	1.35 (1.51)
Median	5.00	6.66	1.00
Range	2.00 to 5.00	0.00 to 89.7	0.00 to 4.00

Table 5.25b Gross Motor Classification System, Gross Motor Function Measure and the Modified Ashworth Test of Spasticity Scores by Feeding Group

Statistic	GMCS		GMFM		Ash. Spasticity	
Gastrostomy?	G-tube	Oral	G-tube	Oral	G-tube	Oral
N	25	12	25	12	25	12
Mean (SD)	4.92 (0.28)	4.42 (0.90)	7.64 (11.5)	23.9 (24.8)	1.16 (1.46)	1.75 (1.60)
Median	5.00	5.00	2.75	21.2	0.00	1.50
Range	4.00 to 5.00	2.00 to 5.00	0.00 to 45.2	0.78 to 89.7	0.00 to 4.00	0.00 to 4.00

Independent t-tests: GMCS p=0.014, GMFM p=0.009, ASH p=0.273

Gross motor function showed positive correlations to RMR and TEE. Mildly significant relationships were found between RMR and the GMFM (PC=0.415, p=0.015) and the GMCS (PC=-0.342, p=0.048). Adjusted RMR showed significant correlations for both GMFM (PC=0.559, p=0.001) and GMCS (PC=-0.517, p=0.002). The same was shown for TEE. TEE (unadjusted) showed a p value of p=0.035 (PC=0.347) with GMFM, but was not significantly related to GMCS. Adjusted TEE was strongly related to both GMFM (PC=0.457, p=0.004) and GMCS (PC=-0.390, p=0.017).

An activity diary and questions about the children's usual habits were also utilized to gather a full picture of the children's gross motor function and physical activity levels. Tables 5.26 and 5.27 report the number of hours the children spend sleeping and engaged in various forms of physical activity.

Table 5.26 Number of Hours Slept at Night and During the Day Reported by Carers for All Children

Statistic	Sleep at Night (hours/24)	Naps during Day (hours/24)
N	36	36
Mean (SD)	9.97 (1.38)	0.68 (1.00)
Median	10.0	0.00
Range	7.00 to 12.0	0.00 to 3.00

Table 5.27 Number of Hours of Physiotherapy, Hydrotherapy and Other Physical Activities per Week Reported by Carers for All Children

Statistic	Physiotherapy (hours/week)	Hydrotherapy (hours/week)	Other Activities (hours/week)
N	36	36	36
Mean (SD)	3.45 (2.64)	0.69 (0.63)	2.44 (2.58)
Median	3.00	1.00	2.00
Range	0.00 to 10.0	0.00 to 2.00	0.00 to 10.0

5.10 PROBLEMS ENCOUNTERED

Obtaining valid RMR measurements was quite problematic in this study. Carers were often unwilling to have their child fast before an appointment or forgot that fasting was required. Reminder phone calls the day before the appointment helped somewhat, but there were also many cases of children requiring food or liquid with necessary medications or not being available for an appointment until the afternoon (in which case fasting all day was not medically appropriate). A second problem encountered with RMR measurements was the inability of the children to understand that they were required to relax throughout the measurement. Although the measurement process itself upset few children, the process excited many. Every attempt at relaxation was made and a variety of methods were used depending on the child: massage, soft singing, television and story reading were all employed. On the other hand, some children fell asleep during the measurement providing a measure of Sleeping Metabolic Rate (SMR), not RMR. However, in comparison with the number of cases of overexcited children, those who slept were in a minority.

The detailed protocol for urine or saliva sampling was also problematic for some families. Every effort was made to make the process as simple as possible for the carers, but there were several instances when carers did not take the required samples or did not record the time of sampling. When this happened, dosing was often repeated at a time when the carer felt they would be able to

comply with the protocol. In a few cases Allison M E Bachlet took the daily samples, travelling either to a local children's hospice or a child's school.

As detailed in Section 4.5, obtaining accurate anthropometric measurements was at times difficult. Every attempt was made to collect as many reliable measures as possible.

Again, as in the Gastrostomy Study, carer completion of diet diaries was at times problematic. Although there were few instances of unreturned diaries, there was often not enough detail recorded to provide an accurate report of the child's energy intake.

5.11 DISCUSSION

Anthropometry

The forty children in this study presented with heights, weights and BMI Z Scores significantly below age-related reference values. As mentioned in Section 4, this light weight and small stature has been reported by numerous research groups (Sterling 1960; Tobis, Saturen et al. 1961; Stevenson, Hayes et al. 1994; Krick, Murphy-Miller et al. 1996).

When weight, height and BMI Z Scores were analyzed by feeding group to evaluate whether or not the presence of a G-tube had an impact upon scores, no significant differences were found. The only measure that approached significance was weight Z score. As shown in Section 4, G-tube feeding does appear to increase weight in disabled children. It is probable that the difference in weight Z scores would have reached significance had the groups been larger.

Pearson correlations revealed that there is a negative trend between age and height, weight and BMI Z scores, indicating that as disabled children get older, they deviate more from reference standards. Linear growth is more affected than weight as age increases, as PC= -0.435 ($p=0.016$) for age and weight Z score, but PC= -0.576 ($p<0.004$) for age and height Z score. The correlation between BMI Z score and age was not significant (PC=-0.166, $p=0.448$). This trend of negative height and weight Z scores with age has also been reported in this

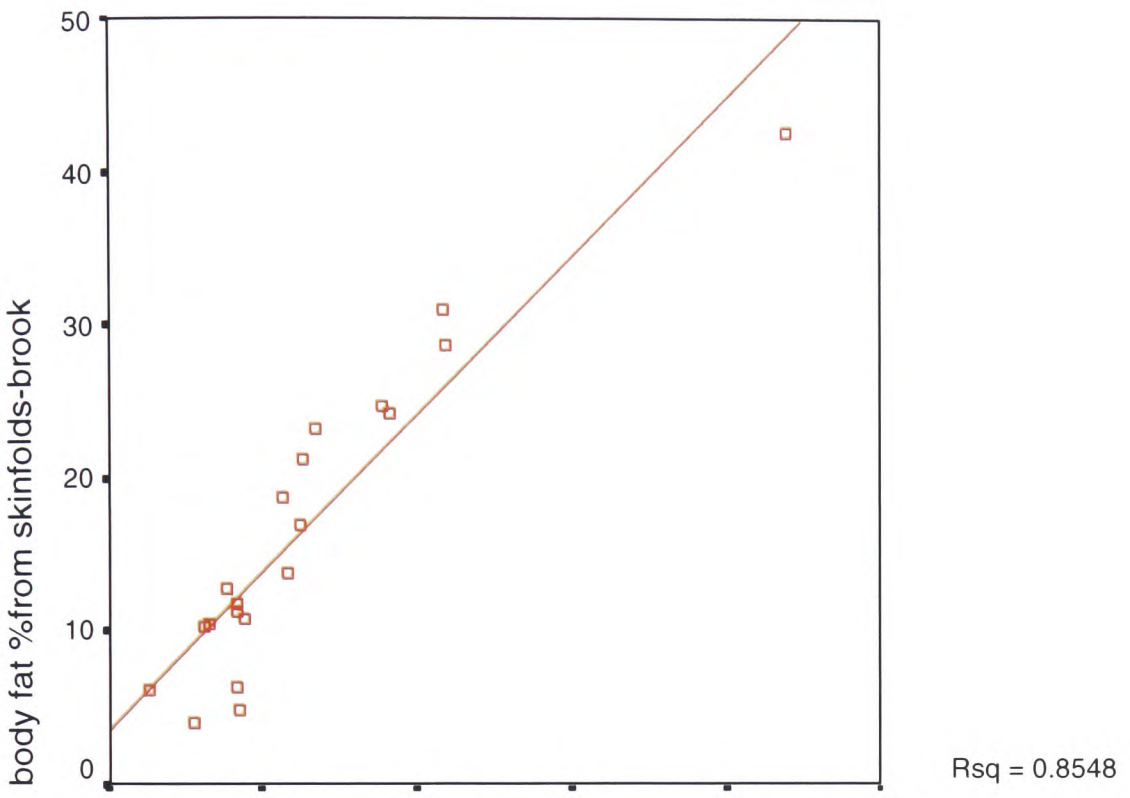
group of children by other researchers (Stevenson, Hayes et al. 1994; Krick, Murphy-Miller et al. 1996). An explanation for this observation has not been clarified, but Stevenson and Samson-Fang have stated that sex, age, cognitive impairment, ambulatory status and nutritional state may all contribute to the poor linear growth seen in disabled children, indicating that the reason is most likely multifactorial in nature (Samson-Fang and Stevenson 1998). It is also hypothesized that the underlying neurological damage experienced by these children influences the programming of linear growth.

Body Composition from Anthropometry

Classic anthropometry was used to estimate body composition, specifically % BF by weight. This method is frequently used in clinical settings because it requires only skinfold measurements. The use of 2 equations was necessary due to the age range of the children. The Brook equation is intended for children aged 1-11 years and Slaughter for those 8-18 years. This means that the mean age of the children evaluated only with the Brook equation was 3.85 (n=15), whereas the mean age of the children evaluated with both Brook and Slaughter was 10.9 (n=21), a significant difference ($p<0.001$).

However, this age difference does not impact upon the fact that the results using the Brook equation found a significant difference in % BF between G-tube and orally fed children. It is possible that the same results would have been found in those evaluated with the Slaughter equation had the numbers been larger. For those children whom both equations could be applied, the agreement was very high (PC=0.925, $p<0.001$), as is illustrated in the following figure.

Figure 5.3 A Scatter Plot of Percentage Body Fat as Determined by the Slaughter Equation vs Percentage Body Fat as Determined by the Brook Equation



The Triceps skinfold is the skinfold most often used to singularly estimate total body sub-cutaneous fat stores. The significant difference in Triceps Z Scores between feeding groups supports the above finding as it also indicates that those children who are G-tube fed have higher levels of fat. Fat gain after G-tube placement has been reported by American research groups (Lewis, Khoshoo et al. 1994; SugarmanIsaacs, Georgeson et al. 1994) and was shown by the data presented in Section 4.

Nutritional Intake

As expected, total energy intake increases with age. However, when compared to the EAR (Estimated Average Requirement) for age and sex according to the Department of Health, 1991, intakes for all children were significantly below the recommended levels ($p<0.001$). Although the presence of a G-tube should make providing nutrients easier, no differences in EAR deficit were found between the G-tube and orally fed children.

Just as total intake increased with age, the EAR deficit also increased proportionally. It is interesting to note that in a quick overview of *all* the children's EAR deficits (see Table 5.5a) not one child met the recommended energy intake for his/her age. As noted in Section 4, there are no standards of nutrient intake specific to this population and both RNI and EAR routinely overestimate intake.

TEE was evaluated in terms of kcal/kg body weight and per kg of FFM. No significant differences were revealed when these terms were tested for differences between the G-tube and orally fed groups. However, the difference in kcal intake per kg was almost significant at $p=0.058$ with the orally fed group having a higher mean intake. One possible explanation for this higher value of kcal/kg is that the orally fed group requires more energy per kg due to higher energy expenditure levels or more FFM per kg body weight. As shown in Sections 5.4 and 5.5, both of these possible explanations are true. The orally fed group does display higher energy expenditure although the difference is not statistically significant. They also have more FFM per kg of body weight.

Macronutrients

Computer analysis of diet records yielded both total grams of each macronutrient as well as % RNI. The data was expressed as % RNI to eliminate the differences in intake expected with differing ages. Interestingly, only protein intake was routinely above 100% of the RNI in both G-tube and orally fed children. Carbohydrate had the lowest % intake. This was also found in earlier epidemiological studies conducted by this research group (Sullivan, Juszczak et al. 2002).

Fats

The % RNI of specific fatty acids was analyzed since it has been hypothesized that the increased fat deposition seen in G-tube fed children may have been a result of the high fat content of enteral feeds. Dietary fat is traditionally viewed as lipogenic due to its metabolic efficiency and high energy density (Prentice 1998). Studies of nutrient balance and metabolism have shown that metabolic fuel selection is primarily dominated by the need to maintain carbohydrate and protein balances. These two fuels have much smaller storage reserves within the body. Fat intake therefore does not affect short term fat oxidation (Tataranni and Ravussin 1997). This theory is supported by several studies, including this one, which found that the orally fed children actually received a higher % of the RNI of all fatty acids (SFA, MUFA, PUFA) as well as cholesterol than those fed via G-tube. All differences were statistically significant, with the exception of PUFA.

Fibre

As discussed in Section 4, adequate fibre intake is extremely important in disabled children because of frequent and chronic constipation. Data analysis by feeding group revealed that the orally fed children had a significantly greater daily intake.

Micronutrients

To further the evaluation of micronutrient status in children fed via G-tube the % RNI of micronutrient intakes were examined. It is widely questioned whether or not the micronutrient intake of disabled children is sufficient and whether a % RNI less than 100% should be acceptable since their energy % RNI is significantly low. This study shows that the % RNI intake for micronutrients is much higher than the % RNI intakes of energy and the other macronutrients. The mean intake for the majority of micronutrients examined was over 100% of the RNI.

As the G-tube fed children received the majority of their nutrition from a highly fortified enteral product it is not surprising that for all nutrients (with the exception of sodium and chloride) the G-tube fed children have a higher %RNI intake of micronutrients. The lower sodium and chloride intakes can be explained by the actual composition of the feeds and foods provided. Paediasure™ (SHS) was the primary feed used by half the children in this study and Paediasure™ has a sodium content of zero. Also, the foods commonly consumed by the children who ate orally tended to be highly processed snacks such as potato crisps and Quavers™, which are extremely high in sodium and chloride.

Despite the G-tube fed children having higher % RNI intakes for all the micronutrients, this difference was only significant for iron, zinc, selenium, niacin, thiamin Vitamin B6 and folate. Whether this higher intake is beneficial to the health status of the G-tube fed children is unknown. Further studies in this area are needed and being undertaken by this research group.

Resting Metabolic Rate

There was no difference in RMR, RMR per kg body weight, RMR per kg FFM mass or RMR adjusted for kg of FFM between children fed via G-tube or orally.

Unlike the trend of increasing EAR deficit with age seen in section 5.3, RMR overestimation does not increase, nor decrease with age. The Schofield prediction equation seemed to be most accurate for those children aged 7 to 10 years (based on the mean and median overestimation) however the range of overestimation is still quite large for this group. Paired t-tests revealed that for the children as a whole group, the overestimation (predicted vs measured values) was statistically significant. When tested by feeding group, it emerged that the overestimation was significant for those who were fed via G-tube, but not those who fed orally. As will be discussed further on, this discrepancy is most likely due to the differences in FFM between these groups.

Body Composition from Doubly Labelled Water

Table 5.15c shows that there was no significant difference in FMI between the feeding groups, but that the orally fed children had significantly higher FFMI values than those who were G-tube fed.

When FMI and FFMI values were compared to reference standards, it became apparent that the children deviate significantly from normal in both measures. However, orally fed children are *less* different in FFMI than the G-tube fed children, a difference that is statistically significant.

When absolute fat mass and % BF were examined there was a significant difference in % BF with the G-tube fed children having a much higher value (32.1% vs 21.0%). Table 5.16b helps to emphasize the limitations of expressing fat as a percentage of body weight. The significant difference in % BF between G-tube and orally fed children would most likely be interpreted (by health care workers and lay people) as an increase in body fat in the G-tube fed children. However, Tables 5.15c/d and 5.17d/e revealed that the main difference between the groups lies not in FM but in FFM.

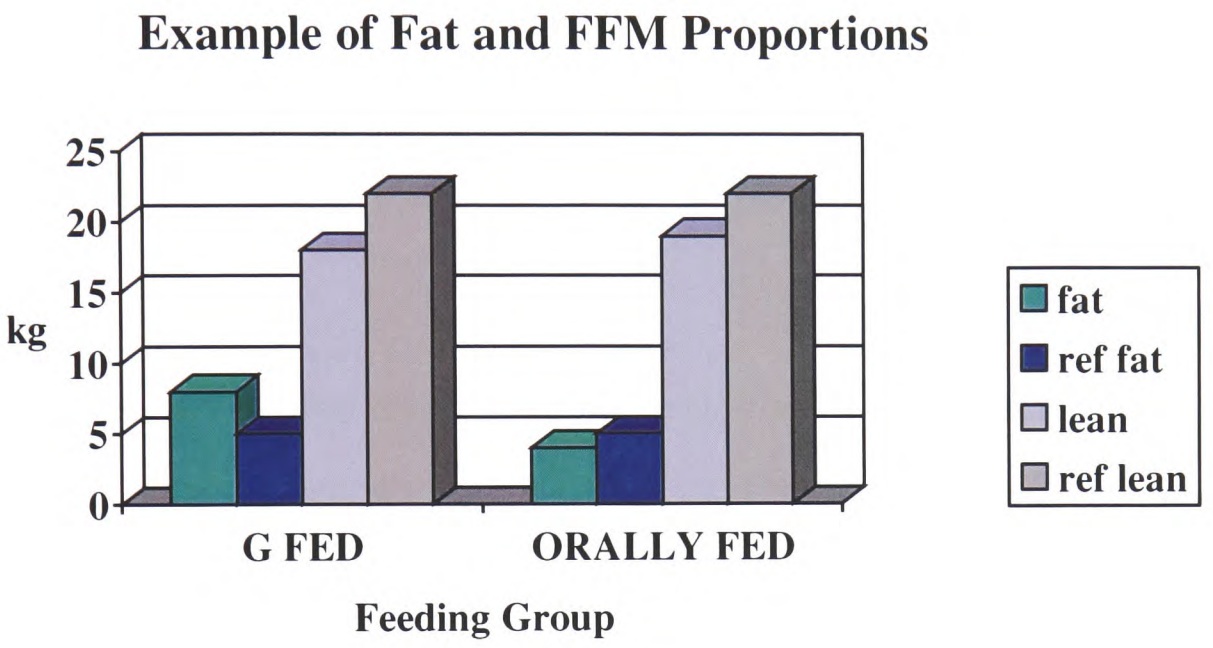
The relationship between the values obtained for % BF from skinfolds and from DLW was good- PC=0.741 ($p<0.001$) for the Slaughter equation and excellent (PC=0.802, $p<0.001$) for the Brook equation. However, correlation is not evidence of validity, and so although many feel that skinfold measurements can provide a relatively accurate value for the % BF in disabled children, this fact has been questioned by several research groups (VandenBerg-Emons, VanBaak et al. 1998). In addition, if % BF is not interpreted correctly, then a true picture of the body composition of the child will not be attained. This point was also made by Vanden Berg-Emons et al., who suggested that skinfold measurement

comparisons between disabled children and healthy controls were more appropriate when done directly and not converted into % BF.

The comparisons of reference FFM and FM to the measured values again illustrates that the main difference in body composition between orally and G-tube fed children is in FFM, not FM. The paired t-tests scores of Table 5.17b revealed that the group as a whole is not significantly difference from reference standards in terms of FM, but has significantly less FFM. Performed by feeding group (Table 5.17e), it emerged that those children fed via G-tube are actually higher in FM than reference, but lower in FFM. The orally fed children are not significantly different from reference standards in terms of FM, but are lower in FFM. Previous work by other research groups also reported that measured FFM in disabled children was lower than reference standards (Bandini, Schoeller et al. 1991; Stallings, Cronk et al. 1995; Azcue, Zello et al. 1996). Similar to the conflicting findings on FM found between the G-tube and orally fed children however, other reports on the FM of disabled children have been mixed and FM has been reported as higher, lower and not significantly different from reference (Shepherd, Roberts et al. 1991; Stallings, Cronk et al. 1995; Azcue, Zello et al. 1996; Chad, McKay et al. 2000). The method of the expression of FM and the method of feeding of the children in these studies most likely contributed to these mixed results.

These differences are well explained diagrammatically, as shown in the Figure 5.4.

Figure 5.4 A Bar Graph to Illustrate the Differences in Fat Mass and Fat-Free Mass between Disabled Children Fed Orally or via Gastrostomy-tube



Total Energy Expenditure from Doubly Labelled Water

The significant difference seen between feeding groups for TEE/kg but not for TEE/kg FFM can possibly be explained by the findings in the previous section on body composition. Although both G-tube and orally fed children have significantly lower FFM than expected, the orally fed children have a higher proportion of FFM for their body weight (as the G-tube fed children have higher fat than expected whereas the orally fed children do not). Since FFM is more metabolically active, it follows that those children with a higher proportion of FFM per kg would have a higher TEE per kg. The fact that TEE/kg FFM is not

different between the groups suggests that the difference in TEE is due to different proportions of active tissue and not a difference in tissue efficiency.

The results of the evaluation of TEE adjusted for FFM also support this hypothesis. Table 5.20b showed that there was no significant difference in the TEE of the feeding groups when FFM was controlled for. It is interesting to recall that the values for RMR/kg were *not* significantly different between feeding groups. This could be due to the small numbers involved in the study, and the various problems encountered with measuring RMR.

Energy Balance

The mean and median energy balance for almost every age group was positive, indicating that in most cases, disabled children are receiving at least the same amount of or more than the energy they expend. Although negative values were encountered in each age group, the lowest mean and median values were found in the age groups 3-6 and 7-10 years. The mean EB in the 7-10 years was most likely affected by the very negative value of –699kcal/24 hours as the median value was +110 kcal/24 hours. The median negative EB of –57 kcal/24 hours in the 3-6 year group was slightly more worrisome. As noted by the average age of participant in the Gastrostomy Study, 3-6 years seems to be the age at which children present with growth and feeding problems serious enough to warrant G-tube placement. I hypothesize that it is at this age that disabled children's energy needs for growth increase to a point where they cannot sustain an increasing intake to match these needs and hence G-tube placement is often suggested as a means to increase energy intake.

The lack of significant difference in EB between the orally and G-tube fed children was a surprising finding. Since the G-tube fed children presented with higher amounts of body fat, it was expected that they would have a higher positive energy balance in order to create fat stores. Recall that the total energy intake of these groups was not statistically different, nor was the RMR or TEE. However, the BC of these groups of children was significantly different, and was reflected in the differences seen in TEE per kg and kcal intake per kg.

The method of recruitment of children for this study may have impacted slightly upon this last finding. Most children were recruited from a Tertiary Feeding Clinic, where they were receiving individualized dietary advice from a multi-disciplinary team. Whether this resulted in a smaller amount of enteral feed due to observed low energy needs in the G-tube fed children, or the introduction of oral supplements in those who fed orally, is hard to determine.

Gross Motor Function

PAL (TEE/RMR) is a very basic measure, but its calculation did reveal that the overall physical activity of this group of children is extremely low. Since PAL is most likely affected by the amount of lean tissue in the body, an adjusted PAL (controlling for FFM) was calculated and revealed that there was no significant difference in PAL between feeding groups when FFM was controlled for. Age and PAL was also explored, but Figure 5.2 revealed a poor relationship, indicating that PAL was low for all ages. Hoos et al. determined that there was a relationship with age in healthy children and used regression to create a PAL reference value of 0.025xage + 1.40 (Hoos, Gerver et al. 2003).

Pearson correlations indicated that there were significant negative relationships between adjusted PAL and FMI, BMI Z score and % BF. (Recall that adjusted PAL was controlled for FFM). Therefore, as PAL increases, fat, as measured by several indices, decreases.

Data from the measures of gross motor function clearly illustrates that G-tube fed children had a significantly higher level of disability. This finding was paramount to help explain everything discussed in this section. The G-tube fed children had higher FM and lower FFM compared to those children fed orally. As a result of these differences in body composition, TEE per kg was lower. Although G-tube feeding contributed to increased weight and fat mass, the major difference in BC between these two groups was in FFM. Since the G-tube fed group were more disabled, their ability to develop and utilize FFM was lower. Unfortunately, it appears that nutrition can do little to change this phenomenon.

Conclusion

This study clearly demonstrated that disabled children who were G-tube fed have higher amounts of body fat than disabled children who were fed orally.

- % BF (from skinfold measurements) was significantly higher in G-tube fed children
- There was a significant difference in FFMI but not FMI between the feeding groups
- % BF (from DLW) was significantly higher in G-tube fed children

- FM was significantly higher than reference and FFM significantly lower than reference in G-tube fed children
- FM was within reference range for orally fed children whereas FFM was significantly lower than reference
- TEE/kg was significantly higher in the orally fed children than those were G-tube fed
- Disability levels were significantly greater in the G-tube fed children as measured by both the GMFM and the GMCS

SECTION SIX: RESULTS AND DISCUSSION- BODY COMPOSITION AND ENERGY METABOLISM CHANGES OVER TWELVE MONTHS

Aim of Section Six

The goal of this study was to evaluate the changes in body composition and energy metabolism in children with severe neurological disabilities who were receiving moderate nutritional intervention and compare the changes between those children who were fed via gastrostomy-tube and those who were oral feeders.

Hypothesis One: Children who are fed via gastrostomy-tube will continue to gain weight, primary as fat, whereas orally fed children will gain both fat and fat-free mass.

Hypothesis Two: Energy metabolism measures will reflect changes in body composition; primarily gaining fat will not increase energy expenditure significantly, but gaining both fat and lean tissue will increase energy expenditure.

Abbreviations used in Section Six

%BF	Percentage Body Fat (by Weight)
BMI	Body Mass Index
CHOL	Cholesterol
DLW	Doubly Labelled Water
RNI	Recommended Nutrient Intake
EAR	Estimated Average Requirement
EB	Energy Balance
EBS	Energy Balance Study
FFM	Fat-free Mass
FFMI	Fat-free Mass Index
FM	Fat Mass
FMI	Fat Mass Index
GMCS	Gross Motor Classification System
GMFM	Gross Motor Function Measure
G-tube	Gastrostomy-tube
kcal	kilo-calories
MUFA	Mono-unsaturated Fatty Acids
PC	Pearson Correlation
PUFA	Poly-unsaturated Fatty Acids
RMR	Resting Metabolic Rate
SD	Standard Deviation
SFA	Saturated Fatty Acids

TEE Total Energy Expenditure

Table Layout

Several tables accompany each sub-section of the following Results to fully illustrate the data. Each table is laid out as follows:

Title

Statistic	List of the statistics used to evaluate the data
G-tube?	Indication of G-Tube or Orally Fed Feeding Group
N	Number of children in the group for which the data applies
Mean (SD)	Mean Value and Standard Deviation
Median	Median Value
Range	Range of the Data

Independent t-tests: These results always apply to the testing of G-tube vs Orally fed children

Paired t-tests: these results always apply to the testing of individuals' values from First to Final Visit. When Feeding Groups are tested separately, this is indicated.

Results Outline

6.1 Participant Details

6.2 Growth from Anthropometry

6.3 Body Composition from Anthropometry

6.4 Nutritional Intake

6.5 Resting Metabolic Rate

6.6 Body Composition from Doubly Labelled Water

6.7 Total Energy Expenditure from Doubly Labelled Water

6.8 Energy Balance

6.9 Gross Motor Function

6.10 Doubly Labelled Water (Technique Accuracy)

6.11 Problems Encountered

6.12 Discussion

RESULTS

6.1 PARTICIPANT DETAILS

Thirty children who took part in the Energy Balance Study (EBS) were followed for 12 months. Twenty-two were male and 8 female, 16 gastrostomy-tube (G-tube) fed and 14 orally fed. Four children had a gastrostomy placed during the course of the year resulting in 20 G-tube fed and 10 orally fed by the final visit. The mean age of the children at the first visit was 7.95 years (SD= 4.79). Median age was 7.52 years with a range of 1.34 to 18.87 years. There was no significant difference in the mean age of children by feeding group (p=0.423).

6.2 GROWTH FROM ANTHROPOMETRY

The weight, height and Body Mass Index (BMI) Z Scores from both the initial and final visits are presented below in Tables 6.1a and b (Freeman, Cole et al. 1995). Paired t-tests reveal that there were no dramatic changes in Z scores over the 12 months the children were observed.

Table 6.1a Weight, Height and BMI Z Scores- First Visit

Statistic	Weight Z Score	Height Z Score	BMI Z Score
N	30	23	23
Mean (SD)	-2.98 (1.85)	-2.05 (1.76)	-1.89 (1.76)
Median	-2.97	-2.28	-2.17
Range	-6.96 to 2.66	-4.74 to 3.03	-5.68 to 1.08

Table 6.1b Weight, Height and BMI Z Scores- Final Visit

Statistic	Weight Z Score	Height Z Score	BMI Z Score
N	29	30	29
Mean (SD)	-2.89 (2.23)	-2.45 (1.75)	-1.85 (2.23)
Median	-2.50	-2.80	-1.34
Range	-7.67 to 2.75	-6.38 to 2.86	-9.96 to 1.26

Paired t-tests: Weight Z Score p=0.993, Height Z Score p=0.853 and BMI Z Score p=0.994.

The Z scores by feeding group are presented below in Tables 6.1c and d. Independent t-tests show that weight Z scores were significantly less negative in

the G-tube fed children at the first visit, but that this significance was lost by the final visit.

Table 6.1c Weight, Height and BMI Z Scores by Feeding Group- First Visit

Statistic	Weight Z Score		Height Z Score		BMI	
Gastrostomy?	G-tube	Oral	G-tube	Oral	G-tube	Oral
N	16	14	12	11	12	11
Mean (SD)	-2.33 (1.78)	-3.73 (1.69)	-1.79 (2.05)	-2.34 (1.41)	-1.29 (1.68)	-2.55 (1.67)
Median	-2.83	-3.83	-2.24	-3.00	-1.47	-2.34
Range	-4.40 to 2.66	-6.96 to 1.60	-4.74 to 3.03	-4.05 to –0.15	-4.35 to 1.08	-5.68 to 0.06

Independent t-tests: Weight p=0.035, Height p=0.463, BMI p=0.085

Table 6.1d Weight, Height and BMI Z Scores by Feeding Group- Final Visit

Statistic	Weight Z Score		Height Z Score		BMI	
Gastrostomy?	G-tube	Oral	G-tube	Oral	G-tube	Oral
N	20	9	20	10	20	9
Mean (SD)	-2.49 (2.29)	-3.77 (1.92)	-2.23 (1.97)	-2.87 (1.19)	-1.34 (1.62)	-2.97 (3.02)
Median	-1.97	-4.00	-2.27	-3.37	-1.03	-1.58
Range	-7.54 to 2.75	-7.67 to –1.21	-6.38 to 2.86	-4.11 to –0.74	-4.92 to 1.26	-9.96 to –0.36

Independent t-tests: Weight p=0.156, Height p=0.354, BMI p=0.068

Changes in Z Scores (Tables 6.1a and b) were calculated by subtracting the first visit Z score from the final visit Z score. As revealed by the paired t-tests (see Table 6.1b), changes in Z scores were extremely small and no differences between G-tube and orally fed children were seen.

Table 6.2a Changes in Weight, Height and BMI Z Score over 12 Months

Statistic	Change in Weight Z Score	Change in Height Z Score	Change in BMI Z Score
N	29	23	23
Mean (SD)	0.01 (0.80)	-0.02 (0.57)	0.002 (1.54)
Median	0.14	0.10	0.12
Range	-1.82 to 1.28	-1.70 to 0.77	-4.28 to 2.44

Table 6.2a Changes in Weight, Height and BMI Z Score by Feeding Group over 12 Months

Statistic	Change in Weight Z Score		Change in Height Z Score		Change in BMI Z Score	
Gastrostomy?	G-tube	Oral	G-tube	Oral	G-tube	Oral
N	20	9	15	8	15	7
Mean (SD)	0.11 (0.76)	-0.19 (0.90)	-0.04 (0.66)	0.01 (0.40)	0.48 (0.90)	-1.01 (2.16)
Median	0.15	-0.51	0.10	0.05	0.22	-1.16
Range	-1.82 to 1.28	-1.55 to 1.11	-1.70 to 0.77	-0.60 to 0.58	-0.41 to 2.44	-4.28 to 2.16

Independent t-tests: Weight p=0.363, Height p=0.843, BMI p=0.123

6.3 BODY COMPOSITION FROM ANTHROPOMETRY

Percentage of body fat by weight was determined from anthropometry according to the equations of Brook and Slaughter (Brook 1971; Slaughter, Lohman et al. 1988). At the first visit the G-tube fed children had significantly higher % BF than the orally fed children as measured by the Brook equation. The children evaluated with the Slaughter equation showed no significant differences.

Table 6.3a Percentage Body Fat from Anthropometry- First Visit

Statistic	% Body Fat (Brook)	% Body Fat (Slaughter)
N	26	13
Mean (SD)	15.56 (8.38)	10.2 (5.83)
Median	12.6	8.35
Range	3.99 to 34.3	2.69 to 21.8

Table 6.3b Percentage Body Fat from Anthropometry by Feeding Group- First Visit

Statistic	% Body Fat (Brook)		% Body Fat (Slaughter)	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	13	13	5	8
Mean (SD)	19.9 (9.13)	11.2 (4.65)	14.7 (6.68)	7.42 (3.09)
Median	19.62	11.2	12.7	7.23
Range	6.33 to 34.3	3.99 to 23.1	8.38 to 21.8	2.69 to 13.6

Independent t-tests: Brook p=0.007, Slaughter p=0.070

Table 6.4d reveals that at the final visit there were no differences between the G-tube and orally fed group with either equation.

Table 6.3c Percentage Body Fat from Anthropometry- Final Visit

Statistic	% Body Fat (Brook)	% Body Fat (Slaughter)
N	28	15
Mean (SD)	17.5 (8.49)	12.9 (7.14)
Median	16.3	9.97
Range	3.16 to 32.4	5.05 to 26.9

Table 6.3d Percentage Body Fat from Anthropometry by Feeding Group- Final Visit

Statistic	% Body Fat (Brook)		% Body Fat (Slaughter)	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	19	9	10	5
Mean (SD)	19.3 (7.87)	13.7 (8.94)	14.6 (7.71)	9.65 (4.93)
Median	17.8	10.5	11.7	8.08
Range	8.64 to 32.4	3.16 to 29.1	6.31 to 26.9	5.05 to 17.9

Independent t-tests: Brook p=0.132, Slaughter p=0.159

As an alternate method of fat storage evaluation, triceps skinfold measurements and Triceps Z Scores (calculated according to (Davies, Day et al. 1993) were compared. Unlike the results of %BF, the differences between the G-tube and orally fed children were significant at both visits, with the G-tube fed children displaying higher fat levels and less negative Z scores. See Tables 6.4a to 6.4d.

Table 6.4a Triceps Skinfold Measurements and Triceps Skinfold Z Scores- First Visit

Statistic	Triceps Skinfold Measurement (mm)	Triceps Skinfold Z Score
N	30	30
Mean (SD)	7.25 (3.77)	-1.36 (1.53)
Median	6.18	-1.65
Range	2.43 to 16.9	-4.53 to 1.80

Table 6.4b Triceps Skinfold Measurements and Triceps Skinfold Z Scores By Feeding Group- First Visit

Statistic	Triceps Skinfold Measurement (mm)		Triceps Skinfold Z Score	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	16	14	16	14
Mean (SD)	9.12 (4.09)	5.12 (1.79)	-0.51 (1.37)	-2.34 (1.06)
Median	8.05	4.71	-0.60	-2.20
Range	4.03 to 16.9	2.43 to 8.93	-2.80 to 1.80	-4.53 to – 0.37

Independent t-tests: Skinfold p=0.002, Skinfold Z Score p<0.001

Table 6.4c Triceps Skinfold Measurements and Triceps Skinfold Z Scores- Final Visit

Statistic	Triceps Skinfold Measurement (mm)	Triceps Skinfold Z Score
N	30	29
Mean (SD)	7.58 (4.00)	-1.14 (1.61)
Median	6.81	-1.26
Range	2.80 to 18.1	-4.44 to 1.96

Table 6.4d Triceps Skinfold Measurements and Triceps Skinfold Z Scores by Feeding Group- Final Visit

Statistic	Triceps Skinfold Measurement (mm)		Triceps Skinfold Z Score	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	20	10	20	9
Mean (SD)	8.68 (4.32)	5.38 (1.95)	-0.71 (1.53)	-2.08 (1.42)
Median	7.75	5.15	-0.67	-1.61
Range	3.37 to 18.1	2.80 to 8.63	-3.50 to 1.96	-4.44 to 0.09

Independent t-tests: Skinfold p=0.008, Skinfold Z Score p=0.031

Paired t-tests were conducted for the group as a whole and by feeding group to see whether the values used to estimate body fat changed dramatically over the year for individuals. No test was significant, as shown in Table 6.5.

Table 6.5 Paired t-test Results (P Values) for Evaluating the Change in Percentage Body Fat, Triceps Skinfold Measurement, and Triceps Skinfold Z Score over 12 Months- by Feeding Group

Group	P Value for % Body Fat (Brook)	P Value for % Body Fat (Slaughter)	P Value for Triceps Skinfold	P Value for Triceps Skinfold Z Score
All 30 Children	0.438	0.119	0.196	0.151
Gastrostomy Fed (20)	0.359	0.356	0.095	0.062
Orally Fed (10)	0.993	0.222	0.794	0.909

6.4 NUTRITIONAL INTAKE

Energy

The total energy intake (in kcal per 24 hours) for each age group at both the first and final visits are presented in Tables 6.6a and b.

Table 6.6a Total Energy Intake by Age Group (kcal/24 hours)- First Visit

Statistic	0-2 yrs	3-6 yrs	7-10 yrs	11-13 yrs	14+ yrs
N	6	8	7	5	4
Mean (SD)	827 (278)	854 (216)	1081 (300)	1301 (395)	1418 (286)
Median	738	890	1049	1250	1468
Range	505 to 1221	520 to 1206	596 to 1442	825 to 1858	1024 to 1710

Table 6.6b Total Energy Intake by Age Group (kcal/24 hours)- Final Visit

Statistic	0-2 yrs	3-6 yrs	7-10 yrs	11-13 yrs	14+ yrs
N	5	4	6	3	2
Mean (SD)	806 (335)	1253 (241)	1041 (223)	1504 (916)	1239 (196)
Median	900	1267	1098	1171	1239
Range	404 to 1115	947 to 1533	758 to 1350	800 to 2540	1100 to 1377

Total energy intake was compared to the EAR (Estimated Average Requirement) for age and sex according to the Department of Health (1991) and EAR deficit was calculated as energy intake – EAR. The deficit was severe at both first and final visit as shown in Table 6.7a. Table 6.7b reveals that there were no significant differences in deficit between the feeding groups.

Table 6.7a EAR Deficit- First and Final Visits

Statistic	EAR Deficit- First Visit kcal/24 hours	EAR Deficit- Final Visit kcal/24 hours
N	30	20
Mean (SD)	-840 (371)	-801 (410)
Median	-825	-878
Range	-1663 to -170	-1378 to –77.0

Paired t-test: First to Final Visit p=0.901

Table 6.7b EAR Deficit by Feeding Group- First and Final Visits

Statistic	EAR Deficit- First Visit		EAR Deficit- Final Visit	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	17	13	15	6
Mean (SD)	-837 (293)	-844 (467)	-838 (368)	-714 (497)
Median	-833	-666	-952	-642
Range	-1255 to -281	-1663 to -170	-1378 to –77	-1317 to –82.0

Independent t-tests: First Visit: p=0.956, Final Visit: p=0.539

Total energy intake was also evaluated in terms of kcal/kg body weight and per kg of FFM. There were no significant changes over the course of the year or between feeding groups, as shown in Tables 6.8a to d.

Table 6.8a Energy Intake per Kg Body Weight- First and Final Visits

Statistic	KCAL/KG at First Visit (kcal/24hours /kg)	KCAL/KG at Final Visit (kcal/24hours /kg)
N	30	20
Mean (SD)	63.0 (22.5)	61.5 (25.9)
Median	60.8	55.6
Range	26.0 to 119	24.2 to 106

Paired t-test: First to Final Visit p=0.831

Table 6.8b Energy Intake per Kg Body Weight by Feeding Group- First and Final Visits

Statistic	KCAL/KG at First Visit (kcal/24hours /kg)		KCAL/KG at Final Visit (kcal/24hours /kg)	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	17	13	14	6
Mean (SD)	58.4 (22.3)	69.0 (22.2)	58.5 (25.0)	68.5 (28.9)
Median	53.8	68.9	54.0	69.0
Range	33.1 to 119	26.0 to 116	24.2 to 99.6	28.2 to 106

Independent t-tests: First Visit p=0.203, Final Visit p=0.445

Table 6.8c Energy Intake per Kg Fat Free Mass- First and Final Visits

Statistic	KCAL/KG FFM at First Visit (kcal/24hours /kg FFM)	KCAL/KG FFM at Final Visit (kcal/24hours /kg FFM)
N	30	18
Mean (SD)	86.0 (27.5)	87.2 (38.5)
Median	86.9	71.0
Range	36.6 to 162	43.4 to 178

Paired t-test: First to Final Visit p=0.810

Table 6.8d Energy Intake per Kg Fat Free Mass by Feeding Group- First and Final Visits

Statistic	KCAL/KG FFM at First Visit (kcal/24hours /kg FFM)		KCAL/KG FFM at Final Visit (kcal/24hours /kg FFM)	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	17	13	12	6
Mean (SD)	86.8 (27.3)	85.0 (28.7)	86.7 (32.8)	88.4 (51.6)
Median	86.9	86.8	79.1	64.9
Range	52.4 to 162	36.6 to 150	45.9 to 143	43.5 to 178

Independent t-tests: First Visit p=0.866, Final Visit p=0.933

Macro and Micronutrients

% RNI was used to evaluate the micro- and macronutrient intake of the children at both the first and final visits.

Table 6.9a reveals that there was an increase in the % RNI for each macronutrient over the year, but table 6.9c indicates that these changes were not significant. By feeding group, the G-tube fed children displayed higher increases in % RNI (with the exception of carbohydrate) but again, these differences were not statistically significant.

Table 6.9a Change in Percentage RNI Intake for Protein, Fat, Carbohydrate and Energy over 12 Months

Statistic	Change in % RNI- Protein	Change in % RNI- Fat	Change in % RNI- Carbo.	Change in % RNI- Energy
N	19	19	19	20
Mean (SD)	5.51 (50.7)	3.20 (24.8)	0.93 (19.9)	2.38 (21.1)
Median	1.00	0.40	0.30	3.00
Range	-63.8 to 105	-33.6 to 50.3	-29.8 to 37.0	-32.5 to 42.2

Table 6.9b Change in Percentage RNI Intake for Protein, Fat, Carbohydrate and Energy over 12 Months by Feeding Group

Statistic	Change in % RNI- Protein		Change in % RNI- Fat		Change in % RNI- Carbo.		Change in % RNI- Energy	
Gastrostomy?	G-tube	Oral	G-tube	Oral	G-tube	Oral	G-tube	Oral
N	13	6	13	6	13	6	14	6
Mean (SD)	6.21 (49.4)	3.98 (58.1)	4.59 (19.7)	0.18 (35.6)	0.52 (18.0)	1.80 (25.4)	2.76 (17.7)	1.50 (29.3)
Median	1.00	-2.60	0.50	-11.5	0.30	0.25	3.00	-2.60
Range	-63.8 to 97.0	-61.4 to 105	-25.3 to 43.8	-33.6 to 50.3	-29.8 to 34.7	-29.0 to 37.0	-24.4 to 42.2	-32.5 to 40.3

Independent t-tests: Protein p=0.932, Fat p=0.785, Carbohydrate p=0.901, Energy p=0.906

Paired t-tests were used to evaluate differences in the % RNI intake of all nutrients between visits. There were no significant changes detected for the group as a whole or by feeding group as revealed by Tables 6.9c and d.

Table 6.9c P Values from Paired t-tests Comparing the % RNI Intakes of Macronutrients, Fats and Fibre Between the First and Final Visits- For the Whole Group and by Feeding Group

P Value for Comparison of:	Whole Group (N=19)	G-tube (N=13)	Oral (N=6)
Protein % RNI	0.642	0.659	0.873
Fat % RNI	0.580	0.416	0.990
Carbo. % RNI	0.841	0.918	0.869
Energy % RNI	0.618	0.570	0.905
SFA % RNI	0.893	0.993	0.870
MUFA % RNI	0.762	0.744	0.897
PUFA % RNI	0.763	0.860	0.796
CHOL (mg)	0.295	0.561	0.405
FIBRE- Southgate (g)	0.428	0.537	0.657
FIBRE- Englyst (g)	0.259	0.241	0.882

Table 6.9d P Values from Paired t-tests Comparing the % RNI Intakes of Micronutrients, Between the First and Final Visits- For the Whole Group and by Feeding Group

P Value for Comparison of:	Whole Group (N=19)	G-tube (N=13)	Oral (N=6)
Sodium% RNI	0.991	0.901	0.873
Potassium % RNI	0.479	0.600	0.670
Calcium% RNI	0.823	0.770	0.990
Magnesium % RNI	0.197	0.333	0.448
Phosphorus % RNI	0.906	0.828	0.945
Iron % RNI	0.098	0.178	0.399
Copper % RNI	0.453	0.394	0.240
Zinc % RNI	0.256	0.389	0.499
Chloride % RNI	0.425	0.426	0.795
Selenium % RNI	0.572	0.305	0.641
Iodine % RNI	0.861	0.637	0.828
Thiamin % RNI	0.289	0.304	0.668
Riboflavin % RNI	0.602	0.545	0.951
Niacin % RNI	0.307	0.583	0.218
Vitamin B6 % RNI	0.571	0.578	0.864
Vitamin B12 % RNI	0.970	0.854	0.799
Folate % RNI	0.441	0.533	0.693
Vitamin C % RNI	0.594	0.918	0.445

6.5 RESTING METABOLIC RATE

RMR was analyzed by age group and with normalization for kg and kg of FFM. RMR measurements by age group at the first and final visits followed the same trend as seen in Section 5.4; increasing until age 14+ years. Paired t-tests revealed a significant increase in the RMR of the children as a group (p=0.020). Evaluated by feeding group the change in RMR was significant for those who were fed via G-tube (p=0.014) but not for those who ate orally (p=0.665).

Table 6.10a RMR by Age Group (Kcal expended/24 hours)- First Visit

Age group	0-2 (yrs)	3-6 (yrs)	7-10 (yrs)	11-13 (yrs)	14+ (yrs)
N	6	7	7	5	4
Mean (SD)	421 (105)	578 (125)	801 (151)	943 (402)	865 (245)
Median	417	562	769	859	923
Range	283 to 553	442 to 791	633 to 1035	641 to 1640	518 to 1094

Table 6.10a RMR by Age Group (Kcal expended/24 hours)- Final Visit

Age group	0-2 (yrs)	3-6 (yrs)	7-10 (yrs)	11-13 (yrs)	14+ (yrs)
N	5	7	6	4	2
Mean (SD)	607 (98)	628 (181)	798 (161)	1032 (388)	844 (255)
Median	604	616	783	888	705
Range	491 to 740	352 to 886	638 to 1090	749 to 1603	352 to 1603

Changes in RMR/kg over the course of the year were not significant, nor were changes in RMR/kg FFM, as shown in Tables 6.11a to d.

Table 6.11a RMR per Kg Body Weight (Kcal expended/24 hours/kg)- First Visit

Statistic	All Children	G-tube	Oral
N	29	17	12
Mean (SD)	40.3 (11.2)	37.8 (10.4)	43.1 (12.1)
Median	39.8	35.4	41.8
Range	22.2 to 60.9	26.0 to 59.5	22.2 to 60.6

Independent t-test: p=0.219

Table 6.11b RMR per Kg Body Weight (Kcal expended/24 hours/kg)- Final Visit

Statistic	All Children	G-tube	Oral
N	24	17	7
Mean (SD)	41.3(13.4)	40.4 (12.9)	43.5 (15.3)
Median	39.2	37.1	47.3
Range	20.7 to 73.1	20.7 to 73.1	25.1 to 69.7

Independent t-test: p=0.626

Paired t-tests: First to Final Visit- Whole group p=0.719, G-tube fed p=0.670 and Orally fed p=0.971.

Table 6.11c RMR per Kg Fat Free Mass (Kcal expended/24 hours/kg FFM)- First Visit

Statistic	All Children	G-tube	Oral
N	29	17	12
Mean (SD)	55.8 (14.5)	57.0 (13.2)	54.1 (16.6)
Median	56.9	57.5	53.1
Range	29.0 to 82.8	33.0 to 80.6	29.0 to 82.8

Independent t-test: p=0.603

Table 6.11c RMR per Kg Fat Free Mass (Kcal expended/24 hours/kg FFM)- Final Visit

Statistic	All Children	G-tube	Oral
N	21	15	6
Mean (SD)	57.5 (19.4)	58.1 (14.1)	56.0 (30.9)
Median	54.6	55.6	41.2
Range	37.7 to 117	37.7 to 84.6	37.7 to 117

Independent t-test: p=0.835

Paired t-tests: First to Final Visit- Whole group p=0.745, G-tube fed p=0.603 and Orally fed p=1.00.

The relationship between RMR and kgFFM was significant at both the first and final visit, as illustrated Figures 6.1a and b. Pearson Correlation at First Visit =0.750 ($p<0.001$). PC at Final Visit =0.819 ($p<0.001$).

Figure 6.1a A Scatter Plot of Fat-Free Mass vs Resting Metabolic Rate at the First Visit

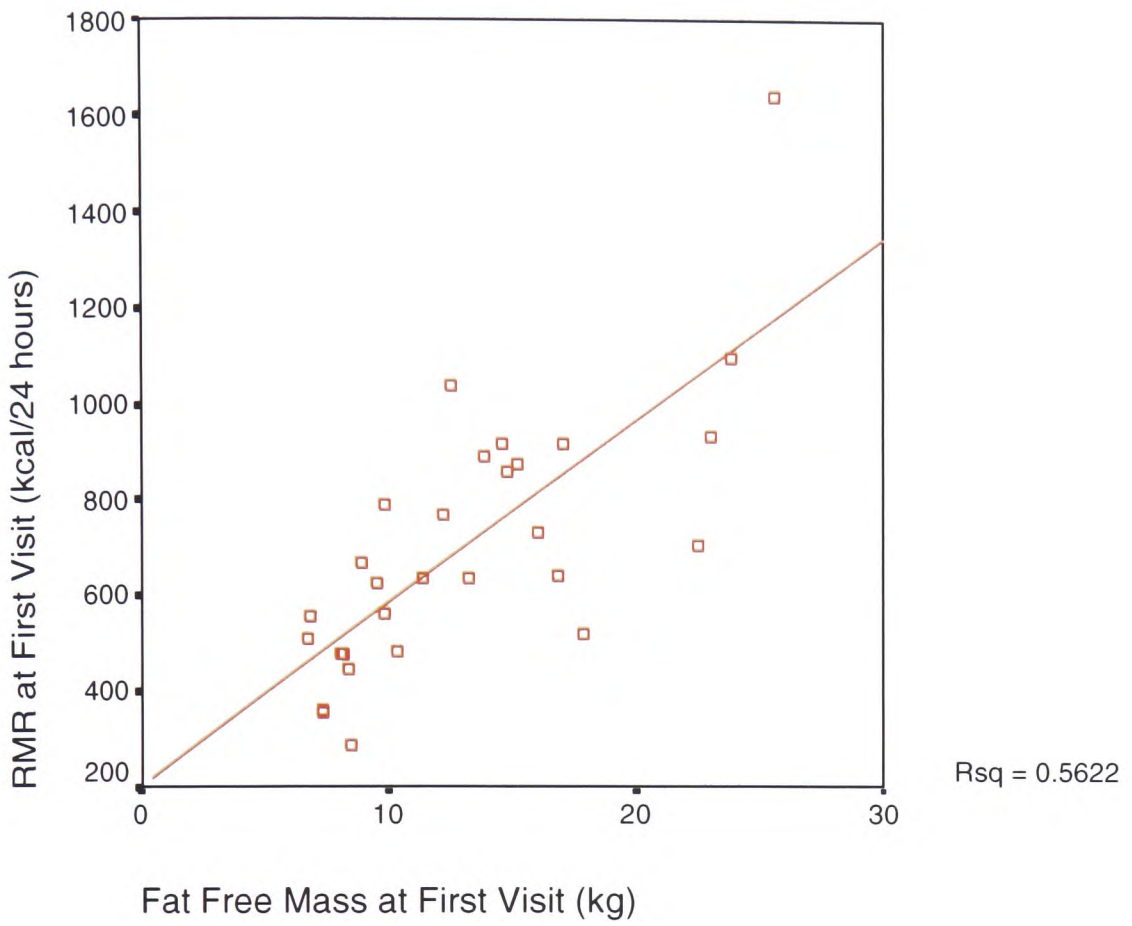
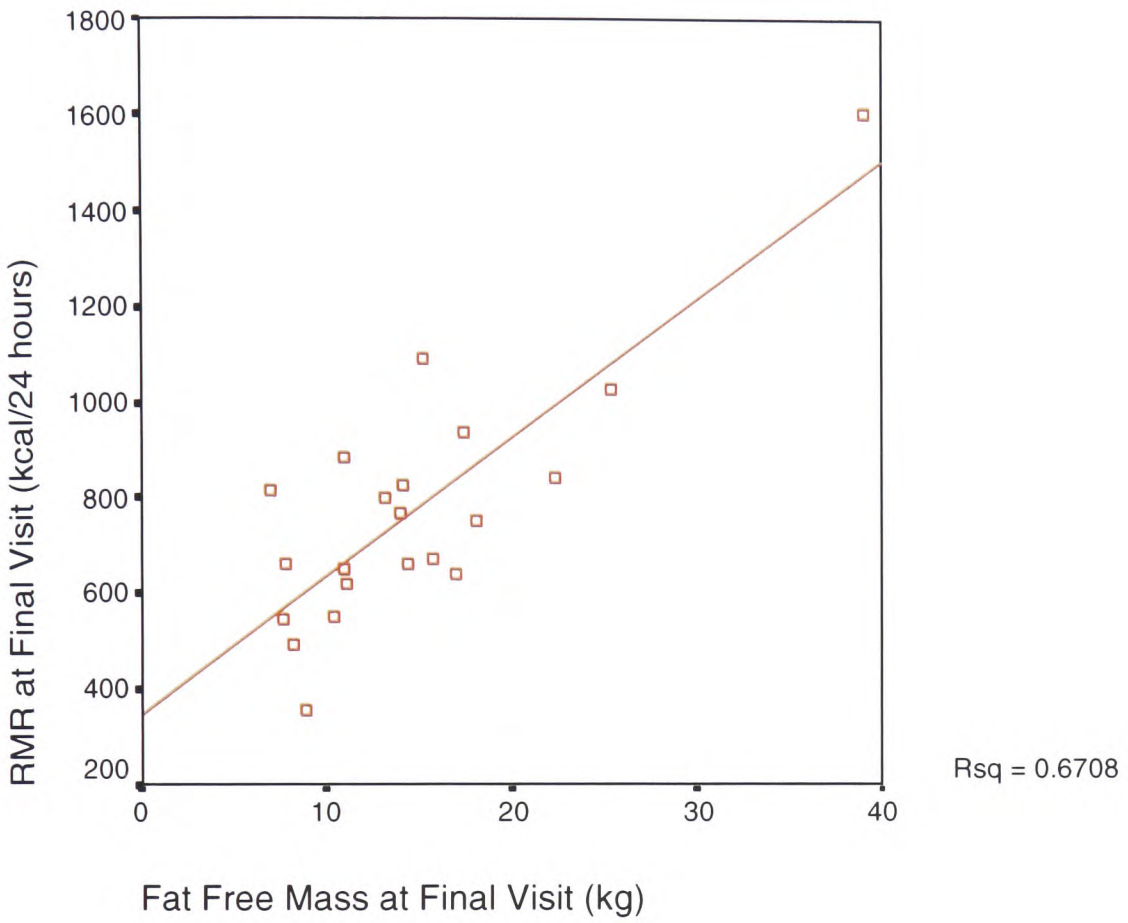


Figure 6.1b A Scatter Plot of Fat-Free Mass vs Resting Metabolic Rate at the Final Visit



Because of this significant relationship, RMR was adjusted to control for FFM using linear regression. There were no significant differences seen in adjusted RMR between the G-tube and orally fed groups at either visit. (See tables 6.12a and b.) Evaluation of changes in adjusted RMR over 12 months by paired t-test reveals an almost significant increase for the group as a whole (p=0.063). When Feeding groups were evaluated separately, it was shown that the orally fed children did not change in terms of RMR adjusted for FFM, but the G-tube fed group showed a significant increase (p=0.032).

Table 6.12a RMR Adjusted for Fat-Free Mass (Kcal/24 hours)- First Visit

Statistic	All Children	G-tube	Oral
N	29	17	12
Mean (SD)	700 (184)	699 (125)	702 (251)
Median	684	684	721
Range	336 to 1161	456 to 914	336 to 1161

Independent t-test: p=0.962

Table 6.12b RMR Adjusted for Fat-Free Mass (Kcal/24 hours)- Final Visit

Statistic	All Children	G-tube	Oral
N	21	15	6
Mean (SD)	777 (149)	767 (149)	802 (162)
Median	753	753	786
Range	527 to 1083	527 to 1083	627 to 1048

Independent t-test: p=0.643

Paired t-tests: First to Final Visit- Whole group p=0.063, Orally fed p=0.679, G-tube fed p=0.032

The Schofield prediction equations for estimating BMR in children were used to calculate a theoretical RMR for each child at the first and final visits (Schofield 1985). The overestimation was significant, as paired t-tests between the measured RMR value and the predicted BMR revealed p values of 0.010 for the first visit and 0.027 for the final visit (see tables 6.13a and b). The statistical significance of this overestimation was the same at each visit (paired t-tests for individuals at First and Final Visits): Whole Group p=0.889, G-tube fed p=0.656, Orally fed p=0.812) and there was no significant difference in overestimation between feeding groups at either visit.

Table 6.13a Overestimation of Schofield Predicted RMR (kcal/24 hours)- First Visit

Statistic	All Children	G-tube	Oral
N	29	17	12
Mean (SD)	97.6 (191)	142 (136)	35.0 (242)
Median	121	138	40.7
Range	-450 to 486	-104 to 337	-450 to 486

Independent t-test: p=0.141

Paired t-test: Predicted to Measured value for the whole group p=0.010

Table 6.13b Overestimation of Schofield Predicted RMR (kcal/24 hours)- Final Visit

Statistic	All Children	G-tube	Oral
N	24	17	7
Mean (SD)	85.3 (177)	110 (159)	24.4 (217)
Median	121	164	-24.0
Range	-218 to 423	-199 to 423	-218 to 391

Independent t-test: p=0.291

Paired t-test: Predicted to Measured value for the whole group p=0.027

Paired t-tests: First to Final Visit- Whole Group p=0.889, G-tube fed p=0.656, Orally fed p=0.812

6.6 BODY COMPOSITION FROM DOUBLY LABELLED WATER

Fat mass and Fat Free Mass Indices were calculated for both visits. Tables 6.14a to d reveal that FFMI remains significantly different between the two feeding groups over the course of the study, but FMI does not. At both First and Final visits the orally fed children have significantly higher values for FFMI than the G-tube fed children. FMI is significantly higher in G-tube fed children at the first visit and although still higher at the final visit, not significantly so.

Table 6.14a Fat Free Mass Index and Fat Mass Index (kg/m^2)- First Visit

Statistic	Fat Free Mass Index	Fat Mass Index
N	30	30
Mean (SD)	10.5 (1.42)	3.73 (2.09)
Median	10.2	3.79
Range	8.44 to 13.3	-0.50 to 8.32

Table 6.14b Fat Free Mass Index and Fat Mass Index by Feeding Group (kg/m^2)- First Visit

Statistic	Fat Free Mass Index		Fat Mass Index	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	16	14	16	14
Mean (SD)	9.72 (1.09)	11.4 (1.17)	4.65 (1.98)	2.67 (1.73)
Median	9.52	11.3	4.29	2.77
Range	8.44 to 12.6	9.85 to 13.3	0.07 to 8.32	-0.50 to 5.57

Independent t-tests: FFMI $p < 0.001$, FMI $p = 0.008$

Table 6.14c Fat Free Mass Index and Fat Mass Index (kg/m^2)- Final Visit

Statistic	Fat Free Mass Index	Fat Mass Index
N	24	24
Mean (SD)	10.2 (1.63)	4.68 (1.96)
Median	9.74	4.66
Range	8.02 to 15.6	0.77 to 8.54

Table 6.14d Fat Free Mass Index and Fat Mass Index by Feeding Group (kg/m^2)- Final Visit

Statistic	Fat Free Mass Index		Fat Mass Index	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	17	7	17	7
Mean (SD)	9.64 (0.84)	11.6 (2.27)	5.01 (1.82)	3.90 (2.22)
Median	9.56	11.2	4.82	3.47
Range	8.51 to 11.4	8.02 to 15.6	2.44 to 8.54	0.77 to 6.74

Independent t-tests: FFMI p =0.005, FMI p =0.215

Tables 6.15a and b show FFMI and FMI comparison to reference values (Fomon, Haschke et al. 1982). There was a significant difference in Reference- Actual FFMI between feeding groups at the first but not the final visit. The difference in deviation from reference FMI was not significant at either visit between the feeding groups.

Table 6.15a Reference – Actual FFMI and FMI by Feeding Group- First Visit

Statistic	Ref – Actual FFMI		Ref – Actual FMI	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	13	8	13	8
Mean (SD)	3.84 (0.99)	2.11 (1.19)	-1.53 (2.10)	0.13 (1.34)
Median	3.63	2.50	-1.56	0.13
Range	2.18 to 5.75	0.42 to 3.48	-5.81 to 3.44	-2.00 to 2.44

Independent t-tests: FFMI p=0.002, FMI p =0.062

Table 6.15b Reference – Actual FFMI and FMI by Feeding Group- Final Visit

Statistic	Fat Free Mass Index		Fat Mass Index	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	11	3	11	3
Mean (SD)	3.47 (0.77)	3.22 (1.11)	-1.91 (1.57)	-1.31 (1.44)
Median	3.60	2.61	-1.26	-0.63
Range	1.74 to 4.45	2.55 to 4.50	-5.79 to – 0.46	-2.96 to – 0.34

Independent t-tests: FFMI p =0.650, FMI p =0.565

Changes in FMI and FFMI were calculated to investigate the change in FM and FFM as normalized for height over the duration of the study. These changes revealed that as a group, the children increased their FMI values, but decreased their FFMI as shown in Table 6.16a. However, paired t-tests show that these changes were extremely small and not statistically significant.

Table 6.16a Change in FFMI and FMI Over 12 Months

Statistic	Change in FFMI	Change in FMI
N	24	24
Mean (SD)	-0.28(1.54)	0.49 (1.67)
Median	-0.10	0.68
Range	-3.53 to 4.05	-3.68 to 3.12

Table 6.16b Change in FFMI and FMI Over 12 Months by Feeding Group

Statistic	Change in FFMI		Change in FMI	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	17	7	17	7
Mean (SD)	-0.44 (1.18)	0.12 (2.26)	0.50 (1.64)	0.49 (1.87)
Median	-0.13	0.07	0.61	0.73
Range	-3.49 to 1.23	-3.53 to 4.05	-3.68 to 3.12	-2.96 to 2.37

Independent t-tests: Change in FFMI p=0.428, Change in FMI p=0.996

Fat mass and fat-free mass were compared to Fomon's reference values for fat and fat-free mass for children of the same age and sex. Paired t-tests (Table 6.17b) show that FFM was significantly lower than normal at both visits, but that FM was not significantly different from normal at visit one and had increased to be significantly *higher* than normal by the final visit.

Table 6.17a Measured Fat Free and Fat Mass Comparisons to Reference Values for Both Fat Free and Fat Mass at the First and Final Visits

(Statistic	FAT MASS First Visit Ref – Actual (kg)	FAT MASS Final Visit Ref – Actual (kg)	FF MASS First Visit Ref – Actual (kg)	FF MASS Final Visit Ref – Actual (kg)
N	21	14	21	14
Mean (SD)	-0.76 (1.90)	-1.35 (1.74)	5.62 (4.11)	6.24 (3.71)
Median	0.05	-1.18	4.21	5.42
Range	-4.64 to 2.31	-5.18 to 1.70	-0.35 to 13.25	0.78 to 13.1

Table 6.17b Paired t-test Values for the Evaluation of Measured and Reference Fat Free and Fat Mass at First and Final Visits

	FAT MASS First Visit Ref – Actual	FAT MASS Final Visit Ref – Actual	FF MASS First Visit Ref – Actual	FF MASS Final Visit Ref – Actual
P value	0.080	0.012	<0.001	<0.001

By feeding group, FM comparisons to reference were significantly different between the two groups at the first visit (with the G-tube fed children having more FM than reference) but this difference was not maintained over the year. FFM was low in all children at both visits. Paired t-tests between measured and reference FM and FFM values by feeding group show that the G-tube fed children are significantly higher in FM and significantly lower in FFM than reference standards over the year. The orally fed children were not significantly different from reference in terms of FM at either visit, but the significantly low

FFM value seen at the first visit was improved to not significantly different by the final visit. (Table 6.17e)

Table 6.17c Comparison of Measured and Reference Fat Mass Values by Feeding Group at the First and Final Visits (kg)

Statistic	FAT MASS First Visit Ref – Actual (kg)		FAT MASS Final Visit Ref – Actual (kg)	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	13	8	11	3
Mean (SD)	-1.40 (2.01)	0.28 (1.16)	-1.55 (1.87)	-0.63 (1.06)
Median	-1.70	0.39	-1.41	-0.35
Range	-4.64 to 2.31	-1.58 to 2.22	-5.18 to 1.70	-1.80 to 0.25

Independent t-tests: First Visit p=0.045, Final Visit p=0.443

Table 6.17d Comparison of Measured and Reference Fat-Free Mass Values by Feeding Group at the First and Final Visits (kg)

Statistic	FF MASS First Visit Ref – Actual (kg)		FF MASS Final Visit Ref – Actual (kg)	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	13	8	11	3
Mean (SD)	6.80 (4.34)	3.69 (3.05)	6.24 (4.11)	6.20 (2.75)
Median	6.60	3.37	5.00	7.74
Range	0.87 to 13.3	-0.35 to 7.69	0.78 to 13.1	3.03 to 7.84

Independent t-tests: First Visit p=0.093, Final Visit p=0.988

Table 6.17e Paired t-test Values for the Evaluation of Measured and Reference Fat Free and Fat Mass at First and Final Visits by Feeding Group

	FAT MASS First Visit Ref – Actual		FAT MASS Final Visit Ref – Actual		FF MASS First Visit Ref – Actual		FF MASS Final Visit Ref – Actual	
Gastrostomy?	G-tube	Oral	G-tube	Oral	G-tube	Oral	G-tube	Oral
P value	0.027	0.517	0.021	0.408	<0.001	0.011	0.001	0.060

6.7 TOTAL ENERGY EXPENDITURE FROM DOUBLY LABELLED WATER

The mean and median TEE for each age group of children is presented in Tables 6.18a and b. The change in TEE over the course of the year was evaluated using paired t tests for the group as a whole and by feeding group. Statistics revealed that there were no significant changes (Whole group p=0.900, G-tube fed p=0.925, Orally fed p=0.700).

Table 6.18a Total Energy Expenditure by Age Group (kcal/24 hours)- First Visit

Statistic	0-2 yrs	3-6 yrs	7-10 yrs	11-13 yrs	14+ yrs
N	6	8	7	5	4
Mean (SD)	680 (183)	810 (290)	987 (146)	1279 (516)	1090 (191)
Median	706	744	926	1132	1094
Range	383 to 875	328 to 1253	830 to 1215	722 to 2061	853 to 1320

Table 6.18b Total Energy Expenditure by Age Group (kcal/24 hours)- Final Visit

Statistic	0-2 yrs	3-6 yrs	7-10 yrs	11-13 yrs	14+ yrs
N	4	6	6	5	3
Mean (SD)	607 (139)	766 (173)	909 (168)	1307 (810)	1409 (668)
Median	618	769	990	1115	1433
Range	431 to 760	514 to 979	605 to 1032	639 to 2690	729 to 2064

Paired t-tests: First to Final Visit- Whole group p=0.900, G-tube fed p=0.925, Orally fed p=0.700

TEE per kg and per kg FFM was also investigated as a total population and by feeding group. A *decrease* in TEE per kg body weight was detected, significant both for the entire group and for those who were fed via G-tube as shown in Tables 6.19a and b. The children who ate orally also displayed a decrease in TEE per kg body weight over the course of the year, but this change was not significant.

Table 6.19a Total Energy Expenditure per Kg Body Weight (kcal/24 hours/kg)- First and Final Visits

Statistic	TEE/KG at First Visit (kcal/24hours/kg)	TEE/KG at Final Visit (kcal/24hours/kg)
N	30	24
Mean (SD)	56.9 (21.5)	47.3 (15.5)
Median	57.4	46.1
Range	20.9 to 94.1	19.1 to 81.8

Paired t-test: First to Final Visit- p=0.026

Table 6.19a Total Energy Expenditure per Kg Body Weight by Feeding Group (kcal/24 hours/kg)- First and Final Visits

Statistic	First Visit		Final Visit	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	16	14	17	7
Mean (SD)	51.7 (21.8)	62.8 (20.2)	45.0 (12.8)	52.9 (20.7)
Median	45.0	62.7	40.9	55.1
Range	20.9 to 94.1	22.7 to 93.6	25.2 to 70.4	19.1 to 81.8

Independent t-tests: First Visit p=0.263, Final Visit p=0.477

Paired t-tests: First to Final Visit- G-tube fed p=0.046, Orally fed p=0.225

Although there was no significant change observed in TEE per kg FFM (for the whole group or by feeding group), paired t-tests revealed that there was a significant *increase* in TEE adjusted for FFM (p=<0.001). This increase was significant in both feeding groups when compared separately (orally fed p=0.023, G-tube fed p=0.001) and is illustrated in Tables 6.21a and b.

Table 6.20a Total Energy Expenditure per Kg FFM (kcal/24 hours/kg FFM)- First and Final Visits

Statistic	TEE/KG FFM at First Visit (kcal/24hours/kgFFM)	TEE/KG FFM at Final Visit (kcal/24hours/kgFFM)
N	30	24
Mean (SD)	76.7 (23.8)	68.4 (20.4)
Median	79.7	66.0
Range	32.1 to 128	28.7 to 118

Paired t-test: First to Final Visit- p=0.236

Table 6.20b Total Energy Expenditure per Kg FFM by Feeding Group (kcal/24 hours/kg FFM)- First and Final Visits

Statistic	First Visit		Final Visit	
Gastrostomy?	G-tube	Oral	G-tube	Oral
N	16	14	17	7
Mean (SD)	77.3 (26.8)	76.0 (20.9)	69.4 (20.4)	66.1 (23.9)
Median	71.1	80.3	64.1	68.9
Range	40.4 to 128	32.1 to 113	45.9 to 118	28.7 to 109

Independent t-tests: First Visit p=0.884, Final Visit p=0.731

Paired t-tests: First to Final Visit- G-tube fed p=0.307, Orally fed p=0.580

TEE values adjusted for FFM were as follows:

Table 6.21a Total Energy Expenditure Adjusted for kg FFM (kcal/24 hours)- First Visit

Statistic	All Children	G-tube	Oral
N	30	17	13
Mean (SD)	935 (262)	897 (231)	985 (300)
Median	899	861	918
Range	327 to 1538	536 to 1387	328 to 1538

Independent t-test: p=0.370

Table 6.21b Total Energy Expenditure Adjusted for kg FFM (kcal/24 hours)- Final Visit

Statistic	All Children	G-tube	Oral
N	23	17	6
Mean (SD)	1456 (564)	1350 (380)	1755 (889)
Median	1341	1295	1503
Range	795 to 3437	795 to 2515	857 to 3437

Independent t-test: p=0.133

Paired t-tests: First to Final Visit- Whole group p=<0.001, Orally fed p=0.023 and G-tube fed p=0.001.

6.8 ENERGY BALANCE

Energy Balance, calculated as Total Energy Intake (kcal) – Total Energy Expenditure (kcal), for the first and final visits are presented by age group in Tables 6.22a and b. Table 6.22c displays the mean and median EB for the entire group and 6.22d by feeding group.

Although it appears that energy balance became more positive over the course of the study, paired t-tests indicate that there was actually no significant change (p=0.467). When grouped according to feeding group, paired t-tests revealed that those orally fed had a p value of 0.875 and those G-tube fed of 0.237. Independent t tests reveal that there was no significant difference at either visit between the orally and G-tube fed children in terms of their energy balance.

Table 6.22a Energy Balance by Age Group (kcal/24 hours)- First Visit

Statistic	0-2 yrs	3-6 yrs	7-10 yrs	11-13 yrs	14+ yrs
N	5	8	7	5	4
Mean (SD)	214 (258)	44.9 (257)	94.3 (223)	66.4 (252)	327 (284)
Median	122	31.0	115	103	368
Range	-4.00 to 648	-336 to 520	-330 to 378	-203 to 359	-56.0 to 630

Table 6.22b Energy Balance by Age Group (kcal/24 hours)- First Visit

Statistic	0-2 yrs	3-6 yrs	7-10 yrs	11-13 yrs	14+ yrs
N	4	5	6	3	2
Mean (SD)	213 (225)	449 (340)	113 (132)	-89.7 (59.5)	158 (694)
Median	215	313	113	-88.0	158
Range	-27.0 to 447	31.0 to 845	-20.7 to 332	-31.0 to – 150	-333 to 648

Table 6.22c Energy Balance (kcal/24 hours) at First and Final Visits

Statistic	Energy Balance at First Visit	Energy Balance at Final Visit
N	29	20
Mean (SD)	129 (253)	191 (308)
Median	119	114
Range	-336 to 648	-333 to 845

Paired t-tests: First to Final Visit- Whole Group p=0.467, G-tube fed p=0.237, Orally fed p=0.875

Table 6.22d Energy Balance by Feeding Group (kcal/24 hours) at First and Final Visits

Statistic	G-tube Energy Balance at First Visit	Oral Energy Balance at First Visit	G-tube Energy Balance at Final Visit	Oral Energy Balance at Final Visit
N	16	13	14	6
Mean (SD)	112 (230)	149 (288)	223 (245)	118 (441)
Median	119	119	156	-51.5
Range	-336 to 520	-203 to 648	-31.0 to 751	-333 to 845

Independent t-tests: First Visit p=0.702, Final Visit p=0.500

6.9 GROSS MOTOR FUNCTION

An evaluation of gross motor function by the Gross Motor Function Measure (GMFM), Gross Motor Classification System (GMCS) and the Modified Ashworth Scale of Spasticity revealed that there were significant differences in the gross motor function of the children fed via G-tube compared to the children fed orally.

Table 6.23 GMFM, GMCS and Spasticity Scores by Feeding Group

Statistic	GMFM		GMCS		Ashworth Spasticity	
Gastrostomy?	G-tube	Oral	G-tube	Oral	G-tube	Oral
N	21	9	21	9	21	9
Mean (SD)	8.36 (12.4)	23.5 (27.2)	4.90 (0.30)	4.33 (1.00)	1.24 (1.55)	1.78 (1.56)
Median	2.75	23.2	5.00	5.00	0.00	2.00
Range	0.00 to 45.2	0.78 to 89.7	4.00 to 5.00	2.00 to 5.00	0.00 to 4.00	0.00 to 4.00

Independent t-tests: GMFM p=0.044, GMCS p=0.128, Spasticity p=0.390

6.10 DOUBLY LABELLED WATER ACCURACY

Percentage error (expressed as %TEE) and the space ratio (N_D/N_O) were used to assess the accuracy of the doubly labelled water method in this study. Two sources of error are involved in estimating TEE. Internal precision involves calculation error (regression lines of slopes and intercepts.) and usually has an error of approximately 5-8%. External precision pertains to the probability of attaining the same value if the measurement is repeated with the same subject. The values provided here as "TEE" error take into account both these potential sources of error. The data presented in this section is from both the first and final visit, for all children who participated. Tables 6.24a to d reveal that there were no significant differences in either % error or space ratio between feeding groups or visits. As discussed in Section 6.12, the values obtained for both % error and space ratio are acceptable by DLW standards.

Table 6.24a Percentage Error (% TEE)- First Visit

Statistic	Whole Group	G-tube	Oral
N	38	21	17
Mean (SD)	8.13 (2.73)	8.01 (2.72)	8.29 (2.82)
Median	7.20	7.20	7.20
Range	4.30 to 13.9	4.30 to 13.9	5.20 to12.9

Independent t-test: p=0.759

Table 6.24b Percentage Error (% TEE)- Final Visit

Statistic	Whole Group	G-tube	Oral
N	25	17	8
Mean (SD)	8.92 (5.44)	8.98 (5.22)	8.80 (6.25)
Median	7.40	7.30	7.75
Range	2.33 to 23.7	2.33 to 23.7	2.33 to 23.3

Independent t-test: p=0.942

Paired t-test: First to Final Visit- Whole group p=0.765

Table 6.24c Space Ratio (N_D/N_O)- First Visit

Statistic	Whole Group	G-tube	Oral
N	38	21	17
Mean (SD)	1.03 (0.002)	1.03 (0.002)	1.03 (0.003)
Median	1.03	1.03	1.03
Range	0.99 to 1.12	0.99 to 1.12	1.00 to 1.12

Independent t-test: p=0.432

Table 6.24c Space Ratio (N_D/N_O)- Final Visit

Statistic	Whole Group	G-tube	Oral
N	25	17	8
Mean (SD)	1.04 (0.005)	1.04 (0.001)	1.04 (0.005)
Median	1.04	1.04	1.04
Range	1.00 to 1.15	1.02 to 1.07	1.00 to 1.15

Independent t-test: p=0.695

Paired t-test: First to Final Visit- Whole group p=0.310

6.11 PROBLEMS ENCOUNTERED

As the protocol was the same, the problems described in Section 5.8 also apply here.

Following the children for one year proved difficult in some cases. Many carers were unwilling to return for follow-up appointments due to busy schedules or other personal reasons. Due to the nature of the measurements of this study, home visits were not a viable option. In a few extreme situations home visits were conducted however this meant that RMR measurements could not be obtained.

A second problem involving the long-term nature of this study was the unwillingness of carers or community dieticians to take or implement dietary suggestions based on the data collection. For example, when a child presented with a large proportion of body fat and was expending significantly less energy than he/she was receiving, it was suggested that his/her energy intake be lowered. This resulted in an inability to see if dietary modification could in fact have an impact upon the child's body composition.

A related problem was the delay sometimes encountered in receiving and processing the first visit's results. In some cases, interpreted results were not available until several months after the child's visit. Unfortunately, a delay in

implementing any changes meant that the full effect of these changes might not have been recognized in the remaining study time.

6.12 DISCUSSION

Section Five presented the results of body composition and energy expenditure investigations for group of disabled children. This section focused on the changes seen in body composition and energy metabolism over twelve months for a sub-group of children who were followed over this time. As mentioned in the Methods section, dietary advice was provided based on the data received from the initial investigations. In some cases this resulted in the suggestion to reduce G-tube feeds and in others the addition of oral supplements to the diet. In four children, G-tube placement was recommended. The children who had a G-tube placed over the course of the study were considered orally fed at the first visit and G-tube fed at the final visit for statistical purposes.

Growth from Anthropometry

Anthropometric measurements revealed that there were no significant changes in weight, height or BMI Z scores over the course of the study (recall Tables 6.1a to d). These observations were supported statistically by insignificant paired t tests. Similar to the results of Section 5, the G-tube fed children had higher height, weight and BMI Z scores compared with children who were fed orally, but weight was the only measure that showed a significant statistical difference between the groups. This trend of G-tube fed children being closer to reference standards for age and sex was maintained over the course of the year. At the final visit, there were no significant differences detected between feeding groups for any of the Z score calculations.

As demonstrated by the lack of significant change in Z scores from first to final visit with paired t-tests, calculation of the changes in weight, height and BMI Z scores reveal that deviation from normal changed little over the course of the year and that feeding method had no impact upon this finding. This suggests that the small sizes seen in disabled children, especially short stature, are not greatly influenced by moderate nutritional intervention.

In terms of weight, these two results seem contradictory. Individuals showed no significant change in weight Z score over the year, but the difference in weight Z scores between feeding groups seen at the first visit disappeared by the final visit. These findings may have been influenced by the relatively small numbers of children in the study and by the four children who were considered orally fed at the first visit and G-tube fed at the final visit. However, actual changes in weight might have been the cause of the change, as the children did receive nutritional advice over the year and as shown in Section 6.6, changes in body composition did occur.

Body Composition from Anthropometry

At the first visit, anthropometric determination of % BF revealed that G-tube fed children had significantly more body fat than those who were fed orally. By the final visit, the significance of this difference had disappeared but the G-tube fed children still displayed higher values. It appears from the measured values that this change in significant difference is due to a gaining of body fat by the orally

fed group, but a paired t test indicated no significant change in the % BF of the group.

Triceps skinfolds measurements and Triceps skinfold Z scores were also used to measure subcutaneous body fat stores. The difference in values between the G-tube and orally fed groups was significant for both triceps skinfold measurements and Z scores to reveal that the G-tube fed children had much higher subcutaneous fat stores. Unlike the % BF measurements, these significant differences were maintained over the course of the year. However, the difference did become less significant, as indicated by the slightly larger p value.

As the differences detected between feeding groups were maintained over the course of the study, paired t-tests (of triceps skinfold measurements and triceps skinfold Z scores) revealed no significant changes in the subcutaneous fat stores of individuals.

The results of this section suggest an explanation for the changes seen in body weight Z scores. The differences in % BF between the G-tube and orally fed children, like the weight Z scores, were lost over the year long study. However, it appears that body fat specific to the upper arm area remained significantly higher in the G-tube fed children. It is possible that the close follow-up and nutritional advice given to the children over the course of the year contributed to the lack of significant difference measured at the end and reduced the incidence of over-feeding sometimes seen in G-tube fed disabled children.

Nutritional Intake

As expected, the total energy intake of the children in the study increased with age at the first visit. However, this trend was not seen at the final visit. The highest energy intakes were recorded for children 3-6 and 11-13 years. This change from the first visit may be due to small numbers or measurement error, but may also be attributable to the dietary advice these children received after their first visit.

When total energy intake was compared to the EAR for age and sex (Department of Health, 1991) intakes at both the first and final visit were significantly low. This supports the findings of both Section 4 and Section 5, as well as the work of many other research groups (Fried and Pencharz 1991; Reilly, Ralston et al. 1994).

The lack of significant changes in energy intake, macro and micronutrients indicates that any dietary changes suggested over the course of the study were relatively minor. It is also possible that suggested changes were not implemented (as was sometimes a problem- see 6.11) or that there was measurement error in dietary intake significant to hide any evidence of significant change in intake.

Resting Metabolic Rate

The changes observed in RMR over the course of the year are slightly confusing at first glance because they do not fit in with the traditional views of RMR and its relation to FFM. RMR increased significantly over the 12 months for the group

as a whole and for the G-tube fed children, but not for those who were fed orally. Changes in RMR/kg and RMR/kg FFM were not significant for any group.

The relationship between RMR and FFM, a strong one as shown by Figures 6.1a and b may be misleading in the interpretation of RMR data for disabled children. This is because the changes in energy metabolism and body composition over time (see Energy Balance below) reveal that positive changes in FFM actually have a negative relationship with RMR and that positive changes in FM have a positive relationship with RMR. The *abnormal proportions* of these two body constituents in disabled children may confound the results of RMR studies.

In support of this theory, RMR adjusted for FFM increased over the duration of the study, almost significantly for the whole group and most significantly for the children who were G-tube fed. This indicates an increase in RMR independent of the effect of FFM. It was demonstrated in Section 6.6 that the children tended to gain FM over the course of the study, and most importantly, the G-tube fed children gained FM and *lost* FFM. The orally fed children showed a pattern of weight gain that could be considered as "normal", just as one would normally expect RMR to be affected by FFM gains.

Since the Schofield prediction equations are based on weight and sex, not age, it is interesting that the overestimation is so significant. Two factors most likely contribute to this fact. First, the Schofield equations aim to predict a true BMR and the measurements taken in this study were mainly RMR. Second, as was discussed above, disabled children have lower amounts of FFM for their given

weight than would be normally expected. As BMR/RMR correlates most positively with FFM (even in this group of children as shown above) the altered proportion of FFM would have an impact upon the energy expended per kg of body weight.

Body Composition from Doubly Labelled Water

The results from this section demonstrate clear differences in the body composition of children fed via G-tube or orally. As a whole, the children increased their FM (as measured by FMI) and decreased their FFM (FFMI). Despite the lack of significance of these findings, the trends reveal a tendency to gain fat as opposed to both fat and fat free mass, which is considered normal growth. Even with the moderate nutritional intervention supplied to these children, this unbalanced growth was observed.

When changes in FMI and FFMI were evaluated by feeding group it appeared that the orally fed children gained in both FMI and FFMI whereas the G-tube fed children gained FMI but lost FFMI. This suggests that the orally fed children grew more "normally" than those fed via G-tube. However, not only did the G-tube fed children gain fat, they *lost* FFM (as normalized for height).

Although these differences were not statistically significant, this trend helps explain the differences in body composition seen between these groups in this Section and in Section 5. The G-tube fed children have significantly more FM than reference children at both first and final visits, whereas the orally fed children do not differ significantly from normal (see Tables 6.17c, d and e). In

terms of FFM, the G-tube fed children are significantly lower than normal at both visits, but the orally fed children, although they do have a lower amount of FFM than normal at visit one, this difference is not significant by the final visit.

These changes suggest that the orally fed children have the potential to increase their FFM, whereas the G-tube fed children do not. A hypothesis to explain this difference is that the children who receive G-tubes have a higher level of disability and therefore lower activity levels. The data from Section 6.9 supports this hypothesis, as it was revealed that the G-tube fed children had significantly lower scores on the GMFM.

Total Energy Expenditure from Doubly Labelled Water

The changes in TEE seen over 12 months are likely related to the concurrent changes in body composition observed in these children. Recall that over the course of the year, the group as a whole increased their fat mass (measured as FMI) and decreased their FFM (FFMI). Also as a group, no significant changes in TEE or TEE/kg FFM were observed, but there was a significant decrease in TEE/kg. One possible explanation for this finding is that because children gained a larger proportion of fat tissue to lean tissue for every given kg (and recall that FFM is more metabolically active) the energy expenditure per kg of total body weight decreased. This hypothesis is supported by the fact that when TEE/kg was examined by feeding group, the G-tube fed children showed a significant change but the orally fed children did not. Just as the G-tube fed children increased FM but lost FFM and the orally fed children gained both.

The increase in TEE adjusted for FFM may also be explained by changes in body composition. Since the value is adjusted for FFM, the changes in FFM observed are irrelevant. But just as both groups gained FM over the course of the year, both groups had increased in their TEE adjusted for FFM.

The significant values of these changes are slightly surprising given that no changes in TEE were found and that FM makes a very small contribution to metabolic activity. The possibility of measurement error and small numbers emphasizing findings must also be considered.

Energy Balance

Energy Balance was found to be positive at the first visit and remained so over the course of the study. The mean energy balance for the group as a whole appears to increase over the course of the year, but this value is not statistically significant.

Although an early hypothesis was that the G-tube fed children must maintain a higher EB in order to gain the fat stores observed, this study shows that the state of EB between the two groups is not significantly different. Also, it must be remembered that both groups gained FM. The difference in body composition resulted from the G-tube fed children gaining only FM and the orally fed children gaining both FM and FFM.

An "ideal state of energy balance" was the goal for the children in this study, although at the start, this value was unknown. Though an evaluation of energy balance of the children at the first visit, it was decided that a positive energy balance of +200kcal/24 hours would be the aim. As revealed by the mean energy balance at the final visit (191kcal/24 hours), this goal was almost met.

The major question that emerged from the study of energy balance of disabled children is why, if the energy balance is the same, do G-tube and orally fed children have such different states of body composition? As described in Section 5, the G-tube fed children in this study had a significantly lower GMFM score than those children who fed orally and so their activity level and gross motor function obviously play a large role in body composition changes over time.

Yearlong Trends

To explore the relationship between activity level, EB and body composition, a series of Pearson correlations were run. The changes in FMI, FFMI, % BF and adjusted TEE, RMR and PAL were compared and revealed the following:

Significant positive correlations exist between:

- FMI and RMR (PC=0.677, p=0.001)
- % BF and RMR (PC=0.705, p<0.001)
- TEE and PAL (PC=0.839, p<0.001)
- FFMI and PAL (PC=0.672, p=0.001)

Significant negative correlations exist between:

- PAL and RMR (PC=-0.708, p<0.001)
- FFMI and RMR (PC=-0.651, p=0.001)
- % BF and TEE (PC=-0.506, p=0.014)
- FMI and TEE (PC=-0.571, p=0.004)
- FMI and PAL (PC=-0.670, p=0.001)
- % BF and PAL (PC=-0.669, p=0.001)

In general, these correlations indicate that TEE is positively associated with FFM and physical activity and FM positively related to RMR. Activity levels and FFM have a negative relationship with RMR and TEE and physical activity have negative relationships with FM.

Doubly Labelled Water (Technique Accuracy)

The mean % error of TEE with DLW falls within an acceptable range, according to experts in the field. As detailed in Appendix A, sources of error in the DLW method include the many assumptions made about the subject's physiology. Although correction factors are applied, small errors will always persist. Many studies quote an error rate of 5% or less based on two error factors (y axis- timing or x axis- enrichment value) and this has been accepted as an achievable standard in DLW research. However, the programme used to calculate TEE in this study (designed by Dr. A Coward) took into consideration three sources of error, the two previously mentioned as well as background variability. Accounting for this additional source of error in TEE calculations means that the error % value was slightly higher than with other methods. However, personal communication with Dr. J Wells confirms that the error % seen in this study were within acceptable limits.

At the first visit the mean space ratio (N_D/N_O) value was 1.03, identical to the ratio accepted as the true biological ratio (Coward, Ritz et al. 1994; Racette, Schoeller et al. 1994). The mean space ratio for the final visit was 1.04. Coward recommends that the space ratio be used to screen for analytical problems, as if the obtained space ratio deviates below 1.015 or above 1.060 the data may be unreliable (Coward 1990).

Body composition does play an important role in the calculation of an individual's space ratio. Although few studies have been performed in children to evaluate

appropriate space ratio values, infant studies have shown that the space ratio values for young infants (who exhibit high rates of energy deposition and high body water content in comparison to adults) are lower than adult values (Wells, Ritz et al. 1998). However, the lack of validated paediatric space ratio data means that the accepted adult value of 1.034 must be used as a standard.

Conclusion

This study confirmed that G-tube fed children have more body fat and gain fat more readily than children who are orally fed.

- There were no significant changes in weight, height or BMI Z score over the course of the 12 month study for children in either feeding group
- The G-tube fed children had significantly higher % BF (from skinfold measurements) at the first visit than orally fed children, but the significance was lost over the year
- Tricep skinfold measurements and Tricep Z Scores were significantly higher in the G-tube fed children and remained so over the course of the study
- FFMI was significantly higher in the orally fed children at the first visit and this difference was maintained over the year
- FMI was significantly higher in the G-tube fed children at the first visit, but this difference was lost by 12 months
- TEE/kg decreased significantly over the course of the study for the G-tube fed children
- TEE adjusted for FFM increased significantly in 12 months for all the children

- GMFM revealed that the G-tube fed children were significantly more disabled than those who were fed orally

SECTION SEVEN: CARER PERCEPTIONS AND QUALITY OF LIFE

Aim of Section Seven

The goal of this section was to evaluate the Quality of Life of the carers of the children who participated in the Gastrostomy Study before and after the intervention of gastrostomy-tube placement.

Hypothesis One: The Quality of Life of the carers of the children in the Gastrostomy Study will increase because the stress associated with trying to feed their disabled children will decrease.

Abbreviations used in Section Seven

G-tube	Gastrostomy tube
OHLS	Oxford Healthy Life Survey
QoL	Quality of Life
SF-36	Short Form 36

Results Outline

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RESULTS

7.1 PARTICIPANT DETAILS

7.1.1 General Information

General information about the child's family was obtained when possible at the Baseline visit. The ethnic origin of participating families was available on 52 of the 57. The majority of families were Caucasian (84.6%). The remaining ethnicities were comprised of Asian (5.8%), African (1.9%), Chinese (1.9%), and of mixed background (5.8%).

The median age of the fathers involved was 34 years (range 22-55) and the mothers 30.5 (range 18-61). The median mother's age at the time of the child's birth was 26 years (range 14-47).

Housing information was obtained for 48/57 participating families. 39 lived in a house (81.3%), 4 (8.3%) in a bungalow, 4 (8.3%) in a flat, and 1 (2.1%) in a maisonette. Only 15 of the children's homes (31.9%) were adapted for disability.

7.1.2 Primary Caregivers

Families reported that in 52/57 (91.2%) of cases the mother of the child did all the feeding and primarily in the home.

7.1.3 Survey Respondents

Although it was not specified who should fill out the questionnaire for this study, in 86% of cases (43/54) it was the mother who provided the requested information. In 8% of cases (4/54) the father completed the QoL survey, and in 4% (2/54) the child's grandmother.

7.2 CARER PERCEPTIONS OF THE CHILD

Carers were keen to share their perspectives on their children's health, growth and feeding problems.

7.2.1 Health

Reports on the children's general health status, as measured by the number of chest infections requiring hospitalization or antibiotics was discussed in Section 4.4.

One of the greatest sources of stress reported by carers was worry over their child's nutritional state. Six months after G-tube placement 63.8% of carers (30/47) said that they were no longer worried about the nutritional state of their child. This reduction in worry was statistically significant with a p value of <0.001. As time passed and carers became more comfortable with G-tube feeding, worry decreased even further. Twelve months after G-tube placement 80.4% (37/46) of carers reported that they were not worried about the nutritional state of their child ($p<0.001$).

7.2.2 Growth

Measured growth was reported in Section 4.2, but it became evident over the course of the study that just as important to families and caregivers as the actual measurement of growth was the perception that their children were growing. Carers were asked at Baseline and at 6 and 12 Months if they felt their child had grown in length, gained weight or required larger clothes/shoes in the 6 months previous to the visit. The results are illustrated in Table 7.1.

Table 7.1 Percentage of Carers who Reported Weight Gain, Length Increase and the Requirement of New Clothes for their Disabled Child at Baseline and 6 and 12 Months after G-tube Placement

Percentage of Carers who Reported:		Baseline	6 Months	12 Months
WEIGHT	Gained	50.0	89.4	84.1
	Lost	25.0	2.1	6.8
	Stayed the Same	25.0	8.5	9.1
LENGTH	Grown	50.0	80.9	88.4
	Stayed the Same	50.0	19.1	11.6
NEW CLOTHES	Yes	73.1	95.7	100.0
	No	26.9	4.3	0.0

Table 7.1 clearly shows that carers saw their child growing after G-tube placement. Caregivers were also asked to reflect on whether or not they felt their child was "too small", "too thin" or "just right." By 12 Months, due to the number of carers who reported it, it was necessary to add the category of "too big." Note that carers were encouraged to interpret these descriptions for themselves. Some commented that their child was too small or thin for the *child's age*, yet others said their child was "just right" for *him/her*. Results are presented in Table 7.2.

Table 7.2 Percentage of Carers who Reported that their Disabled Child was "Too Small, Too Thin, Just Right or Too Big" at Baseline and 6 and 12 Months after G-tube Placement

Percentage of Carers who Reported Their Child:	Baseline	6 Months	12 Months
Too small	47.4	36.2	32.6
Too Thin	49.1	29.8	17.4
Just Right	35.5	59.6	67.4
Too Big	---	---	13.0

7.2.3 Feeding Problems

7.2.3.1 Overview of Feeding Problems

The feeding problems encountered in the children who participated in the Gastrostomy Study were severe (Recall Section 4.1). 53/57 (93%) of families had had previous help for feeding difficulties before being evaluated for G-tube placement and enrolled into the study. Of the 53, 40 reported being helped in the last six months only, with 13 reporting feeding help more than six months previous.

Previous help came from a variety of sources, as shown in table 7.3.

Table 7.3 Sources of Previous Help for Feeding Problems and the Proportion of Families Who had Sought Help from These Sources

Help From:	Proportion of Families Who Had Help:	Percentage of Families Who Had Help:
Paediatrician	37/57	64.9
Dietician	47/57	82.5
Physiotherapist	12/57	21.1
Speech and Language Therapist	47/57	82.5
Community Nurse	9/57	15.8
Occupational therapist	8/57	14
General Practitioner	5/57	8.8

Carers categorized the children's appetite and interest in eating/drinking as good (11/57- 19.3%), poor (20/57- 35.1%), or variable (26/57- 45.6%). They were then asked whether or not they believed their child's feeding problems were behavioural. The majority said no (49.1), but 7 (12.7%) said yes, and 21 (38.2%) sometimes. Three families (5.5%) had had psychological assessment and input for food behaviour problems.

The types of problematic feeding behaviours encountered are listed in Table 7.4, along with the proportion of carers who reported the behaviour as being a problem for them and their child.

Table 7.4 Problematic Feeding Behaviours Encountered and the Proportion of Families who Reported the Behaviour

Problem Behaviour:	Proportion of Families Who Reported the Behaviour:	Percentage of Families Who Reported the Behaviour:
Turns head away	22/55	40
Clamps mouth	17/55	30.9
Vomits	7/55	12.7
Tantrums during meals	11/55	20
Spits during feeding	10/55	18.2
Ruminates during meals	2/55	3.6
Food refusal	24/55	43.6
Antisocial eating habits	6/55	10.9
Easily distracted whilst feeding	13/55	23.6
Only allows feeding by one person	10/55	18.2

In addition, a number of clinically problematic feeding problems were reported by carers and rated for frequency of occurrence. Table 7.5 displays these problems.

Table 7.5 Clinically Problematic Feeding Problems and the Proportion of Families Who Reported them

Problem:	Proportion of Families Who Reported the Problem:	Percentage of Families Who Reported the Problem:
Always/Often Coughs while eating	27/57	47.4
Always/Often Coughs while drinking	27/57	47.4
Always/Often Chokes/Gags while eating	23/57	40.4
Always/Often Chokes/Gags while drinking	25/57	43.9
Always/Often Drools	31/57	54.4
Always/Often Ruminates	5/57	8.8
Always/Often Vomits during meals	9/57	15.8
Occasional Haematemsis	3/57	5.3

Tongue thrust was a barrier to assisted feeding in 25/54 (46.3%) of the children in the Gastrostomy Study. Only 3.7% of the children had severe tongue thrust, the majority having either mild (20.4%) or moderate (22.2) problems.

Tonic jaw biting was also a problem, but was not as common as tongue thrust. 35.2% of the children (19/54) exhibited jaw tonic biting with 16.7% displaying mild, 11.1% moderate and 7.4% severe symptoms.

Almost half the children (25/54 - 46.3%) were classified as having good lip closure, 20 (37%) with moderate lip closure and 9 (16.7%) with poor lip closure.

In terms of food preparation and modification, of the children who were only fed orally at Baseline, 13/47 (27.7%) required mashed food and 22/47 (46.8%) pureed. Only 2 of the 57 children could feed themselves.

7.2.3.2 Feeding Times

The length of time required for feeding was a major concern amongst carers. At Baseline, carers reported spending an average of 76 minutes to feed their child a main meal, 21 minutes to give a drink and 14 minutes for a snack. The mean total length of time reported feeding per day was 186 minutes and ranged from 50-1440 minutes. In addition, carers spent an average of 40 minutes preparing special food and drink for their child and 44 minutes cleaning up after feeding. At 6 Months after G-tube placement the mean number of feeding minutes per day had been reduced to 97 (p=0.012). At 12 Months, the mean time spent feeding per day was 72 minutes, a significant decrease from before G-tube placement (p=0.001) and even from 6 Months prior (p=0.034).

7.2.3.3 Drug Administration

Only 5.5% (3/55) of carers said that administering necessary medications to their child was easy at Baseline. 25/55 (45.5%) reported easy administration, but only due to the presence of a naso-gastric feeding tube. Of those fed only orally, 30% (9/30) reported drug administration as "variable", 40% (12/30) as "difficult", and 20% (6/30) as "very difficult- never gets full dose."

At 6 Months 66.0% of caregivers reported improved ease of drug administration. 10.6% said that drug administration was not a previous problem and 23.4% had had a naso-gastric tube to facilitate drug administration prior to gastrostomy placement.

By 12 Months 84.8% reported an improvement in ease of drug administration, while 15.2% said that administration had not been a problem previously.

7.3 CARER QUALITY OF LIFE

7.3.1 Short Form 36

Quality of Life (QoL) of the carers of the disabled children who took part in the Gastrostomy Study was evaluated with the Short Form 36 (SF-36) questionnaire, a standardized and validated tool for measuring QoL. Recall from the Methods Section that the SF-36 has eight domains: Physical Functioning, the Role Limitations due to Physical Problems, Role Limitations due to Emotional Problems, Social Functioning, Mental Health, Energy/Vitality, Bodily Pain and General Health Perception. The maximum score for each domain is 100. There is also a category in which change in health is evaluated. The mean score of the carers for each of the eight domains of the SF-36 are shown in Table 7.6a. Table 7.6b displays the p values from paired t-tests that compared each carer's score at 6 and 12 Months to their previous scores. These scores reveal that by 6 Months after G-tube placement significant improvements were noted in the mental health and change in health of carers. By 12 Months, significant improvements had occurred in social functioning, mental health, energy/vitality, general health perception and change in health.

Table 7.6a The Mean (and Standard Deviation) Scores of the SF-36 in Carers of Children with Severe Disabilities at Baseline and 6 and 12 Months after G-tube Placement

Domains of the SF-36	Baseline	6 Months	12 Months
(N)	49	36	33
Physical Functioning	83.5 (19.5)	87.4 (15.6)	86.3 (16.8)
Role of Physical Functioning	73.4 (30.1)	81.3 (23.3)	80.6 (24.9)
Role of Emotional Functioning	68.1(31.1)	75.7 (25.1)	73.5 (27.3)
Social Functioning	63.5 (33.9)	71.1 (30.6)	76.6 (25.0)
Mental Health	58.5 (21.1)	65.9 (17.3)	68.4 (16.0)
Energy/Vitality	41.6 (23.6)	46.0 (21.6)	51.6 (22.5)
Pain	78.3 (21.4)	81.6 (18.5)	74.4 (23.3)
General Health Perception	68.0 (20.2)	67.4 (20.7)	72.9 (18.3)
Change in Health	49.0(19.5)	61.8 (18.7)	60.1 (18.1)

Table 7.6b P Values for Paired t-tests to compare Carers' Scores at Baseline to 6 and 12 Months after G-tube Placement

Domains of the SF-36	Baseline- 6 Months	Baseline - 12 Months
Physical Functioning	0.125	0.349
Limit. of Physical Functioning	0.412	0.527
Limit. of Emotional Functioning	0.080	0.459
Social Functioning	0.161	0.028
Mental Health	0.037	0.015
Energy/Vitality	0.141	0.012
Pain	0.343	0.235
General Health Perception	0.764	0.045
Change in Health	0.003	0.029

In another measure of the SF-36 results, carers' scores were compared to scores from a reference population- the results of the Oxford Healthy Life Survey (OHLS). Paired t-tests were used to compare the carers' scores to the reference standards at each visit and the results are shown in table 7.7. The comparison reveals that at Baseline there were significant differences in scores between the carers and the normative population in the domains of role limitations due to physical functioning, role limitations due to emotional functioning, social functioning, mental health and energy vitality, with the carers scores being lower

in each. By 6 Months however, the differences in scores were less significant, and only evident for role limitations due to emotional functioning, social functioning, mental health and energy/vitality. At 12 Months, the only significant difference in score that remained was for role limitations due to emotional functioning.

Table 7.7 The P Values from Paired t-tests Between Carers Scores and the Oxford Healthy Life Survey Reference Scores at Baseline and at 6 and 12 Months after G-tube Placement

Domains of the SF-36	Baseline	6 Months	12 Months
(N)	49	36	33
Physical Functioning	0.110	0.833	0.516
Limit. of Physical Functioning	0.003	0.148	0.111
Limit. of Emotional Functioning	<0.001	0.024	0.007
Social Functioning	<0.001	0.030	0.132
Mental Health	<0.001	0.043	0.170
Energy/Vitality	<0.001	0.002	0.076
Pain	0.857	0.371	0.238

7.3.2 Cerebral Palsy Specific Questionnaire

As the Cerebral Palsy Specific Questionnaire used in this programme of research was designed specifically for this study, there were no normative scores on which to base comparisons. It was hoped that the scores would increase over the course of the study, as this would have indicated that worry over feeding problems had lessened. The total numerical scores for carers at each visit are presented in table 7.8. The scores did increase with each visit, and this increase was most dramatic in the first six months. Paired t-tests of individual carers scores indicated that there was a significant improvement in score from Baseline to 6 Months ($p=0.002$) and from Baseline to 12 Months ($p=0.002$). The change in score between 6 and 12 Months was not significant, $p=0.967$.

Table 7.8 Total Scores for the Cerebral Palsy Specific Questionnaire of Carers at Baseline and 6 and 12 Months after G-tube Placement

Statistic	Baseline	6 Months	12 Months
N	49	35	38
Mean (SD)	60.02 (11.1)	64.7 (13.2)	65.5 (14.3)
Median	58.0	65.0	65.5
Range	42.0 to 90.0	42.0 to 88.0	41.0 to 96.0

7.3.3 Carer Comment Forms

The comment sheets given to carers at 6 and 12 Month visits contained four brief questions. Carers were asked to write freely in response to:

1. What are the best things about/ advantages of your child now having a gastrostomy? What positive things happened over the past 6 months?
2. What are the worst things about/ disadvantages of your child now having a gastrostomy? What negative things have happened over the past 6 months?
3. If you have more spare time since your child had a gastrostomy fitted, what things are you now able to do that you couldn't before?
4. If you have less time, why do you think this is?

6 Month Responses

Twenty-eight carers returned the comment forms. The three most frequent advantages mentioned were the child gaining weight, the child being much happier in him/herself, and the child being healthier in general (which included comments stating reduced epileptic seizures and hospital visits.) Also mentioned by numerous carers were the benefits of decreased stress within the family, not having to deal with a nasogastric tube, the child seeming more alert/progressing towards developmental milestones and having more time for other activities.

The majority of caregivers stated "nothing" in the space allotted to disadvantages. Problems with the site or gastrostomy were the most common minor complaint, followed by wind/digestive disruption.

The two most frequently mentioned activities undertaken in the additional time found in carers' days were "going out more" (with their child) and "housework". Playing with the child and spending time with other children/family were also noted.

12 Month Responses

Twenty-four comment forms were returned after the third visit. In terms of advantages, the most frequently mentioned benefit after 12 months of G-tube feeding was the child being healthier. Weight gain and improved administration of medications followed. Also mentioned were improved nutrition, "the child seems happier" and no nasogastric tube.

As at 6 Months, the majority of carers reported that there were "no disadvantages" to the G-tube. Problems with the site and tube were mentioned by some carers, as were social unease (feeding while out or by others) and the high care required of maintaining and using the G-tube.

An overwhelming majority of carers reported using the time freed up from not having to feed their child orally to play with him/her. Spending time with other children, housework and going out more were also mentioned.

At both 6 and 12 months, most carers did not share their thoughts about why they may have less time, if that was the case. The only time consuming aspect of G-tube feeding mentioned was the care and preparation of feeds, and ensuring that pump feeds were set up correctly.

7.4 PROBLEMS ENCOUNTERED

There were very few problems encountered when collecting the data for this section. If questionnaires were not returned, follow-up phone calls were made to ask carers in order to request that they be completed.

One problem that was encountered several times was the misunderstanding by carers that they were to complete the QoL questionnaire on behalf of their child. It was always evident upon entering data when this had happened, and carers were provided with another questionnaire and asked to redo it, keeping in mind that the questions were about themselves.

7.5 **DISCUSSION**

This was perhaps the most important section of this thesis. The previous sections have demonstrated that G-tube feeding can improve the growth and the general health of disabled children but that these physical changes are accompanied by an increase in body fat for which the implications are not known.

The fact that G-tube placement *also* significantly improves the QoL of the primary caregivers of disabled children, reduces the length of time spent feeding the disabled child, and decreases the stress and worry surrounding these children's health and nutritional status is of utmost importance in families dealing with chronically ill children. The stresses experienced by carers, especially mothers, of disabled children have been well documented and the intervention of G-tube placement has itself been described as a stressful event for families (Lambrenos, Weindling et al. 1996; Chaplen 1997; Thorne, Radford et al. 1997; Thorne, Radford et al. 1997; Adams, Gordon et al. 1999; Manual, Naughton et al. 2003). Although medical interventions should only ever be done in the best interests of the patient, this section has demonstrated that G-tube placement in disabled children has far-reaching benefits.

SECTION EIGHT: OVERALL DISCUSSION

8.1 GASTROSTOMY FEEDING IN DISABLED CHILDREN

The Oxford Gastrostomy Study was the first longitudinal study of G-tube placement in disabled children and the first of its kind to investigate so many variables related to health and well-being.

It revealed the many positive aspects of this form of enteral feeding mentioned by other research groups including improved weight gain and general health (Rempel, Colwell et al. 1988; SugarmanIsaacs, Georgeson et al. 1994; Sugarman-Isaacs, Georgeson et al. 1994; Corwin, Sugarman-Isaacs et al. 1996; Brant, Stanich et al. 1999).

The Gastrostomy Study also supported earlier suggestions that G-tube feeding increases fat stores in disabled children with findings of increased skinfold measures and percentage body fat after G-tube placement (Amundson, Sherbondy et al. 1994; Sugarman-Isaacs, Georgeson et al. 1994). The Energy Balance Study provided additional support for this statement by revealing that when the body composition of orally and G-tube fed children were compared using anthropometry and other measures of fat mass the G-tube fed children had much higher levels of fat.

In addition, the study confirmed that serious complications associated with G-tube feeding were very rare.

8.2 ENERGY BALANCE

As mentioned in the introduction, measuring energy balance directly (energy in vs energy out) has never been described in a group of disabled children, nor have the differences in energy balance between groups of disabled children (fed orally or by G-tube) been looked at.

Three groups have conducted research in the area of body composition and energy expenditure in disabled children, and the next section will review their findings and compare them to the results of this programme of study.

In a group of adolescents with CP, Bandini et al. reported low PAL and hypothesized that both RMR and activity levels contributed to the low values seen (Bandini, Schoeller et al. 1991). The data presented in this thesis supports these findings, as measured RMR, TEE and PAL were found to be low in all children who took part in the study. Bandini's findings of short stature and light weight for age were also reproduced, as well as reports of high % BF, yet low FFM compared to reference. As this study did, they also found that % BF from skinfold measurements correlated well with % BF from the dilution method. In contrast, Bandini et al. found no correlation between FFM and RMR, whereas figures 6.1a and b revealed that a significant relationship was found in this study.

In 1995, Bandini et al. calculated energy balance in a group of children with severe CNS impairment by measuring changes in energy stores with changes in weight (assumed to be FM in older children and FM and FFM in younger children still growing). They recommended that this technique be used to make alterations in the diet of individuals desiring weight loss, gain, or stability, but pointed out that the difficulty with this technique was knowing where to start in terms of caloric recommendations (Bandini, Puelzl-Quinn et al. 1995). The major benefit of the technique used in our study was that energy needs could be determined quickly and suggested changes could be made immediately, not only after months of careful body fat stores evaluation. As stated by Bandini, however, the problem remains of having no appropriate standards to base energy intake advice for these children. Not one single variable, but many showed significant positive correlation to TEE in this study. It was demonstrated that individual attention and follow-up can make a positive impact upon body composition, but the data did not suggest the possibility of generalized nutritional standards for disabled children.

Azcue et al. demonstrated low RMR in a group of G tube fed children with SQCP in a 1996 study and found that the best indicator of RMR in their group was ICW (as determined by NaBr dilution) (Azcue, Zello et al. 1996). As already mentioned, the EBS study also showed low RMR in disabled children, but as it did not measure ICW it was not possible to correlate it to RMR. Significant correlations were found between RMR and age, weight, height, FM and FFM. The main hypothesis made by Azcue was that the low RMR measurements were a result of CNS damage. Support for the importance of neurological function in

energy balance has been demonstrated by studies such as the 2003 study by Lustig et al. that revealed the high prevalence of obesity in children surviving brain tumours (Lustig, Post et al. 2003). All the children who participated in the EBS study had severe CNS damage and this may have been a contributing factor to their low RMR measurements. However, almost all the study children were also immobile. This lack of mobility, and its obvious impact on body composition also contributed greatly to the low RMRs seen.

Also in 1996, Stallings et al. investigated BC and EE in a group of orally fed disabled children. They found that the children with lower triceps skinfolds (the "poorly nourished" children) had lower PAL scores than those children that were considered "better nourished". EBS data also revealed a significant correlation between PAL, PAL adjusted for FFM and triceps Z score. However, the BC data indicates that the classification of their subjects as "poorly" or "better" nourished may not have been accurate. Classification was made based on skinfold percentile scores; children with skinfold measurements >25 centile were classified as "better nourished" and those with measurements <25 centile "poorly nourished". The children in the EBS showed significantly negative triceps Z scores (the chosen method of comparison to normal) yet when FM itself was compared to reference standards, there was no significant difference. Therefore, were the children in fact "poorly" nourished? Energy Balance measurements (from the EBS) revealed that the majority of disabled children receive the nutrients they require and that when weight is gained, it is almost entirely made up of FM. Stallings concluded that the growth failure and low RMR measurements exhibited by this group of disabled children were attributable to

low energy intake. Again, the direct EB measurements of the EBS contradict this statement.

The hypothesis of low energy intake contributing to the RMR and TEE seen in disabled children is one that makes theoretical sense given the results of human starvation experiments and studies of humans with chronic undernutrition or anorexia nervosa. In these studies, participants routinely have low RMR and "metabolic economy" is the explanation given (Grande, Anderson et al. 1958; Casper, Schoeller et al. 1991; Soares and Shetty 1991). In addition, evidence of fat gain accompanying refeeding has been found in these groups (Bjorntortp and Yang 1982; Dulloo and Girardier 1990; Dulloo and Jacquet 1998). Unfortunately, the RMR measurements taken during the EBS do not seem to fit this theory. Although there was a definite tendency to gain fat mass after the initiation of G-tube feeding no significant changes in RMR were observed between the children who were G-tube fed and those who were orally fed. However, it is possible that significant changes in RMR were not detected due to the relatively small study numbers or the difficulties that were encountered with taking RMR measurements. It is also possible that low RMR in disabled children is adaptive in nature, as it has also been found that healthy children with constitutional leanness also have low RMRs (Tounian, Dumas et al. 2003).

Stallings also evaluated TEE as part of her 1996 study. Comparing TEE measurements to dietary intake records, it was concluded that the records overestimated intake by 45-55%, as intake and expenditure for the control group showed a ratio of 0.98. Black et al. proposed using DLW to validate the energy

intake of individuals in EB because energy intake must equal energy expended in this population. However, this method is only applicable to individuals who are maintaining a steady weight and are truly in EB (Black, Prentice et al. 1993). Although there are always errors involved in dietary intake studies, Stallings use of this method indicates that EB was assumed in this group of children, a fact that had not yet been confirmed.

Finally, Stallings also reported low RMR in the disabled children in the study as did Bandini, Azcue and was confirmed in this study. They found that the severity of oral-motor problems were associated with RMR. Although oral-motor dysfunction was not measured in the EBS, earlier work from Oxford found a correlation between oral-motor dysfunction and over-all disability severity (Sullivan, Lambert et al. 2000). In addition, mildly significant relationships between RMR and the GMFM (PC=0.415, p=0.015) and the GMCS (PC=-0.342, p=0.048) were reported in this study. Adjusted RMR showed much more significant correlations for both GMFM (PC=0.559, p=0.001) and GMC (PC=-0.517, p=0.002).

QUALITY OF LIFE

As is increasingly being recognized in medical research, QoL is a critical element of health. The inability to measure QoL in children with severe disabilities poses great difficulties in the evaluation of QoL of this group, but the results of the measures of QoL in the carers of the GS participants confirmed the appropriateness of G-tube feeding in this group of children. GS data revealed that the stresses associated with caring for a disabled child decreased and that QoL increased significantly after G-tube placement. Comments revealed that these changes had dramatic positive effects on family dynamics, changes that can only be viewed as positive for the child his/herself.

FUTURE RESEARCH

This programme of study has shown that the intervention of G-tube feeding in disabled children has positive benefits, both for the child and for the family. In addition, as G-tube feeding may lead to increased fat mass, continuous follow-up and dietary adjustments are required to optimize body composition.

The possible health effects of the changes seen in body composition after G-tube feeding is initiated are an area that requires further study. Although the risks of obesity most likely differ in disabled children than those normally discussed, consequences must be examined. Practical problems in caring for large children and respiratory problems due to excess weight have already been cited in disabled children (Bax 1993).

Further study into the body composition of disabled children would be informative. Abnormal fat deposition in the form of reduced triceps skinfold measures without the reduction of subscapular fat was reported in a group of disabled children by Spender et al. in 1988 (Spender, Cronk et al. 1988). Use of MRI fat scanning to establish where body fat is stored within disabled children is a potential future direction in research on disabled children. This method was explored during the course of this programme of study but unfortunately was not feasible within the scope of the project.

A closer investigation into the FFM of disabled children is also warranted. Although it is known that FFM is reduced in these children, most likely due to a multitude of factors including restricted mobility, the EBS revealed that this group of children does not gain FFM easily, and that FFMI actually decreases over time.

An area that deserves much future study, and one that is currently being pursued by the Oxford Feeding Group is an investigation into the role of micronutrients in the health of disabled children. It has been concluded that the energy needs of this group's are significantly reduced from reference standards, but no studies have been able to determine this group's specific needs in terms of micronutrients.

SECTION NINE: CONCLUSION

The Use of Gastrostomy Tubes in Disabled Children

This programme of research has contributed significantly to the understanding of the effects of G-tube feeding in children with severe neurological disabilities.

We hypothesized the positive effects of weight gain and improved general health, both of which were clearly demonstrated. Improved nutritional status (as measured by fat stores) was also predicted and observed. Although moderate improvements in nutritional intake were detected, increases in macronutrient intake did not occur.

Energy Balance and Body Composition in Disabled Children

The hypotheses of Sections Five and Six were that fat deposition and energy metabolism would be higher in those children who were fed by G-tube.

The study results indicated that the majority of children with severe neurological disabilities are in a state of positive energy balance regardless of method of feeding. Lowered RMR, TEE and PAL reduce energy requirements so that energy intakes significantly below reference standards, in most cases, are enough to provide the energy required.

FM was higher than expected in both G-tube and orally fed children, but differences in the FFM of this group were significant. The G-tube fed children

had a tendency to gain FM but not FFM. The disability levels were higher in these children, and so TEE and energy intakes were often lower.

Orally fed children also had a tendency to gain FM, but showed the ability to gain FFM as well. The disability and activity levels of this group were usually higher, resulting in higher energy needs.

Practical/Clinical Messages:

This project was designed in order that its results would provide information useful to clinicians working with disabled children. Although the most important message for clinicians is that each disabled child is individual and required careful long-term monitoring, these general guidelines can be stated:

It is more likely that G-tube fed children will present with undernutrition; it more likely that over-nutrition will be seen. These children will be smaller and lighter than age specific standards, but since FFM is so low and almost impossible to increase in this disability group, weight gain will be primarily gains in body fat.

The disability level of orally fed children as a group is much wider in range than that of the G-tube fed children. Hence, energy needs and prescriptions will be very individualized. Some children may present with undernutrition due to feeding problems and moderate energy expenditures. Others may have extremely low energy expenditures and energy needs.

Quality of Life and Ethics

The final question in this programme of research involved the role of nutritional intervention (specifically G-tube feeding) in the Quality of Life of the carers of these disabled children. The QoL portion of the Gastrostomy Study clearly demonstrated how beneficial the use of G-tube feeding could be to the carers and families of disabled children.

There are many difficult questions encountered when dealing with the care of children with severe neurological disabilities. This study has revealed that the positive effects of G-tube feeding greatly outweigh any risks involved. This message should be provided to carers of disabled children in order to assist them with their difficult task of caring for a disabled child.

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SECTION ELEVEN: PUBLICATIONS AND PRESENTATIONS

PUBLICATIONS

Sullivan, P.B., A.G. Thomas, M. Eltumi, B. Lambert, A. Bachlet, A. Vernon-Roberts, E. McLean, E. Juszczak. (2002) "A 12-Month Prospective Study of Gastrostomy Feeding in Disabled Children"

- Archives of Disease in Childhood 86 (suppl 1): A22.
- Journal of Pediatric Gastroenterology and Nutrition 34(4): 480.
- Developmental Medicine and Child Neurology 44(10): 12-13.
- And will be published in the programme for the 57th Annual Meeting of the AACPDM (American Academy for Cerebral Palsy and Developmental Medicine), 10-13 September 2003, Montreal Canada.

Sullivan, P.B., A.G. Thomas, M. Eltumi, H. Grant, B. Lambert, E. McLean, A. Bachlet, E. Juszczak, C. Jenkinson. (2002) "Gastrostomy-tube Feeding Improves Quality of Life in Caregivers of Disabled Children"

- Archives of Disease in Childhood 86(suppl 1): A61.
- Journal of Pediatric Gastroenterology and Nutrition 34(4): 485.
- Developmental Medicine and Child Neurology 44(10): 34.
- And will be published in the programme for the 57th Annual Meeting of the AACPDM (American Academy for Cerebral Palsy and Developmental Medicine), 10-13 September 2003, Montreal Canada.

Vernon-Roberts, A., Bachlet, A.M.E., Lambert, B., McLean, E., Thomas, A.G., Eltumi, M., Juszczak, E., Sullivan, P.B., Grant, H. (2003) "Gastrostomy Tube Insertion Improves the Nutrition of Neurologically Impaired Children with Oro-Motor Dysfunction"

- Poster Presentation at: BAPS (British Association of Paediatrics Surgeons) 50th Annual International Congress, Estoril Portugal, 15-18 July 2003.

Vernon-Roberts, A., Bachlet, A.M.E., Lambert, B., McLean, E., Thomas, A.G., Eltumi, M., Juszczak, E., Jenkinson, C., Sullivan, P.B., Grant, H. (2003) "Effect of Gastrostomy Tube on the Quality of Life of Neurologically Handicapped Children and their Carers"

- Poster Presentation at: BAPS (British Association of Paediatrics Surgeons) 50th Annual International Congress, Estoril Portugal, 15-18 July 2003.

Bachlet, A., A. Vernon-Roberts, L. Stirling, J. Warner, J. Wells, E. Juszczak, P.B. Sullivan. (2002) "Feeding Children with disabilites- how much do they really need?"

- Developmental Medicine and Child Neurology 44(10): 13.

Vernon-Roberts, A., A. Bachlet, J. Warner, J. Wells, P.B. Sullivan. (2002) "Energy Balance and Body Composition in Children with Cerebral Palsy"

- Journal of Pediatric Gastroenterology and Nutrition 34(4): 478.

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AME Bachlet, A Vernon-Roberts, L Stirling, J Wells, J Warner, PB Sullivan. (2003) "Body Composition in Severely Disabled Children fed either Orally or via Gastrostomy"

- Archives of Disease in Childhood 88 (suppl 1): 71.
- Journal of Pediatric Gastroenterology and Nutrition (as part of the ESPGHAN Prague 2003 conference abstracts)
- And will be published in the programme for the 57th Annual Meeting of the AACPDM (American Academy for Cerebral Palsy and Developmental Medicine), 10-13 September 2003, Montreal Canada.

INVITED LECTURES/PRESENTATIONS

ESPGHAN (European Society for Paediatric Gastroenterology, Nutrition and Heptology)

36th Annual Conference in Prague, Czech Republic, 4-7 June, 2003

"Body Composition in Severely Disabled Children fed either Orally or via Gastrostomy"

** NOTE: A Young Investigator's Travel Award Grant was received for this Abstract

Nutricia Clinical Care Symposia

London, England, November 2002

Leeds, England, January 2003

Birmingham, England, February 2003

"Feeding Children with Severe Disabilities - Energy Balance and Body Composition"

European Academy of Childhood Disability

14th Annual Conference in Pisa, Italy, 24-26 October 2002

"Feeding Disabled Children; How much do they really need?"

"Gastrostomy-tube Feeding in Children with Severe Neurological Disabilities"

British Association of Paediatric Endoscopic Surgeons

Annual Meeting, Oxford, England, September 24, 2002

"Gastrostomy tube feeding improves the Quality of Life of Caregivers of Children with Severe Neurological Impairment"

** note: this talk was voted best presentation at the conference

Focus on Feeding Symposium

Central Remedial Clinic, Dublin, Ireland, May 8, 2002

"Energy Balance and Body Composition in Children with Severe Disabilities"

SECTION TWELVE: APPENDICES

APPENDIX A: PROBLEMATIC ASSUMPTIONS WITH THE DOUBLY LABELLED WATER METHOD

Source: The Doubly-Labelled Water Method for Measuring Energy Expenditure
Technical recommendations for use in humans
A consensus report by the IDECG Working Group
Editor: AM Prentice
International Atomic Energy Agency, Vienna, 1990

The problematic assumptions with the DLW method include:

1. Body Water Pool Size
2. Isotope Sequestration and Exchange
3. Fractionation
4. Isotopic Variations
5. Analytical Variation
6. Metabolic Fuel Source

Body Water Pool Size

The problem encountered with the theory of body water pool sizes in this method is that one is forced to utilise a single pool system to calculate total body water (TBW) when in fact the body is made up of multiple smaller pools. If there is rapid recycling of isotope between all the body pools, then there is little error in calculating the outwards flow of tracer since the measured rate will contain a level of isotope that is representative of the level in TBW. Unfortunately, if the level of recycling is smaller and slower, one may overestimate the rate of isotope loss, as some isotope will be transferred to alternate pools in the body and stay there (Prentice 1990).

The difficulties surrounding water turnover are that it is very individualized and greatly affected by many disease states. When water turnover is high, (i.e., water moves quickly through the body,) there is a lower ko/kd ratio, which results in a much greater potential for error in the final calculations. If there are no step-wise changes in water intake/CO_2 production, then increasing the number of data points can compensate for a decreased ko/kd ratio (Prentice 1990).

Isotope Sequestration and Exchange

Isotope exchange is the process by which the labelled isotopes administered "exchange" places with non-labelled atoms in body components other than H_2O or CO_2. The most common exchange observed is deuterium taking the place of labile hydrogen in body solids, resulting in a calculated dilution space greater than the actual body water pool. O^{18} can also exchange with oxygen in the body, particularly bicarbonate and with other substances not yet isolated. This oxygen exchange also results in the body water pool being over-estimated. The only correction that can be utilized to combat this problem is to use independent pool sizes.

Sequestration is a much more serious concern than exchange and is defined as "isotope incorporation into body solids during reductive biosynthesis." The only way to combat this problem is to estimate the rate of isotope incorporation and then correct the calculated rCO_2 and r H_2O. Unfortunately however, there has not been sufficient data collected to determine accurate rates of isotope sequestration and correction factors have not been established.

Body fat poses the largest problem in the area of sequestration since it is highly reduced and therefore provides an abundance of labile hydrogen with which the isotope can exchange. There are also a large number of exchangeable hydrogen in protein, but due to the relatively miniscule exchange rate observed, Haggarty claims that "the effect of protein synthesis can be ignored when calculating the effects of sequestration" (Prentice 1990). For carbohydrate exchange, the greatest concern is liver glycogen. Again, Haggarty believes that sequestration is unlikely to significantly affect the obtained results, but that fluctuations in glycogen stores (and hence exchange) could affect the precision.

The H and O incorporated into faeces and urine and subsequently lost from the body is also considered sequestration but a correction factor for this loss **has** been determined. For a "normal adult male" the estimated error on rCO_2 production is –4L/day.

The effect of H_2 sequestration is considerably more significant than that of O^{18}. However, any O^{18} sequestration will work to offset errors created by the sequestration of H_2. In general, sequestration of isotope during DLW studies will lead to an under-estimation of rCO_2 and an over-estimation of rH_2O. Due to the smaller volume of CO_2, the percent error for rCO_2 is considerably larger.

Fractionation

Fractionation, or changes in the relative abundance of isotopes due to their differences in mass, is a phenomenon that contributes significant error to DLW, but the error can be reduced with correction factors.

Fractionation can be of two types; kinetic fractionation occurs when one isotope reacts more readily in an irreversible system, and equilibrium fractionation when one isotope concentrates in one component of a reversible system. For kinetic reactions, it is usually the lighter isotope that reacts more rapidly and so the product is lighter than the reactant. In fractionating equilibriums, the component containing a higher concentration of the heavier isotope is called "enriched or heavy" and the other "depleted or light." It must be noted that fractionation only occurs when reactions do not go to completion.

The fractionation factor is represented by f and is mathematically defined as:

$$f = \frac{\text{(heavy/light) product}}{\text{(heavy/light) reactant}} \quad \{f>1 = \text{enriched},\ f<1 = \text{depleted}\}$$

In order to correct for fractionation-derived errors, the amount of fractionation occurring in various body fluids must be known. The first studies on this subject were performed by Lifson and were in vitro studies, conducted at 25 degrees Celsius. In 1980, Nagy et al. performed the first in vivo experiments with a toad. It is currently agreed that breath and transcutaneous water loss ARE fractionated whereas sweat and urine are NOT, as was determined by Schoeller et al in 1986 (Schoeller, Leitch et al. 1986). This group also claim that Lifson's original correction factors are correct, and encourage researchers to use the accepted literature values. Although calculation experiments were performed on adults, Wells declares, "the (correction) values are assumed to be valid for all age groups" (Wells 1998).

There are three fractionation correction equations available: Lifson's original model, Schoeller's method- which separates water loss into fractionated and non-fractionated components, and Coward's equation- which further divides the fractionated water losses into respiratory and skin losses. With each, there is a potential error in the estimation of fractionated water loss. This quantity depends on water turnover, an individualized characteristic heavily affected by pathological state. Lifson proposed that 50% of water loss was fractionated, but more recent studies have contradicted this claim and shown that this value is an overestimation in most populations. Coward's method involves estimating breath water loss as a function of CO_2 production and assuming a constant value for transcutaneous water loss. Schoeller estimates water loss from both the body surface area and the ventilatory volume as functions of the CO_2 produced.

Isotopic Variations

The cost of O^{18} is very high so researchers aim to administer the smallest dose possible that will still produce reliable results. This means that variations in the natural abundance of O^{18} (and H^2) are very significant to the interpretation of post-dose levels.

Isotope levels are measured in per mL units; ‰, which is the difference in the ratio of heavy to light isotope relative to the ratio in the standard, times 1000. Mathematically:

$$\delta = \frac{R_u - R_{std}}{R_{std}} \times 1000$$

The accepted standard in DLW experiments is SMOW (Standard Mean Ocean Water), which has an assigned value of 0‰. Water itself is the main source of the body's H and O, and therefore has the most impact on isotopic variations taking place within the body. As water evaporates from the oceans, a kinetic isotopic process takes place, rendering the water vapour depleted in H^2 and O^{18} relative to SMOW. This occurs because as water vapour moves inland the heavy isotopes are lost first and so the remaining vapour and resulting precipitation is "light." Rain and snow is also isotopically fractioned due to an equilibrium process. Surface water is also subject to evaporation, with lighter isotopes being lost first. These natural occurrences partly explain why human body water has varying isotope concentration. As well, human treatment of water can influence isotopic distribution. Partially distilled water for example will leave the recaptured water full of lighter isotopes while boiled water will contain heavier isotopes since the lighter ones will boil off first.

Baselines levels of human body isotopic concentration can be affected by moves to a different community or country, seasonal changes (especially in regions with wet and dry seasons) and by changes in food or liquid sources (the commencement of total parenteral nutrition for example.) In DLW experiments, the natural abundance of each subject, as determined by a pre-dose sample, is traditionally subtracted from the post-dose values (Ritz, Cole et al. 1996). However, natural abundances are NOT constant (Schoeller 1983). Methods to combat this problem have been suggested by Schoeller include:

- Ensuring that the subject has had sufficient time to equilibrate if water source has been changed.
- Model the anticipated baseline changes due to the composition of the new water source.
- Have a placebo group; measure the changes in background abundances in a control group who do not receive DLW over the study duration.
- Increase the amount of dose given.
- Decrease the study length {from (Prentice 1990).}

3

In 1983, Dale Schoeller stated that the changes in natural abundances was not a huge concern for DLW calculations, since it was believed that as long as the

elimination rates for ^{18}O and H_2 were equal the CO_2 production calculation would not be affected (Schoeller 1983). Ritz et al. have further studied the effects of changing natural abundances and in 1996 stated that CO_2 production **is** affected. They found that the imprecision resulting from variations in natural abundance was 3.54% $\pm$ 2.04. They have provided a model with which to assess and avoid this imprecision, but it requires that numerous pre-dose samples be taken (Ritz, Cole et al. 1996).

Analytical Variation

As with any research, analytical and methodological errors can lead to errors in the determination of final results.

Metabolic Fuel Source

The metabolic fuel source of each subject is crucial to the determination of total CO_2 production since the heat equivalent per mole of expired CO_2 depends on the fuel utilized by the body (Prentice 1990).

Fuel consumption is commonly expressed as a respiratory quotient (RQ), which is the ratio of CO_2 production to O_2 consumption during food oxidation. In many studies, RQ is calculated from FQ (food quotient). Black et al. support the use of FQ in DLW studies since energy balance is usually maintained over the course of the study and if in nutrient and energy balance, FQ will equal RQ (Black, Prentice et al. 1986). Special consideration must be taken in clinical studies involving rapid changes in body composition, in infants less than 6 months of age, in those showing catch up growth following an episode of malnutrition and in adults dieting. Dietary surveys indicate that the average RQ of a Western diet is 0.85, however special diets (enteral or parenteral feeds for example) must not be considered "average" and considered in detail. One also must be aware of any changes in the dietary habits of subjects as altered food intake will lead to a change in RQ and errors in CO_2 production (Jones, Winthrop et al. 1988). Wells has indicated that in paediatric studies, an average RQ should not be assumed, but that FQ should be obtained from diet records for accuracy (Wells 1998).

References for Appendix A:

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APPENDIX B: FORMS USED FOR THE GASTROSTOMY STUDY

2.0 HISTORY visit 1

DISABILITY

Limbs involved	2.1 **left arm** 2.2 **right arm** 2.3 **left leg** 2.4 **right leg**		
Type of disability	2.5 **monoplegia** 2.7 ☐ **spastic diplegia** 2.9 **right hemiplegia** 2.11 **ataxic** 2.13 **not physically disabled**		2.6 ☐ **spastic quadriplegia** 2.8 ☐ **left hemiplegia** 2.10 ☐ **extrapyramidal** 2.12 **mixed (specify)**
Severity of disability	**Mobility** 2.14 **sits independently** 2.15 **sits with support** 2.16 ☐ **walks unaided** 2.17 ☐ **walks with help** 2.18 ☐ **cannot walk**	**Hand mobility** 2.19 ☐ **normal** 2.20 ☐ **impaired** 2.21 **cannot use hands to feed self** 2.22 **cannot use hands to grasp**	2.23 **Learning difficulty** **1 none** **2 mild** **3 moderate** **4 severe** **5 profound**
Isolated oromotor dysfunction	2.24 **1 no 2 bulbar palsy 3 Worster-Drought syndrome 4 other**		
Structural abnormalities	2.25 **1 no 2 yes** 2.26 ☐ **lips** 2.27 ☐ **tongue** 2.28 ☐ **palate** 2.29 **other**		

AETIOLOGY OF DISABILITY

2.30 **Gestation: /40 weeks**	2.31 **Timing 1 in utero 2 neonatal 3 postnatal**
2.32 **neuromuscular disease,** 2.33: 2.34 **degenerative disease,** 2.35: 2.36 **brain stem tumour,** 2.37: 2.38 **brain insult,** 2.39:	

2.0 HISTORY visit 1 continued

VISION

2.40 **Visual impairment**	**1 normal vision 2 mild 3 moderate 4 severe 5 no useful vision**

BEHAVIOUR PROBLEMS WITH FEEDING

2.41 **1 no 2 yes 3 sometimes**

2.42 **turns head away**	2.43 **clamps mouth**	2.44 **vomits**
2.45 **tantrums during meals**	2.46 **spits**	2.47 **ruminates**
2.48 **food refusal**	2.49 **antisocial eating habits**	
2.50 **easily distracted whilst feeding**	2.51 **only allows feeding by one person**	

2.52 **Psychological input / assessment for feeding behaviour problems 1 yes 2 no**

DRUGS

2.53 **Parent / carer perception of ease of drug administration:**	**1 easy 2 variable 3 difficult** **4 very difficult, child never gets all doses prescribed**

EPILEPSY

2.54 **1 never**	**2 not now**	**3 yes, current problem**
2.55 **seizure type**	**0 none 1 absence 2 myoclonic 3 tonic-clonic** **4 tonic 5 atonic 6 partial**	
2.56 **frequency**	**0 none 1 daily 2 weekly 3 monthly 4 rarely 5 variable**	
2.57 **number of fits**		

drugs for epilepsy	**name** 2.58, 2.60, 2.62 (0 = none)	**dose** 2.59, 2.61, 2.63 (0=none)
	1 carbamazepine	
	2 clobazam	
	3 clonazepam	
	4 diazepam	
	5 lamotrigine	
	6 lorazepam	
	7 phenobarbitone	
	8 phenytoin	
	9 primidone	
	10 sodium valproate	
	11 vigabatrin	
	12 other	

2.0 HISTORY visit 1 continued

BOWELS

2.64 **diarrhoea**	**1 no**	**2 yes**	**3 sometimes**	
2.65 **constipation**	**1 no**	**2 yes**	**3 sometimes**	
2.66 **bowel movements**	**1 daily** **4 every 5-7 days**	**2 every 1-2 days** **5 less than once a week**	**3 every 3-4 days**	
2.67 **treatment** **1 none** **2 daily** **3 sometimes**	**medication** 2.68, 2.70, 2.72, 2.74	**dose** 2.69, 2.71, 2.73, 2.75	**medication** 2.68, 2.70, 2.72, 2.74	**dose** 2.69, 2.71, 2.73, 2.75
	1 loperamide		**6 sodium picosulphate**	
	2 sodium docusate		**7 senna**	
	3 liquid parafin		**8 supositories**	
	4 lactulose		**9 high fibre diet**	
	5 fybogel		**10 other**	
2.76 **colostomy**	**1 no** **2 yes**	2.77 **age at formation:**		**years**
2.78 **ileostomy**	**1 no** **2 yes**	2.79 **age at formation:**		**years**

CHEST INFECTIONS

2.80 **no. chest infections requiring antibiotics in the previous 6 months**	
2.81 **no. chest infections requiring hospital admission in previous 6 months**	

BACK

Scoliosis 2.82 **1 yes** **2 no**	**Scoliosis surgery** 2.83 **1 no** **2 yes,** 2.84 **at age:** **years**

HIPS

Dislocation 2.85 **1 yes** **2 no**	**Hip surgery** 2.86 **1 no** **2 yes,** 2.87 **at age:** **years**

Wears a body brace	2.88 **1 yes** **2 no**	
Wears splints	2.89 **legs 1 yes 2 no**	2.90 **arms 1 yes 2 no**

3.0 SYMPTOMS visit 1

FEEDING

Problem	frequency 1 always = on every occasion 2 often = at least once a day 3 occasionally = once every few days - once a week 4 rarely = less than once a week 5 never = not a problem to the child as never happens
3.1 coughs whilst eating	1 always 2 often 3 occasionally 4 rarely 5 never
3.2 coughs whilst drinking	1 always 2 often 3 occasionally 4 rarely 5 never
3.3 chokes / gags with food	1 always 2 often 3 occasionally 4 rarely 5 never
3.4 chokes / gags with liquids	1 always 2 often 3 occasionally 4 rarely 5 never
3.5 drools	1 always 2 often 3 occasionally 4 rarely 5 never
3.6 ruminates	1 always 2 often 3 occasionally 4 rarely 5 never
vomiting : 3.7 during meals	1 always 2 often 3 occasionally 4 rarely 5 never
3.8 after meals	1 always 2 often 3 occasionally 4 rarely 5 never
3.9 whilst prone	1 always 2 often 3 occasionally 4 rarely 5 never
3.10 during the night	1 always 2 often 3 occasionally 4 rarely 5 never
3.11 haematemesis	1 always 2 often 3 occasionally 4 rarely 5 never
3.12 coffee grounds with vomits	1 always 2 often 3 occasionally 4 rarely 5 never

Current medications for feeding problems 3.13, 3.15, 3.17, 3.19,	0 nothing	Dose 3.14, 3.16, 3.18, 3.20
	1 Cimetidine (Tagamet)	
	2 Gaviscon	
	3 Omeprozole (Losec	
	4 Cisapride (Prepulsid)	
	5 Ranitidine (Zantac)	
	6 Domperidome	
Other current medications 3.21, 3.23, 3.25	1 baclofen	3.22, 3.24, 3.26
	2 antibiotics	
	3	

4.0 FEEDING ASSESSMENT visit 1

Infant feeding method	Used up until aged about: (enter a whole number, e.g. 3)		
4.1 **breast** **1 never 2 yes**	4.2 **weeks** ☐	**OR** 4.3 **months** ☐	
4.4 **bottle** **1 never 2 yes**	☐	☐	
4.7 **nasogastric tube** **1 never 2 yes** **3 used intermittently, e.g. when child ill**	4.8 **weeks** ☐	**OR** 4.9 **months** ☐	**OR** 4.10 **years** ☐

4.11 **age solids introduced** **1 never 2 yes**	4.12 **months** ☐	**OR**	4.13 **years** ☐

Current feeding methods

4.14 **fluids**	**1 breast 2 bottle 3 cup 4 nasogastric tube**		
4.15 **nasogastric tube** **1 no** **2 yes**	**in use for past:** 4.16 **months** ☐	**OR** 4.17 **years** ☐	
food / enteral feed	4.18 **oral route only** **1 yes 2 no**		
	4.19 **oral and nasogastric** **1 yes 2 not applicable**		

age of onset of feeding difficulties	4.20 **months** ☐	**OR** 4.21 **years** ☐	

4.0 FEEDING ASSESSMENT visit 1 continued

Current feeding difficulties (from parents / carers perspective)	4.22 **child is slow to feed, takes too long** 4.23 **only one person can feed child** 4.24 **child doesn't eat much/enough** 4.25 **child doesn't drink much/enough** 4.26 **parent/carer doesn't enjoy feeding** 4.27 **feeding un-enjoyable for child** 4.28 **distressing to feed child** 4.29 **modification to food 0 none 1 chopping 2 mashing 3 pureeing** 4.30 **spillage of food 0 none 1 quarter 2 half 3 three quarters** 4.31 **spillage of drink 0 none 1 quarter 2 half 3 three quarters**

4.32 **Child's appetite and interest in eating and drinking**	**1 good 2 poor 3 variable**

4.33 **Child's feeding ability** **1 feeds self always, no help needed** **2 needs help sometimes** **3 cannot feed self, always needs help**	**Cutlery and utensils used to feed** 4.34 **Cutlery: 1 normal 2 adapted** 4.35 **spoon** 4.36 **fork** 4.37 **knife** 4.38 **Utensils: 1 normal 2 adapted**
4.39 **Child's drinking ability** **1 can give own drinks, no help needed** **2 needs help sometimes** **3 cannot give own drinks, always needs help**	4.40 **Drinking vessel used** **1 Bottle** **2 Normal cup** **3 Adapted cup 4 doidy cup**

4.41 **Previous input and help with feeding problems** **1 yes 2 never** 4.42 **when?** **1 in last 6 months** **2 more than 6 months ago**	**from whom?** 4.43 **paediatrician** 4.44 **dietitian** 4.45 **physiotherapist** 4.46 **speech and language therapist** 4.47 **school nurse** 4.48 **occupational therapist** 4.49 **GP** 4.50 **other? who:**

4.0 FEEDING ASSESSMENT visit 1 continued

If child needs help with feeding, who does this the most often?	4.51 **at home**	**1 mother 2 father** **3 sister 4 brother** **5 grandma 6 grandad** **7 aunt 8 uncle** **9 foster mother** **10 carer, e.g. social services** **11 nanny / mothers help / au pair** **12 other:**
	4.52 **at school or respite care**	**1 carer 2 dinner lady 3 school nurse** **4 teacher 5 not fed whilst at school/respite**

Average time taken by parent / carer to give child :	4.53 **A main meal**	**minutes**
	4.54 **A drink**	**minutes**
	4.55 **A snack**	**minutes**
Total time taken to feed child each day	4.56 **hours**	**hours**

Modification to and preparation of foods and drinks

4.57 **Consistency of food eaten**	**1 normal, no modification required** **2 chopped** **3 mashed** **4 pureed**
4.58 **Liquids:**	**1 normal 2 thickened**
4.59 **Average total time spent preparing food and drink just for child daily**	**hours**
4.60 **Average total extra time spent clearing up after feeding just for child daily**	**hours**

5.0 EXAMINATION visit 1

chest	5.1 **chest wall deformity** 5.2 **clinical signs consistent with aspiration** 5.3 **crepetations** 5.4 **wheeze** 5.5 **asthma** 5.6 **cyanosis**
neurological function / problem	**limbs involved** 5.8 **left arm** 5.9 **right arm** 5.10 **left leg** 5.11 **right leg**
	5.12 **monoplegia** 5.13 ☐ **spastic quadriplegia** 5.14 ☐ **spastic diplegia** 5.15 ☐ **Hemiplegia** 5.16 **left side** 5.17 **right side** 5.18 ☐ **extrapyramidal** 5.19 ☐ **spastic** 5.20 **ataxic** 5.21 **mixed (specify)** 5.22 **not physically disabled**
5.23 **dysmorphic**	**1 yes** **2 no** **3 genetic disorder,** 5.24 **name:**
5.25 **microcephaly**	**1 yes** **2 no**
5.26 **hydrocephalus**	**1 yes** **2 no** 5.27 **shunt in situ: 1 yes 2 no**
5.28 **anaemia** **clinical signs present**	**1 yes** **2 no** **3 not sure**
5.29 **drooling**	**1 no** **2 mild** **3 moderate** **4 severe**

6.0 NUTRITIONAL ASSESSMENT visit 1

6.1 **is child wasted**	**1 yes** **2 no**			
6.2 **is child stunted**	**1 yes** **2 no**			
6.3 **child last weighed**	**1 in last 6 months** **2 more than 6 months ago**			
6.4 **in last 6 months has child either:**	**1 lost weight** **2 gained weight** **3 stayed the same weight**			
previous documented weights (from medical notes or 'red book')	**date** (e.g. 2.3.95)	**weight (kg)**	**date** (e.g.2.3.95)	**weight (kg)**
	1.		**4.**	
	2.		**5.**	
	3.		**6.**	
6.5 **child last measured**	**1 in last 6 months** **2 more than 6 months ago**			
has child grown in last 6 months	6.6 **measured growth increase** **1 yes** **2 no** 6.7 **parent/carers say child needs bigger clothes/shoes** 1yes 2 no			
previous documented lengths (from medical notes or 'red'	**date**	**length (cm)**	**date**	**length (cm)**
	1.		**3.**	

	2.				4.			

6.0 NUTRITIONAL ASSESSMENT visit 1 continued

6.8 **skin condition**	**1 good**	**2 fair**	**3 poor**	
6.9 **pressure sores**	**1 no**	**2 yes**	6.10 **location:**	
6.11 **hair condition**	**1 good**	**2 fair**	**3 poor**	
6.12 **angular cheilitis**	**1 no**	**2 yes**		
6.13 **peripheries**	**1 warm**	**2 cold**		
6.14 **subcutaneous fat stores**	**1 good**	**2 moderate**	**3 poor**	
6.15 **muscle bulk**	**1 good**	**2 moderate**	**3 poor**	
6.16 **rickets**	**1 no**	**2 yes**	**3 not sure**	
6.17 **nails**	**1 normal**	**2 abnormal**		
do parents / carers think child is	6.18 **too thin** 6.20 **the right size**		6.19 **too small for age**	
6.21 **are parents / carers concerned about child's nutritional status**	**1 yes**	**2 no**	**3 not sure**	

7.0 ORAL MOTOR FUNCTION

tongue thrust	7.1 **1 yes**	**2 no**		
	7.2 **0 not present**	**1 mild**	**2 moderate**	**3 severe**
jaw: **tonic biting**	7.3 **1 yes**	**2 no**		
	7.4 **0 not present**	**1 mild**	**2 moderate**	**3 severe**
lip closure	7.5 **1 good**	**2 moderate**	**3 poor**	
palate	7.6 **cleft**	**1 yes**	**2 no**	
	7.7 **abnormal shape**	**1 yes**	**2 no**	

speech: degree of dysarthria	7.8 **1 none**	**2 mild**	**3 moderate**	**4 severe**	**5 communicates in other ways**

language comprehension level	7.9 **1 good**	**2 moderate**	**3 poor**	**4 non existent**	

FOLLOW UP VISIT 2

8.0 Gastrostomy details

Date of Birth	day	month	year	Age today	8.1 years	8.2 months

8.3 **Date of gastrostomy insertion**	(e.g.15.11.98)
8.4 **Type of gastrostomy**	**1 PEG** **2 open** **3 Stamn**
8.5 **Revision to button**	**1 no** **2 yes** 8.6 **date:** (e.g. 20.03.99)
8.7 **Fundoplication**	**1 no** **2 thall** **3 nissen's**

Problems with gastrostomy tube and site since insertion	8.8 **granulation tissue** 8.9 **leakage** 8.10 **infection** (8.11 **number**) 8.12 **peritonitis** 8.13 **fistula** 8.14 **migration of tube** 8.15 **blockages**
Treatments given	8.16 **antibiotics** 8.17 **silver nitrate** 8.18 **topical ointments** 8.19 **other**

9.0 CURRENT MEDICATIONS

9.1 **same as previous visit**	**1 yes** **2 no**	9.3 **epilepsy** 9.4 **bowels** 9.5 **anti-reflux** 9.6 **antibiotics** 9.7 **muscle relaxants**
9.2 **started since visit one**	**1 yes** **2 no**	
9.8 **improved ease of drug administration since gastrostomy**		**1 yes** **2 no** **3 not a previous problem**

10.0 CHEST INFECTIONS

10.1 **number of chest infections requiring antibiotics since visit one**	
10.2 **number of chest infections requiring hospital admission since visit one**	

FOLLOW UP VISIT 2 continued

11.0 SYMPTOMS

Problem	frequency 1 always = on every occasion 2 often = at least once a day 3 occasionally = once every few days - once a week 4 rarely = less than once a week 5 never = not a problem to the child as never happens
11.1 **coughs whilst eating**	**1 always 2 often 3 occasionally 4 rarely 5 never**
11.2 **coughs whilst drinking**	**1 always 2 often 3 occasionally 4 rarely 5 never**
11.3 **chokes / gags with food**	**1 always 2 often 3 occasionally 4 rarely 5 never**
11.4 **chokes / gags with liquids**	**1 always 2 often 3 occasionally 4 rarely 5 never**
vomiting : 11.5 **during meals**	**1 always 2 often 3 occasionally 4 rarely 5 never**
11.6 **after meals**	**1 always 2 often 3 occasionally 4 rarely 5 never**
11.7 **whilst prone**	**1 always 2 often 3 occasionally 4 rarely 5 never**
11.8 **during the night**	**1 always 2 often 3 occasionally 4 rarely 5 never**
11.9 **haematemisis**	**1 always 2 often 3 occasionally 4 rarely 5 never**
11.10 **coffee grounds with vomits**	**1 always 2 often 3 occasionally 4 rarely 5 never**
11.12 **drools**	**1 always 2 often 3 occasionally 4 rarely 5 never**
11.13 **ruminates**	**1 always 2 often 3 occasionally 4 rarely 5 never**
11.14 **retches**	**1 always 2 often 3 occasionally 4 rarely 5 never**
11.15 **dumps after feeds**	**1 always 2 often 3 occasionally 4 rarely 5 never**
11.16 **gas**	**1 always 2 often 3 occasionally 4 rarely 5 never**
11.17 **bloating / abdominal distension**	**1 always 2 often 3 occasionally 4 rarely 5 never**
11.18 **constipation**	**1 always 2 often 3 occasionally 4 rarely 5 never**
11.19 **diarrhoea**	**1 always 2 often 3 occasionally 4 rarely 5 never**

FOLLOW UP VISIT 2 continued

12.0 NUTRITIONAL ASSESSMENT

12.1 **is child wasted**	**1 yes 2 no**
12.2 **is child stunted**	**1 yes 2 no**
12.3 **since visit one has child either :**	**1 lost weight 2 gained weight 3 stayed the same weight**
has child grown since visit one	12.4 **measured growth increase 1 yes 2 no** 12.5 **parent/carers say child needs bigger clothes/shoes 1 yes 2 no**

12.6 **skin condition**	**1 good 2 fair 3 poor**	
12.7 **pressure sores**	**1 no 2 yes**	12.8 **location:**
12.9 **hair condition**	**1 good 2 fair 3 poor**	
12.10 **angular cheilitis**	**1 no 2 yes**	
12.11 **peripheries**	**1 warm 2 cold**	
12.12 **subcutaneous fat stores**	**1 good 2 moderate 3 poor**	
12.13 **muscle bulk**	**1 good 2 moderate 3 poor**	
12.14 **rickets**	**1 no 2 yes 3 not sure**	
12.15 **nails**	**1 normal 2 abnormal**	
do parents / carers think child is	12.16 **too thin** 12.18 **the right size**	12.17 **too small for age**
12.19 **are parents / carers concerned about child's nutritional status**	**1 yes 2 no 3 not sure**	

13.0 GASTROSTOMY FEEDING DETAILS visit 2

13.1 Feed used	
1 frebini 2 nutrini 3 nutrini extra 4 paediasure 5 paediasure with fibre 6 SMA high energy 7 infant formula 8 infant formula and energy supplements 9 soya infant formula 10 soya infant formula and energy supplements 11 neocate 12 pepdite 2+	13 ensure 14 ensure plus 15 fortisip 16 fresubin 17 fresubin isofibre 18 jevity 19 jevity plus 20 nutrison energy 21 nutrison fibre 22 nutrison soya 23 nutrison standard 24 osmolite 25 elemental 028 26 nutrison MCT 27 nutrison pepti
13.2 volume of feed given per 24 hours	mls

Gastrostomy feeding regime

		number of hours fed	number of feeds
13.3 overnight only via pump	1 yes 2 no		X
13.4 daytime only via pump	1 yes 2 no		X
13.5 day and night via pump	1 yes 2 no		X
13.6 daytime bolus feeds	1 yes 2 no	X	
13.7 daytime bolus feeds and feeds via pump at night	1 yes 2 no		
13.8 bolus feeds given via 0 N/A 1 gravity 2 syringe 3 pump			

13.0 GASTROSTOMY FEEDING visit 2 continued

13.12 **bolus feed volume**	**mls**
13.13 **hourly pump rate**	**mls**

oral food intake	13.14 **none** 13.15 **breakfast** 13.16 **lunch** 13.17 **tea** 13.18 **snacks**
oral fluid intake	13.19 **none** 13.20 **breakfast** 13.21 **lunch** 13.22 **tea** 13.23 **snacks**

13.24 **average total time spent feeding child each day since gastrostomy**	**hours**
13.25 **has gastrostomy reduced feeding times**	**1 yes 2 no 3 don't know**
13.26 **who carries out gastrostomy feeding at home**	**1 mother 2 father** **3 sister 4 brother** **5 grandma 6 grandad** **7 aunt 8 uncle** **9 foster mother / father** **10 carer, e.g. social services** **11 nanny / mothers help / au pair** **12 other:**
13.27 **is child fed at school / respite via gastrostomy**	**1 yes 2 no 3 carers being trained**

13.28 **problems with feed since visit one** **1 no** **2 yes**	13.29 **suspected feed intolerance** 13.30 **vomiting** 13.31 **diarrhoea** 13.32 **bloating/distension** 13.33 **feed changed, problem resolved**
13.34 **problems with feeding regime since visit one** **1 no** **2 yes**	13.35 **regime altered, problem resolved** 13.36 **still problems with regime**

FOLLOW UP VISIT 3

14.0 Gastrostomy details

Date of Birth	day		month		year		Age today	14.1 years	14.2 months

14.3 **Date of gastrostomy insertion**	e.g 20.09.98
14.4 **Type of gastrostomy**	**1 PEG** **2 open** **3 Stamn**
14.5 **Revision to button**	**1 no** **2 yes** 14.6 **date:** (e.g. 20.03.99)
14.7 **Fundoplication**	**1 no** **2 thall** **3 nissen's**

Problems with gastrostomy tube and site since visit two	14.8 **granulation tissue** 14.9 **leakage** 14.10 **infection** (14.11 **number)** 14.12 **peritonitis** 14.13 **fistula** 14.14 **migration of tube** 14.15 **blockages**
Treatments given	14.16 **antibiotics** 14.17 **silver nitrate** 14.18 **topical ointments** 14.19 **other**

15.0 CURRENT MEDICATIONS

15.1 **same as previous visit**	**1 yes** **2 no**	15.3 **epilepsy** 15.4 **bowels** 15.5 **anti-reflux** 15.6 **antibiotics** 15.7 **muscle relaxants**
15.2 **started since visit two**	**1 yes** **2 no**	
15.8 **improved ease of drug administration since gastrostomy**		**1 yes** **2 no** **3 not a previous problem**

16.0 CHEST INFECTIONS

16.1 **number of chest infections requiring antibiotics since visit two**	
16.2 **number of chest infections requiring hospital admission since visit two**	

FOLLOW UP VISIT 3 continued

17.0 SYMPTOMS

Problem	frequency 1 always = on every occasion 2 often = at least once a day 3 occasionally = once every few days - once a week 4 rarely = less than once a week 5 never = not a problem to the child as never happens
17.1 **coughs whilst eating**	1 always 2 often 3 occasionally 4 rarely 5 never
17.2 **coughs whilst drinking**	1 always 2 often 3 occasionally 4 rarely 5 never
17.3 **chokes / gags with food**	1 always 2 often 3 occasionally 4 rarely 5 never
17.4 **chokes / gags with liquids**	1 always 2 often 3 occasionally 4 rarely 5 never
vomiting : 17.5 **during meals**	1 always 2 often 3 occasionally 4 rarely 5 never
17.6 **after meals**	1 always 2 often 3 occasionally 4 rarely 5 never
17.7 **whilst prone**	1 always 2 often 3 occasionally 4 rarely 5 never
17.8 **during the night**	1 always 2 often 3 occasionally 4 rarely 5 never
17.9 **haematemisis**	1 always 2 often 3 occasionally 4 rarely 5 never
17.10 **coffee grounds with vomits**	1 always 2 often 3 occasionally 4 rarely 5 never
17.12 **drools**	1 always 2 often 3 occasionally 4 rarely 5 never
17.13 **ruminates**	1 always 2 often 3 occasionally 4 rarely 5 never
17.14 **retches**	1 always 2 often 3 occasionally 4 rarely 5 never
17.15 **dumps after feeds**	1 always 2 often 3 occasionally 4 rarely 5 never
17.16 **gas**	1 always 2 often 3 occasionally 4 rarely 5 never
17.17 **bloating / abdominal distension**	1 always 2 often 3 occasionally 4 rarely 5 never
17.18 **constipation**	1 always 2 often 3 occasionally 4 rarely 5 never
17.19 **diarrhoea**	1 always 2 often 3 occasionally 4 rarely 5 never

FOLLOW UP VISIT 3 continued

18.0 NUTRITIONAL ASSESSMENT

18.1 **is child wasted**	**1 yes 2 no**
18.2 **is child stunted**	**1 yes 2 no**
18.3 **since visit two has child either:**	**1 lost weight 2 gained weight 3 stayed the same weight**
has child grown since visit two	18.4 **measured growth increase 1 yes 2 no** 18.5 **parent/carers say child needs bigger clothes/shoes 1 yes 2 no**

18.9 **skin condition**	**1 good 2 fair 3 poor**
18.10 **pressure sores**	**1 no 2 yes** 12.11 **location:**
18.13 **hair condition**	**1 good 2 fair 3 poor**
18.14 **angular cheilitis**	**1 no 2 yes**
18.15 **peripheries**	**1 warm 2 cold**
18.16 **subcutaneous fat stores**	**1 good 2 moderate 3 poor**
18.17 **muscle bulk**	**1 good 2 moderate 3 poor**
18.18 **rickets**	**1 no 2 yes 3 not sure**
18.19 **nails**	**1 normal 2 abnormal**
do parents / carers think child is	18.20 **too thin** 18.21 **too small for age** 18.22 **the right size**
18.23 **are parents / carers concerned about child's nutritional status**	**1 yes 2 no 3 not sure**

19.0 GASTROSTOMY FEEDING DETAILS visit 3

19.1 **Feed used**	
1 frebini 2 nutrini 3 nutrini extra 4 paediasure 5 paediasure with fibre 6 SMA high energy 7 infant formula 8 infant formula and energy supplements 9 soya infant formula 10 soya infant formula and energy supplements 11 neocate 12 pepdite 2+	13 ensure 14 ensure plus 15 fortisip 16 fresubin 17 fresubin isofibre 18 jevity 19 jevity plus 20 nutrison energy 21 nutrison fibre 22 nutrison soya 23 nutrison standard 24 osmolite 25 elemental 028 26 nutrison MCT 27 nutrison pepti
19.2 **volume of feed given per 24 hours**	mls

Gastrostomy feeding regime

		number of hours fed	number of feeds
19.3 **overnight only via pump**	1 yes 2 no		X
19.4 **daytime only via pump**	1 yes 2 no		X
19.5 **day and night via pump**	1 yes 2 no		X
19.6 **daytime bolus feeds,**	1 yes 2 no	X	
daytime bolus feeds and feeds via pump at night	1 yes 2 no	19.7	19.8
daytime bolus feeds	1 yes 2 no	19.9	19.10
19.11 **bolus feeds given via** 0 N/A 1 gravity 2 syringe 3 pump			

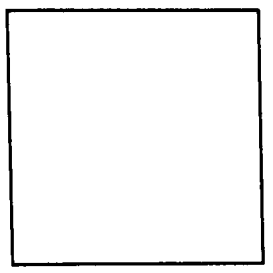
19.0 GASTROSTOMY FEEDING visit 3 continued

19.12 **bolus feed volume**	**mls**
19.13 **hourly pump rate**	**mls**

oral food intake	19.14 **none** 19.15 **breakfast** 19.16 **lunch** 19.17 **tea** 19.18 **snacks**
oral fluid intake	19.19 **none** 19.20 **breakfast** 19.21 **lunch** 19.22 **tea** 19.23 **snacks**

19.24 **average total time spent feeding child each day since gastrostomy**	**hours** ☐
19.25 **has gastrostomy reduced feeding times**	**1 yes 2 no 3 don't know**
19.26 **who carries out gastrostomy feeding at home**	**1 mother 2 father** **3 sister 4 brother** **5 grandma 6 grandad** **7 aunt 8 uncle** **9 foster mother / father** **10 carer, e.g. social services** **11 nanny / mothers help / au pair** **12 other:**
19.27 **is child fed at school / respite via gastrostomy**	**1 yes 2 no 3 carers being trained**

19.28 **problems with feed since visit two** **1 no** **2 yes**	19.29 **suspected feed intolerance** 19.30 **vomiting** 19.31 **diarrhoea** 19.32 **bloating/distension** 19.33 **feed changed, problem resolved**
19.34 **problems with feeding regime since visit two** **1 no** **2 yes**	19.35 **regime altered, problem resolved** 19.36 **still problems with regime**



APPENDIX C: QUALITY OF LIFE QUESTIONNIARE

The Gastrostomy Study

Quality of Life Questionnaire©

Patient Sticky / name

Study Number	

Visit Number (ring)	1 2 3
Date questionnaire completed	

Please would you kindly fill out the following questionnaire. It will help us find out about problems that may be experienced by you or your child.

The questionnaire is in two parts.

Part One is to find out your views on **your life and health.**

Part two is to try and find out about the concerns you may have about your child and their feeding.

Please answer all the questions. If you have difficulties with any, please contact one of the following, who will be happy to help:

Manchester children: Dr Adrian Thomas, Consultant Paediatrician, 0161 220 5566

Watford children: Liz McLean, Research Nurse, Tel: 01459 113429 (pager)

Oxford children: Bridget Lambert, Dietitian, 01865 222000 or 07880 500075 (mobile)

When you have completed the questionnaire, please return it in the FREEPOST envelope provided to:

The Gastrostomy Study
Oxford University Department of Paediatrics
Level 4
John Radcliffe Hospital

Oxford, OX3 9DU

Thank you very much for your time and help

PART ONE

OVERALL HEALTH

The following questions ask for your views about your health and how you feel about **life in general.** If you are unsure about how to answer any question, try and think about **your overall health** and give the best answer you can.

Do not spend too much time answering as your immediate response is likely to be the most accurate.

1. **in general,** would you say that your health is: PLEASE CIRCLE **ONE** NUMBER ONLY	Excellent **1** Very good **2** good **3** fair **4** poor **5**
2. Compared to **six months ago** how would you rate your health in general now? PLEASE CIRCLE **ONE** NUMBER ONLY	Much better than six months ago..... **1** Somewhat better than six months ago..... **2** About the same..... **3** Somewhat worse than six months ago..... **4** Much worse than six months ago..... **5**

HEALTH AND DAILY ACTIVITIES

3. The following questions are about activities you might do during a typical day. Does **your health** limit you in these activities? If so, how much?	PLEASE CIRCLE **ONE** NUMBER ON EACH LINE		
	Yes, limited a lot	Yes limited a little	No, not limited at all
a) **vigorous activities**, such as running , lifting heavy objects, participating in strenuous sports	**1**	**2**	**3**
b) **moderate activities** such as moving a table, pushing a vacuum cleaner, bowling or playing golf	**1**	**2**	**3**
c) lifting or carrying groceries	**1**	**2**	**3**
d) climbing **several** flights of stairs	**1**	**2**	**3**
e) climbing **one** flight of stairs	**1**	**2**	**3**
f) bending, kneeling or stooping	**1**	**2**	**3**
g) walking **more than a mile**	**1**	**2**	**3**
h) walking **half a mile**	**1**	**2**	**3**
i) walking **100 yards**	**1**	**2**	**3**

j) bathing and dressing	1	2	3

4. During the **past 4 weeks**, how much time have you had any of the following problems with your work or other regular daily activities **as a result of your physical health?**	PLEASE CIRCLE **ONE** NUMBER ON EACH LINE				
	All of the time	Most of the time	Some of the time	A little of the time	None of the Time
a) cut down on the **amount of time** you spent on work and other activities	1	2	3	4	5
b) **accomplished less** than you would like	1	2	3	4	5
c) were limited in the **kind** of work or other activities	1	2	3	4	5
c) had **difficulty** performing the work or other activities (e.g. it took more effort)	1	2	3	4	5

5. During the **past 4 weeks** how much time have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)	PLEASE CIRCLE **ONE** NUMBER ON EACH LINE				
	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a) cut down on the **amount of time** you spent on work and other activities	1	2	3	4	5
b) **accomplished less** than you would like	1	2	3	4	5
c) did work or other activities less **carefully** than usual	1	2	3	4	5

6. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family friends, neighbours or groups? PLEASE CIRCLE **ONE** NUMBER ONLY	Not at all ..... 1 Slightly ..... 2 Moderately ..... 3 Quite a bit ..... 4 Extremely 5
7. How much bodily pain have you had during the **past 4 weeks?** PLEASE CIRCLE **ONE** NUMBER ONLY	None ..... 1 Very mild ..... 2 Moderate ..... 3 Severe ..... 4 Very severe 5
8. During the **past 4 weeks**, how much did **pain** interfere with your normal work (both outside the home and housework)	Not at all ..... 1 A little bit ..... 2 Moderately 3

PLEASE CIRCLE **ONE** NUMBER ONLY	Quite a bit ..... **4** Extremely **5**

YOUR FEELINGS

9. These questions are about how you feel and how things have been with you **during the past month**. For each question please give the one answer that comes closest to the way you have been feeling. How much time during the **last month:**	PLEASE CIRCLE **ONE** NUMBER ON EACH LINE				
	All the time	Most of the time	Some of the time	A little of the time	None of the time
a) Did you feel full of life?	**1**	**2**	**3**	**4**	**5**
b) Have you been very nervous?	**1**	**2**	**3**	**4**	**5**
c) Have you felt so down in the dumps that nothing could cheer you up?	**1**	**2**	**3**	**4**	**5**
d) Have you felt calm and peaceful?	**1**	**2**	**3**	**4**	**5**
e) Did you have a lot of energy?	**1**	**2**	**3**	**4**	**5**
f) Have you felt downhearted and low?	**1**	**2**	**3**	**4**	**5**
g) Did you feel worn out?	**1**	**2**	**3**	**4**	**5**
h) Have you been happy?	**1**	**2**	**3**	**4**	**5**
i) Did you feel tired?	**1**	**2**	**3**	**4**	**5**

10. During the past 4 weeks how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc?)	All of the time ..... **1** Most of the time ..... **2** Some of the time ..... **3** A little of the time ..... **4** None of the time **5**

HEALTH IN GENERAL

11. How TRUE or FALSE is **each** of the following statements for you?	PLEASE CIRCLE **ONE** NUMBER ON EACH LINE				
	Definitely true	Mostly true	Not sure	Mostly false	Definitely false
a) I seem to get ill more easily than other people	**1**	**2**	**3**	**4**	**5**
b) I am as healthy as anybody I know	**1**	**2**	**3**	**4**	**5**
c) I expect my health to get worse	**1**	**2**	**3**	**4**	**5**

c) My health is excellent	1	2	3	4	5

Thank you for completing part one of this questionnaire.
Please continue with Part Two on the following pages.

Section A – On the next two pages you will find questions about problems that may be experienced by you or your child. We are trying to find out how much of a concern these problems are to you. Please ring the number that you consider answers the question best. Please answer all the questions.

1. How often are you concerned that your child needs a lot of help with feeding?	Always	Often	Sometimes	Rarely	Never
	1	2	3	4	5
2. How often are you concerned that your child cannot eat normal lumpy food?	Always	Often	Sometimes	Rarely	Never
	1	2	3	4	5
3. How often are you concerned that your child is unable to eat enough food?	Always	Often	Sometimes	Rarely	Never
	1	2	3	4	5
4. How often are you concerned about your child's weight	Always	Often	Sometimes	Rarely	Never
	1	2	3	4	5
5. How often are you concerned about your child needing surgery because of their feeding problems?	Always	Often	Sometimes	Rarely	Never
	1	2	3	4	5
6. How often are you concerned about other people feeding your child?	Always	Often	Sometimes	Rarely	Never
	1	2	3	4	5
7. How often are you concerned about your child's ability to communicate or interact with others?	Always	Often	Sometimes	Rarely	Never
	1	2	3	4	5
8. How often are you concerned if your child has learning difficulties	Always	Often	Sometimes	Rarely	Never
	1	2	3	4	5
9. How often are you concerned about your child being constipated?	Always	Often	Sometimes	Rarely	Never
	1	2	3	4	5
10. How often are you concerned about your child being stiff?	Always	Often	Sometimes	Rarely	Never
	1	2	3	4	5

How true or false are the following statements for you?

As a consequence of having a disabled child:	PLEASE CIRCLE **ONE** NUMBER ON EACH LINE				
	Definitely true	Mostly true	Not sure	Mostly false	Definitely false
11. I feel no-one else can look after my child as well as I can	1	2	3	4	5
12. I find there are always adequate changing facilities when I need them for my child	1	2	3	4	5
13. Other people understand my child's problems	1	2	3	4	5
14. Other people understand my problems with regard to the care and needs of my child	1	2	3	4	5
15. I am worried about the future for my child	1	2	3	4	5
16. I have concerns about my own future	1	2	3	4	5
17. There is good respite care available for my disabled child	1	2	3	4	5
18. Having a disabled child can make me feel depressed	1	2	3	4	5
19. I have problems getting a babysitter for my disabled child	1	2	3	4	5
20. Having a disabled child makes it difficult to go on holiday	1	2	3	4	5
21. Feeling tired is a problem for me	1	2	3	4	5
22. Having a disabled child can be stressful	1	2	3	4	5
23. Having a disabled child makes it difficult to get a break when I need it	1	2	3	4	5
24. I find it easy to take my disabled child out	1	2	3	4	5
25. I have difficulty running day-to-day errands because of my disabled child	1	2	3	4	5
26. I have difficulty with sleeping because of my disabled child	1	2	3	4	5

Thank you very much for your time and help.
Please now post the questionnaire in the FREEPOST envelope provided.

APPENDIX D:
DIET DIARY FOR THE GASTROSTOMY STUDY

GASTROSTOMY FEEDING STUDY

VISIT 1

FOOD DIARY

Name:

Date of birth:

Dates you filled in this diary:

If you have any problems completing this diary, please contact:

Bridget Lambert
Paediatric Research Dietitian
University of Oxford Department of Paediatrics
John Radcliffe Hospital
Oxford
OX3 9DU

☎01865 222000

HOW TO FILL IN THIS FOOD DIARY

Please read this section FIRST

If you have any queries about filling in this diary, please ring the number on the front of the booklet

✍ Record **all** the foods and drinks taken by your child for **3** days.

Include **2** weekdays and **1** weekend day.

Please write down:

◆The names of all foods, drinks or feed (including any 'brand names').

◆ A description of consistency (e.g. chopped, mashed, puréed)

◆ Weight of food or volume of drink.
You can put this in 'handy measures', such as :
'1 tablespoon mashed potato',
'1/2 medium slice white bread',
'1/4 cup of milk'.

◆ For "mixed" meals, such as shepherds pie, cauliflower cheese, chicken and vegetable curry, please describe the amount of each food making up the meal,

e.g. 1 tablespoon mince and 2 tablespoons mashed potato;
2 tablespoons sauce and 2 tablespoons cauliflower.

◆ Write down the method of cooking e.g. boiled, grilled, fried, microwave, casseroled

8. Cooking methods.
How do you cook foods such as beefburgers or fishfingers for your child?

Fry grill Microwave Not eaten

9. Which of these best describes the consistency of food your child is able to eat? You can tick more than one box.

normal, no chopping, mashing or pureeing required
chopped up
mashed
pureed / liquidised – smooth texture, no lumps
extra gravy / sauce needed

10. Dietary supplements.
(**a**) Does your child take any vitamin and / or mineral supplements?

Daily Occasionally Never
Name or brand and amount taken :

Does a doctor prescribe these? Yes No

(b) Does your child use calorie supplements, e.g. Maxijul, Caloreen, Duocal?

No Occasionally Daily
Name and amount used:

(c) Does your child take any special drinks, e.g. Polycal, Fortisip, Ensure Plus, Paediasure, Fortijuce?

No Occasionally Daily

Name and amount:

d) Does your child have a thickener, e.g. Nestargel, Vitaquick, Carobel, Thick'n easy, added to food and / or drink?

No Occasionally Daily

Name and amount used:

11. a) Does your child have nasogastric tube feeds?

no (if so, go to Q12) yes sometimes

b) When does your child have feeds?
overnight only
daytime and overnight
continuously, 20 – 24 hours daily

c) What feed does your child have?

Name: _____

Daily amount: _____ mls

If you make a feed from powder or mix ingredients together, please write out th recipe:

12.How would you describe your child's appetite and feeding' You can tick more than one box.
Excellent, always eats and drinks well
Has good days and bad days
Has a poor appetite
Fussy, will only eat certain foods
Prefers snacks to meals
Prefers sweet foods
Eats better with some people than with others, Who?
Behaves badly at mealtimes , Describe:

Any other comments:

DAY 1/2/3

Date:

	Food or drink	Amount eaten or drunk	Total time taken to eat or drink (approx. mins)
Breakfast			
Mid morning snacks			

Day Date:	Food or drink	Amount eaten or drunk	Total time taken to eat/drink (approx. mins)
Lunch			
Afternoon snacks			

Please can you answer the following questions. They will help to analyse your child's diet more accurately. Tick all the boxes that apply or write in the spaces.

1. Does your child need help with feeding?

No, feeds self yes, always some help required

2. How much liquid does your child lose from their mouth whilst drinking?
If the amount varies, please tick the best answer only.

None
Small amount (less than 1/4)
Moderate amount (1/3rd)
Large amount (1/2)
Nearly all (3/4 plus)
My child does not take liquids by mouth

3. How much food does your child lose from their mouth whilst eating?
I f the amount varies, please tick the best answer only.

None
Small amount (less than 1/4)
Moderate amount (1/3rd)
Large amount (1/2)
Nearly all (3/4 plus)
My child does not take food by mouth

4. Drinks.

(**a**) What volume of fluid does the cup/mug/bottle hold that your child usually uses?

Volume = _____ mls/floz

(**b**) How much undiluted squash is used in each drink?

Volume = _____ mls/floz

(**c**) How much sugar is added to tea/coffee? _____teaspoons

5. Milk.

(**a**) How much milk in total does your child usually have in one day? (Include all drinks of milk or with milk in, and any used on cereal)

Volume = _____ mls/floz

(**b**) What type of milk do they usually have?

Full cream Semi-skimmed Skimmed

Infant formula name: _____

Other (e.g. Soya) _____

6. Bread.

(**a**) What type of bread does your child have?

	Always	Occasionally	Never
White			
Granary			
Wholemeal			

(**b**) What is the thickness of a slice?

Thin Medium Thick

(**c**) What is the size of the loaf?

Small Medium Large

7. Fats for spreading and cooking.

(**a**) What type of margarine / butter / low fat spread or oil does your child have?

on bread/ toast ? name: _____

in baking/cooking ? name: _____

(**b**) How is this spread on their bread?

Scrape only Thinly Thickly

◆ For tinned, packet and ready-made foods, please record the brand name, size or weight of tin or packet and the amount eaten. As an example: 1/3rd 450g tin Ambrosia full cream Devon custard.

✪ **Please describe items as fully as possible.**

✪ **Only record the amount of food and drink that your child actually has. If they spill any from their mouth whilst eating or drinking, please take these losses into consideration.**

✔ Remember to include **all** snacks as well as meals.

✔ Remember to include **all** drinks (don't forget sugar, if added)

✔ Don't forget to record foods and drinks eaten outside the home, for example, at a friends or relatives house. Send this book along for someone else to write in if necessary.

❀ If your child has meals at school, ask if they can record what he or she eats during the day.

🕓 Finally, record approximately how long it takes for your child to eat and drink at each meal and snack, in minutes.

It is important that you do not alter what you normally give your child to eat and drink just because you are writing it down. Please give them whatever they usually have.

Filling out this diary will take some time but will give us valuable information about the nutritional intake of your child.

Thank you for your time and help.

AN EXAMPLE TO SHOW HOW TO FILL OUT THE FOOD DIARY

Day and date	Food or drink	Amount eaten	Approx. total time taken to eat and/or drink
Breakfast	Weetabix Sugar, white Milk, full cream Tea, with full milk 60mls - no sugar	½ 1 tsp. 100mls 100mls	25 mins
Morning snacks	fresh orange juice (Asda) McVities rich tea biscuit	50mls 1/2	15 mins
Lunch	Heinz macaroni cheese, pureed Asda baked beans, mashed chocolate sponge, homemade custard (full cream milk) blackcurrant drink (Ribena)	2 tbsp 1 tbsp. 1 tbsp. 1 tbsp. 100mls	40 mins

QUESTIONNAIRE

Day Date:	Food or drink	Amount eaten or drunk	Total time taken to eat or drink (approx. mins)
Evening meal			
Evening or bedtime snacks			
During the night			

You can use this page for writing any other comments or information about your child's diet or feeding that you wish to tell us. Any you give will be confidential.

Thank you for completing this diary.

Please return in the FREEPOST envelope provided to:
The Gastrostomy Study
University Department of Paediatrics
John Radcliffe Hospital, Headington, Oxford.
Tel: 01865 222000

OR

Give to Bridget Lambert or Dr Sullivan when you next visit

ENERGY BALANCE STUDY
FOOD DIARY

NAME:
DATE OF BIRTH:
WHO FILLED IN THIS DIARY:

If you have any problems completing this diary, please contact:

Allison Bachlet
University of Oxford Department of Paediatrics
John Radcliffe Hospital
Headington, Oxford
OX3 9UD
☎ 01865 222000

IMPORTANT!!

HOW TO FILL IN THIS FOOD DIARY

- Record **all** the foods and drinks taken by your child for **3** days.
- Include 2 weekdays and 1 weekend day. These days do not have to be consecutive!
- If your child is tube fed, record the feed amount plus any oral snacks/drinks.
- When describing the food:
  - Write down the names of all foods and drinks
  - Include brand names if possible
  - Record the weight or volume. This can be done in handy measures such as:
    '1 tablespoon mashed potato'
    '1/2 medium slice white bread'
    '1/4 cup of milk'
    OR in grams. (Please use grams if you have a kitchen scale.)
- For "mixed" meals, such as shepherds pie, cauliflower cheese, chicken and vegetable curry, please describe the amount of each food making up the meal,
  e.g. 1 tablespoon mince and 2 tablespoons mashed potato;
  2 tablespoons sauce and 2 tablespoons cauliflower.
- Write down the method of cooking e.g. boiled, grilled, fried, microwave, casseroled
- For tinned, packet and ready-made foods, please record the brand name, size or weight of tin or packet and the amount eaten. As an example: 1/3rd 450g tin Ambrosia full cream Devon custard

TIPS:

- ✓ Describe items as fully as possible.
- ✓ Only record the amount of food and drink that your child actually has. If they spill any from their mouth whilst eating or drinking, please take these losses into consideration.
- ✓ Remember to include **all** snacks as well as meals.
- ✓ Remember to include **all** drinks (don't forget sugar, if added)
- ✓ Don't forget to record foods and drinks eaten outside the home, for example, at a friends or relatives house. Send this book along for someone else to write in if necessary.
- ✓ If your child has meals at school, ask if they can record what he or she eats during the day.

❖It is important that you do not alter what you normally give your child to eat and drink just because you are writing it down. Please give them whatever they usually have.❖

QUESTIONNAIRE

Please answer the following questions. They will help to analyse your child's diet more accurately. Tick all the boxes that apply or write in the spaces.

1. Does your child need help with feeding?

❒ no, feeds self ❒ yes, always ❒ some help required

2. How much liquid does your child lose from their mouth whilst drinking?
If the amount varies, please tick the best answer only.

❒ None
❒ Small amount (less than 1/4)
❒ Moderate amount (1/3rd)
❒ Large amount (1/2)
❒ Nearly all (3/4 plus)
❒ My child does not take liquids by mouth

3. How much food does your child lose from their mouth whilst eating?
I f the amount varies, please tick the best answer only.

❒ None
❒ Small amount (less than 1/4)
❒ Moderate amount (1/3rd)
❒ Large amount (1/2)
❒ Nearly all (3/4 plus)
❒ My child does not take food by mouth

4. Drinks.

(a) What volume of fluid does the cup/mug/bottle hold that your child usually uses?

Volume = _____ mls/floz

(b) How much undiluted squash is used in each drink?

Volume = _____ mls/floz

(c) How much sugar is added to tea/coffee? _____teaspoons

5. Milk.

(a) How much milk in total does your child usually have in one day? (Include all drinks of milk or with milk in, and any used on cereal)

Volume = _____ mls/floz

(b) What type of milk do they usually have?

❒ Full cream ❒ Semi-skimmed ❒ Skimmed ❒ Other (ie: soya) ↓

❒ Infant formula ➔ _____

6. Bread.

(a) What type of bread does your child usually have?
❒ White ❒ Granary ❒ Wholemeal

(b) What is the thickness of a slice?
❒ Thin ❒ Medium ❒ Thick

(c) What is the size of the loaf?
❒ Small ❒ Medium ❒ Large

7. Fats for spreading and cooking.

(a) What type of margarine / butter / low fat spread or oil does your child have?

on bread/ toast ? name: _____

in baking/cooking ? name: _____

(b) How is this spread on their bread?
❒ Scrape only ❒ Thinly ❒ Thickly

8. Cooking methods.

How do you cook foods such as beefburgers or fishfingers for your child?
❒ Grill ❒ Fry ❒ Microwave ❒ Other ❒ Not eaten

9. Which of these best describes the consistency of food your child is able to eat? You can tick more than one box.

❒ normal, no chopping, mashing or pureeing required
❒ chopped up
❒ mashed
❒ pureed / liquidised – smooth texture, no lumps
❒ extra gravy / sauce needed

10. Dietary supplements.

(a) Does your child take any vitamin and / or mineral supplements?
❒ Daily ❒ Occasionally ❒ Never
Name or brand and amount taken : _____

Does a doctor prescribe these? ❒ Yes ❒ No

(b) Does your child use calorie supplements, e.g. Maxijul, Caloreen, Duocal?
❒ Daily ❒ Occasionally ❒ Never
Name and amount used: _____

(c) Does your child take any special drinks, e.g. Polycal, Fortisip, Ensure Plus, Paediasure, Fortijuce?
❒ Daily ❒ Occasionally ❒ Never
Name and amount used: _____

d) Does your child have a thickener, e.g. Nestargel, Vitaquick, Carobel, Thick'n easy, added to food and / or drink?

❒ Daily ❒ Occasionally ❒ Never

Name and amount used: _____

11. Tube Feeding

a) Does your child have nasogastric tube feeds?

❒ Daily ❒ Occasionally ❒ Never

b) When does your child have feeds?

- ❒ overnight only
- ❒ daytime and overnight
- ❒ continuously, 20 – 24 hours daily

c) What feed does your child have?

Name: _____

Daily amount: _____ mls

If you make a feed from powder or mix ingredients together, please write out the recipe:

a) Is your child fed with a gastrostomy tube?

❒ Daily ❒ Occasionally ❒ Never

b) When does your child have feeds?

- ❒ overnight only
- ❒ daytime and overnight
- ❒ continuously, 20 – 24 hours daily

c) What feed does your child have?

Name: _____

Daily amount: _____ mls

12. Appetite and Feeding

How would you describe your child's feeding? (You may tick more than one box.)

- ❒ Excellent, always eats and drinks well
- ❒ Has good days and bad days
- ❒ Has a poor appetite
- ❒ Fussy, will only eat certain foods
- ❒ Prefers snacks to meals
- ❒ Prefers sweet foods
- ❒ Eats better with some people than with others, Who?
- ❒ Behaves badly at mealtimes , Describe:

DAY ONE

DATE:

MEAL	FOOD OR FEED	AMOUNT
Breakfast Morning Snack		
Lunch Afternoon Snack		
Dinner Evening Snack		
Overnight Night Snack		

DAY TWO

DATE:

MEAL	FOOD OR FEED	AMOUNT
Breakfast Morning Snack		
Lunch Afternoon Snack		
Dinner Evening Snack		
Overnight Night Snack		

DAY THREE

DATE:

MEAL	FOOD OR FEED	AMOUNT
Breakfast Morning Snack		
Lunch Afternoon Snack		
Dinner Evening Snack		
Overnight Night Snack		

GROSS MOTOR FUNCTION MEASURE (GMFM)
SCORE SHEET (GMFM-88 and GMFM-66 scoring)

Version 1.0

Child's Name: _____ ID #: _____

Assessment date: _____
year / month /day

Date of birth: _____
year / month /day

Chronological age: _____
years/months

GMFCS Level [1]

☐ ☐ ☐ ☐ ☐
I II III IV V

Testing Conditions (eg, room, clothing, time, others present)

Evaluator's Name: _____ _____

_____ _____

The GMFM is a standardized observational instrument designed and validated to measure change in gross motor function over time in children with cerebral palsy. The scoring key is meant to be a general guideline. However, most of the items have specific descriptors for each score. It is imperative that the guidelines contained in the manual be used for scoring each item.

SCORING KEY
0 = does not initiate
1 = initiates
2 = partially completes
3 = completes
NT = Not tested [used for the GMAE scoring*]

It is now important to differentiate a true score of "0" (child does not initiate) from an item which is Not Tested (NT) if you are interested in using the GMFM-66 Ability Estimator Software.

*The GMFM-66 Gross Motor Ability Estimator (GMAE) software is available with the GMFM manual (2002). The advantage of the software is the conversion of the ordinal scale into an interval scale. This will allow for a more accurate estimate of the child's ability and provide a measure that is equally responsive to change across the spectrum of ability levels. Items that are used in the calculation of the GMFM-66 score are shaded and identified with an asterisk (*). The GMFM-66 is only valid for use with children who have cerebral palsy.

Contact for Research Group:
Dianne Russell, *CanChild* Centre for Childhood Disability Research, McMaster University, Institute for Applied Health Sciences, McMaster University, 1400 Main St. W., Rm. 408, Hamilton, L8S 1C7
Tel: North America - 1 905 525-9140 Ext: 27850
Tel: All other countries - 001 905 525-9140 Ext: 27850
E-mail: canchild@mcmaster.ca Fax: 1 905 522-6095
Website: www.fhs.mcmaster.ca/canchild

[1] GMFCS level is a rating of severity of motor function. Definitions are found in Appendix I of the GMFM manual (2002).

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Check (✓) the appropriate score: if an item is not tested (NT), circle the item number in the right column

Item		A: LYING & ROLLING	SCORE				NT
	1.	SUP, HEAD IN MIDLINE: TURNS HEAD WITH EXTREMITIES SYMMETRICAL	0 ☐	1 ☐	2 ☐	3 ☐	1.
*	2.	SUP: BRINGS HANDS TO MIDLINE, FINGERS ONE WITH THE OTHER	0 ☐	1 ☐	2 ☐	3 ☐	2.
	3.	SUP: LIFTS HEAD 45°	0 ☐	1 ☐	2 ☐	3 ☐	3.
	4.	SUP: FLEXES R HIP AND KNEE THROUGH FULL RANGE	0 ☐	1 ☐	2 ☐	3 ☐	4.
	5.	SUP: FLEXES L HIP AND KNEE THROUGH FULL RANGE	0 ☐	1 ☐	2 ☐	3 ☐	5.
*	6.	SUP: REACHES OUT WITH R ARM, HAND CROSSES MIDLINE TOWARD TOY	0 ☐	1 ☐	2 ☐	3 ☐	6.
*	7.	SUP: REACHES OUT WITH L ARM, HAND CROSSES MIDLINE TOWARD TOY	0 ☐	1 ☐	2 ☐	3 ☐	7.
	8.	SUP: ROLLS TO PR OVER R SIDE	0 ☐	1 ☐	2 ☐	3 ☐	8.
	9.	SUP: ROLLS TO PR OVER L SIDE	0 ☐	1 ☐	2 ☐	3 ☐	9.
*	10.	PR: LIFTS HEAD UPRIGHT	0 ☐	1 ☐	2 ☐	3 ☐	10.
	11.	PR ON FOREARMS: LIFTS HEAD UPRIGHT, ELBOWS EXT., CHEST RAISED	0 ☐	1 ☐	2 ☐	3 ☐	11.
	12.	PR ON FOREARMS: WEIGHT ON R FOREARM, FULLY EXTENDS OPPOSITE ARM FORWARD	0 ☐	1 ☐	2 ☐	3 ☐	12.
	13.	PR ON FOREARMS: WEIGHT ON L FOREARM, FULLY EXTENDS OPPOSITE ARM FORWARD	0 ☐	1 ☐	2 ☐	3 ☐	13.
	14.	PR: ROLLS TO SUP OVER R SIDE	0 ☐	1 ☐	2 ☐	3 ☐	14.
	15.	PR: ROLLS TO SUP OVER L SIDE	0 ☐	1 ☐	2 ☐	3 ☐	15.
	16.	PR: PIVOTS TO R 90° USING EXTREMITIES	0 ☐	1 ☐	2 ☐	3 ☐	16.
	17.	PR: PIVOTS TO L 90° USING EXTREMITIES	0 ☐	1 ☐	2 ☐	3 ☐	17.

TOTAL DIMENSION A ☐

Item		B: SITTING	SCORE				NT
*	18.	SUP, HANDS GRASPED BY EXAMINER: PULLS SELF TO SITTING WITH HEAD CONTROL	0 ☐	1 ☐	2 ☐	3 ☐	18.
	19.	SUP: ROLLS TO R SIDE, ATTAINS SITTING	0 ☐	1 ☐	2 ☐	3 ☐	19.
	20.	SUP: ROLLS TO L SIDE, ATTAINS SITTING	0 ☐	1 ☐	2 ☐	3 ☐	20.
*	21.	SIT ON MAT, SUPPORTED AT THORAX BY THERAPIST: LIFTS HEAD UPRIGHT, MAINTAINS 3 SECONDS	0 ☐	1 ☐	2 ☐	3 ☐	21.
*	22.	SIT ON MAT, SUPPORTED AT THORAX BY THERAPIST: LIFTS HEAD MIDLINE, MAINTAINS 10 SECONDS	0 ☐	1 ☐	2 ☐	3 ☐	22.
*	23.	SIT ON MAT, ARM(S) PROPPING: MAINTAINS, 5 SECONDS	0 ☐	1 ☐	2 ☐	3 ☐	23.
*	24.	SIT ON MAT: MAINTAINS, ARMS FREE, 3 SECONDS	0 ☐	1 ☐	2 ☐	3 ☐	24.
*	25.	SIT ON MAT WITH SMALL TOY IN FRONT: LEANS FORWARD, TOUCHES TOY, RE-ERECTS WITHOUT ARM PROPPING	0 ☐	1 ☐	2 ☐	3 ☐	25.
*	26.	SIT ON MAT: TOUCHES TOY PLACED 45° BEHIND CHILD'S R SIDE, RETURNS TO START	0 ☐	1 ☐	2 ☐	3 ☐	26.
*	27.	SIT ON MAT: TOUCHES TOY PLACED 45° BEHIND CHILD'S L SIDE, RETURNS TO START	0 ☐	1 ☐	2 ☐	3 ☐	27.
	28.	R SIDE SIT: MAINTAINS, ARMS FREE, 5 SECONDS	0 ☐	1 ☐	2 ☐	3 ☐	28.
	29.	L SIDE SIT: MAINTAINS, ARMS FREE, 5 SECONDS	0 ☐	1 ☐	2 ☐	3 ☐	29.
*	30.	SIT ON MAT: LOWERS TO PR WITH CONTROL	0 ☐	1 ☐	2 ☐	3 ☐	30.
*	31.	SIT ON MAT WITH FEET IN FRONT: ATTAINS 4 POINT OVER R SIDE	0 ☐	1 ☐	2 ☐	3 ☐	31.
*	32.	SIT ON MAT WITH FEET IN FRONT: ATTAINS 4 POINT OVER L SIDE	0 ☐	1 ☐	2 ☐	3 ☐	32.
	33.	SIT ON MAT: PIVOTS 90°, WITHOUT ARMS ASSISTING	0 ☐	1 ☐	2 ☐	3 ☐	33.
*	34.	SIT ON BENCH: MAINTAINS, ARMS AND FEET FREE, 10 SECONDS	0 ☐	1 ☐	2 ☐	3 ☐	34.
*	35.	STD: ATTAINS SIT ON SMALL BENCH	0 ☐	1 ☐	2 ☐	3 ☐	35.
*	36.	ON THE FLOOR: ATTAINS SIT ON SMALL BENCH	0 ☐	1 ☐	2 ☐	3 ☐	36.
*	37.	ON THE FLOOR: ATTAINS SIT ON LARGE BENCH	0 ☐	1 ☐	2 ☐	3 ☐	37.

TOTAL DIMENSION B ☐

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Item		C: CRAWLING & KNEELING	SCORE				NT
	38.	PR: CREEPS FORWARD 1.8m (6')	0 ☐	1 ☐	2 ☐	3 ☐	38.
*	39.	4 POINT: MAINTAINS, WEIGHT ON HANDS AND KNEES, 10 SECONDS	0 ☐	1 ☐	2 ☐	3 ☐	39.
*	40.	4 POINT: ATTAINS SIT ARMS FREE	0 ☐	1 ☐	2 ☐	3 ☐	40.
*	41.	PR: ATTAINS 4 POINT, WEIGHT ON HANDS AND KNEES	0 ☐	1 ☐	2 ☐	3 ☐	41.
*	42.	4 POINT: REACHES FORWARD WITH R ARM, HAND ABOVE SHOULDER LEVEL	0 ☐	1 ☐	2 ☐	3 ☐	42.
*	43.	4 POINT: REACHES FORWARD WITH L ARM, HAND ABOVE SHOULDER LEVEL	0 ☐	1 ☐	2 ☐	3 ☐	43.
*	44.	4 POINT: CRAWLS OR HITCHES FORWARD 1.8m (6')	0 ☐	1 ☐	2 ☐	3 ☐	44.
*	45.	4 POINT: CRAWLS RECIPROCALLY FORWARD 1.8m (6')	0 ☐	1 ☐	2 ☐	3 ☐	45.
*	46.	4 POINT: CRAWLS UP 4 STEPS ON HANDS AND KNEES/FEET	0 ☐	1 ☐	2 ☐	3 ☐	46.
	47.	4 POINT: CRAWLS BACKWARDS DOWN 4 STEPS ON HANDS AND KNEES/FEET	0 ☐	1 ☐	2 ☐	3 ☐	47.
*	48.	SIT ON MAT: ATTAINS HIGH KN USING ARMS, MAINTAINS, ARMS FREE, 10 SECONDS	0 ☐	1 ☐	2 ☐	3 ☐	48.
	49.	HIGH KN: ATTAINS HALF KN ON R KNEE USING ARMS, MAINTAINS, ARMS FREE, 10 SECONDS	0 ☐	1 ☐	2 ☐	3 ☐	49.
	50.	HIGH KN: ATTAINS HALF KN ON L KNEE USING ARMS, MAINTAINS, ARMS FREE, 10 SECONDS	0 ☐	1 ☐	2 ☐	3 ☐	50.
*	51.	HIGH KN: KN WALKS FORWARD 10 STEPS, ARMS FREE	0 ☐	1 ☐	2 ☐	3 ☐	51.

TOTAL DIMENSION C ☐

Item		D: STANDING	SCORE				NT
*	52.	ON THE FLOOR: PULLS TO STD AT LARGE BENCH	0 ☐	1 ☐	2 ☐	3 ☐	52.
*	53.	STD: MAINTAINS, ARMS FREE, 3 SECONDS	0 ☐	1 ☐	2 ☐	3 ☐	53.
*	54.	STD: HOLDING ON TO LARGE BENCH WITH ONE HAND, LIFTS R FOOT, 3 SECONDS	0 ☐	1 ☐	2 ☐	3 ☐	54.
*	55.	STD: HOLDING ON TO LARGE BENCH WITH ONE HAND, LIFTS L FOOT, 3 SECONDS	0 ☐	1 ☐	2 ☐	3 ☐	55.
*	56.	STD: MAINTAINS, ARMS FREE, 20 SECONDS	0 ☐	1 ☐	2 ☐	3 ☐	56.
*	57.	STD: LIFTS L FOOT, ARMS FREE, 10 SECONDS	0 ☐	1 ☐	2 ☐	3 ☐	57.
*	58.	STD: LIFTS R FOOT, ARMS FREE, 10 SECONDS	0 ☐	1 ☐	2 ☐	3 ☐	58.
*	59.	SIT ON SMALL BENCH: ATTAINS STD WITHOUT USING ARMS	0 ☐	1 ☐	2 ☐	3 ☐	59.
*	60.	HIGH KN: ATTAINS STD THROUGH HALF KN ON R KNEE, WITHOUT USING ARMS	0 ☐	1 ☐	2 ☐	3 ☐	60.
*	61.	HIGH KN: ATTAINS STD THROUGH HALF KN ON L KNEE, WITHOUT USING ARMS	0 ☐	1 ☐	2 ☐	3 ☐	61.
*	62.	STD: LOWERS TO SIT ON FLOOR WITH CONTROL, ARMS FREE	0 ☐	1 ☐	2 ☐	3 ☐	62.
*	63.	STD: ATTAINS SQUAT, ARMS FREE	0 ☐	1 ☐	2 ☐	3 ☐	63.
*	64.	STD: PICKS UP OBJECT FROM FLOOR, ARMS FREE, RETURNS TO STAND	0 ☐	1 ☐	2 ☐	3 ☐	64.

TOTAL DIMENSION D ☐

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Item		E: WALKING, RUNNING & JUMPING	SCORE				NT
*	65.	STD, 2 HANDS ON LARGE BENCH: CRUISES 5 STEPS TO R	0 ☐	1 ☐	2 ☐	3 ☐	65.
*	66.	STD, 2 HANDS ON LARGE BENCH: CRUISES 5 STEPS TO L	0 ☐	1 ☐	2 ☐	3 ☐	66.
*	67.	STD, 2 HANDS HELD: WALKS FORWARD 10 STEPS	0 ☐	1 ☐	2 ☐	3 ☐	67.
*	68.	STD, 1 HAND HELD: WALKS FORWARD 10 STEPS	0 ☐	1 ☐	2 ☐	3 ☐	68.
*	69.	STD: WALKS FORWARD 10 STEPS	0 ☐	1 ☐	2 ☐	3 ☐	69.
*	70.	STD: WALKS FORWARD 10 STEPS, STOPS, TURNS 180°, RETURNS	0 ☐	1 ☐	2 ☐	3 ☐	70.
*	71.	STD: WALKS BACKWARD 10 STEPS	0 ☐	1 ☐	2 ☐	3 ☐	71.
*	72.	STD: WALKS FORWARD 10 STEPS, CARRYING A LARGE OBJECT WITH 2 HANDS	0 ☐	1 ☐	2 ☐	3 ☐	72.
*	73.	STD: WALKS FORWARD 10 CONSECUTIVE STEPS BETWEEN PARALLEL LINES 20cm (8") APART	0 ☐	1 ☐	2 ☐	3 ☐	73.
*	74.	STD: WALKS FORWARD 10 CONSECUTIVE STEPS ON A STRAIGHT LINE 2cm (3/4") WIDE	0 ☐	1 ☐	2 ☐	3 ☐	74.
*	75.	STD: STEPS OVER STICK AT KNEE LEVEL, R FOOT LEADING	0 ☐	1 ☐	2 ☐	3 ☐	75.
*	76.	STD: STEPS OVER STICK AT KNEE LEVEL, L FOOT LEADING	0 ☐	1 ☐	2 ☐	3 ☐	76.
*	77.	STD: RUNS 4.5m (15'), STOPS & RETURNS	0 ☐	1 ☐	2 ☐	3 ☐	77.
*	78.	STD: KICKS BALL WITH R FOOT	0 ☐	1 ☐	2 ☐	3 ☐	78.
*	79.	STD: KICKS BALL WITH L FOOT	0 ☐	1 ☐	2 ☐	3 ☐	79.
*	80.	STD: JUMPS 30cm (12") HIGH, BOTH FEET SIMULTANEOUSLY	0 ☐	1 ☐	2 ☐	3 ☐	80.
*	81.	STD: JUMPS FORWARD 30 cm (12"), BOTH FEET SIMULTANEOUSLY	0 ☐	1 ☐	2 ☐	3 ☐	81.
*	82.	STD ON R FOOT: HOPS ON R FOOT 10 TIMES WITHIN A 60cm (24") CIRCLE	0 ☐	1 ☐	2 ☐	3 ☐	82.
*	83.	STD ON L FOOT: HOPS ON L FOOT 10 TIMES WITHIN A 60cm (24") CIRCLE	0 ☐	1 ☐	2 ☐	3 ☐	83.
*	84.	STD, HOLDING 1 RAIL: WALKS UP 4 STEPS, HOLDING 1 RAIL, ALTERNATING FEET	0 ☐	1 ☐	2 ☐	3 ☐	84.
*	85.	STD, HOLDING 1 RAIL: WALKS DOWN 4 STEPS, HOLDING 1 RAIL, ALTERNATING FEET	0 ☐	1 ☐	2 ☐	3 ☐	85.
*	86.	STD: WALKS UP 4 STEPS, ALTERNATING FEET	0 ☐	1 ☐	2 ☐	3 ☐	86.
*	87.	STD: WALKS DOWN 4 STEPS, ALTERNATING FEET	0 ☐	1 ☐	2 ☐	3 ☐	87.
*	88.	STD ON 15cm (6") STEP: JUMPS OFF, BOTH FEET SIMULTANEOUSLY	0 ☐	1 ☐	2 ☐	3 ☐	88.

TOTAL DIMENSION E ☐

Was this assessment indicative of this child's "regular" performance? YES ☐ NO ☐

COMMENTS:

GMFM RAW SUMMARY SCORE

DIMENSION	CALCULATION OF DIMENSION % SCORES	GOAL AREA (indicated with ✓ check)
A. Lying & Rolling	$\frac{\text{Total Dimension A}}{51} = \frac{\quad}{51} \times 100 = \quad\%$	A. ☐
B. Sitting	$\frac{\text{Total Dimension B}}{60} = \frac{\quad}{60} \times 100 = \quad\%$	B. ☐
C. Crawling & Kneeling	$\frac{\text{Total Dimension C}}{42} = \frac{\quad}{42} \times 100 = \quad\%$	C. ☐
D. Standing	$\frac{\text{Total Dimension D}}{39} = \frac{\quad}{39} \times 100 = \quad\%$	D. ☐
E. Walking, Running & Jumping	$\frac{\text{Total Dimension E}}{72} = \frac{\quad}{72} \times 100 = \quad\%$	E. ☐

TOTAL SCORE = $\frac{\%A + \%B + \%C + \%D + \%E}{\text{Total \# of Dimensions}}$

$= \frac{\quad + \quad + \quad + \quad + \quad}{5} = \frac{\quad}{5} = \quad\%$

GOAL TOTAL SCORE = $\frac{\text{Sum of \% scores for each dimension identified as a goal area}}{\text{\# of Goal areas}}$

$= \frac{\quad}{\quad} = \quad\%$

GMFM-66 Gross Motor Ability Estimator Score [1]

GMFM-66 Score = _____ _____ to _____ 95% Confidence Intervals

previous GMFM-66 Score = _____ _____ to _____ 95% Confidence Intervals

change in GMFM-66 = _____

[1] from the Gross Motor Ability Estimator (GMAE) Software

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TESTING WITH AIDS/ORTHOSES

Indicate below with a check (✓) which aid/orthosis was used and what dimension it was first applied. (There may be more than one).

AID		DIMENSION	ORTHOSIS		DIMENSION
Rollator/Pusher	☐	____	Hip Control	☐	____
Walker	☐	____	Knee Control	☐	____
H Frame Crutches	☐	____	Ankle-Foot Control	☐	____
Crutches	☐	____	Foot Control	☐	____
Quad Cane	☐	____	Shoes	☐	____
Cane	☐	____	None	☐	____
None	☐	____	Other	☐	____
Other	☐	____	_____ (please specify)		

_____
(please specify)

RAW SUMMARY SCORE USING AIDS/ORTHOSES

DIMENSION	CALCULATION OF DIMENSION % SCORES	GOAL AREA (indicated with ✓ check)
F. Lying & Rolling	$\frac{\text{Total Dimension A}}{51} = \frac{\quad}{51} \times 100 = \quad\%$	A. ☐
G. Sitting	$\frac{\text{Total Dimension B}}{60} = \frac{\quad}{60} \times 100 = \quad\%$	B. ☐
H. Crawling & Kneeling	$\frac{\text{Total Dimension C}}{42} = \frac{\quad}{42} \times 100 = \quad\%$	C. ☐
I. Standing	$\frac{\text{Total Dimension D}}{39} = \frac{\quad}{39} \times 100 = \quad\%$	D. ☐
J. Walking, Running & Jumping	$\frac{\text{Total Dimension E}}{72} = \frac{\quad}{72} \times 100 = \quad\%$	E. ☐

TOTAL SCORE = $\frac{\%A + \%B + \%C + \%D + \%E}{\text{Total \# of Dimensions}}$

$= \frac{\quad + \quad + \quad + \quad + \quad}{5} = \frac{\quad}{5} = \quad\%$

GOAL TOTAL SCORE = $\frac{\text{Sum of \% scores for each dimension identified as a goal area}}{\text{\# of Goal areas}}$

$= \quad = \quad\%$

GMFM-66 Gross Motor Ability Estimator Score [1]

GMFM-66 Score = _____ _____ to _____ 95% Confidence Intervals

previous GMFM-66 Score = _____ _____ to _____ 95% Confidence Intervals

change in GMFM-66 = _____

[1] from the Gross Motor Ability Estimator (GMAE) Software

GROSS MOTOR CLASSIFICATION SYSTEM FOR CHILDREN WITH CP

Child:
Age:
Date of Analysis:

Level	Level One	Level Two	Level Three	Level Four	Level Five
Mobility	Walks without restrictions, limitations in more advanced gross motor skills	Walks with assisted devices, limitations walking outdoors	Walks with assisted mobility devices, limitations walking outdoors	Self-mobility with limitations, children are transported or use power mobility	Self-mobility is severely limited even with the use of assistive technology
Before 2 years	Crawl, manipulate objects, sit on floor	Sit on floor but use hands for balance, creep on stomach, may pull themselves up to standing	Sit if back supported, roll or creep on stomach	Head control but no trunk support, roll to supine, may roll to prone	2-12 years Very limited voluntary movements, require assistance to roll, unable to maintain anti-gravity positions All areas of motor function are limited, problems sitting and standing are not fully compensated for by adaptive equipment, no means of independent mobility
2-4 years	Sit and stand without assistance, walking preferred	Sit and stand without assistance, crawl, can move along furniture	Maintain floor sitting but may require assistance to be seated, creep on stomach or hands/knees, may cruise for short distances	Frequently require adaptive equipment for sitting and standing, self-mobility may be achieved through rolling or creeping	
4-6 years	Can sit and get up independently, walk and climb stairs	Can sit and stand but may require a stable surface to push or pull, walk, climb stairs using a railing	Sit on regular chairs but may require pelvic or trunk support, move in and out of chairs by pushing/pulling, short walks	Need adaptive seating, sit and stand with assistance, walk short distances on even surfaces, may achieve self-mobility with a powered wheelchair	
6-12 years	Walk and climb stairs with no limitations, run and jump, but speed, balance and coordination may be reduced	Walk and climb stairs but may have difficulties on uneven surfaces or in crowded areas, limited running and jumping	Walk with an assistive mobility device, climb stairs with railing, may propel a wheelchair manually	Maintain level of function achieved by 6 years, or rely on wheeled mobility, may achieve self-mobility with a powered wheelchair	

Source: Development and Reliability of a system to classify gross motor function in children with cerebral palsy
Pallisano et al. DM&CN (1997) 39:214-223

APPENDIX G: SUMMARY OF THE GMCS

APPENDIX H: MODIFIED ASHWORTH SCALE FOR GRADING SPASTICITY

GRADE	DESCRIPTION
0	No increase in muscle tone
1	Slight increase in muscle tone, manifested by a catch and release or by minimal resistance at the end of the range of motion when the affected part(s) is moved in flexion or extension
1+	Slight increase in muscle tone, manifested by a catch, followed by minimal resistance throughout the remainder (less than half) of the range of movement
2	More marked increase in muscle tone through most of the range of movement, but affected part(s) easily moved
3	Considerable increase in muscle tone, passive movement difficult
4	Affected part(s) rigid in flexion or extension

Taken from: (Bohannon and Smith 1987)

Bohannon, R. and M. Smith (1987). "Interrater Reliability of a Modified Ashworth Scale of Muscle Spasticity." Physical Therapy **67**(2): 206-207.

APPENDIX I: ACTIVITY DIARY FOR THE ENERGY BALANCE STUDY

ENERGY BALANCE STUDY
ACTIVITY RECORD

Participant:
Record Taker:

Please answer the following questions regarding your child's usual activity level:

Question:	Answer:
1. My child usually sleeps _____ hours each night.	
2. During the day, my child will spend _____ hours napping.	
3. My child spends the majority of the day in bed or lying down.	T / F
4. My child spends the majority of the day in his/her chair.	T / F
5. My child is always fidgeting.	T / F
6. My child has very tense muscles much of the time.	T / F
7. My child attends _____ hours per week of physiotherapy.	
8. My child attends _____ hours per week of hydrotherapy.	
9. My child attends _____ hours per week of other physical activities.	
10. My child actively participates in these sessions.	T / F

Here are some examples of activities your child may participate in:

Time	Duration	Activity	Participation of Child
10am	1 hour	Swimming	(Child) held and moved through water. Enjoyed session!
1pm	30 min	Swimming	(Child) moved his arms and legs vigorously in the water.
2:30 pm	1 hour	Playing on floor	(Child) rolled and reached for toys.
4 pm	45 min	Physiotherapy	Therapist worked with (child's) legs and arms. (Child) did not move herself.

ACTIVITY RECORD

	Time	Duration	Activity	Child's Participation
DAY ONE				
DAY TWO				
DAY THREE				

Thank you very much for taking the time to fill out this form.
Any Questions? Please call Allison or Angharad on 01865 222000.

APPENDIX J: ABBREVIATIONS USED

% BF	Percentage Body Fat (by Weight)
BC	Body Composition
BCM	Body Cell Mass
BMC	Bone Mineral Content
BMD	Bone Mineral Density
BMI	Body Mass Index
BMR	Basal Metabolic Rate
CHOL	Cholesterol
CNS	Central Nervous System
CO_2	Carbon Dioxide
CP	Cerebral Palsy
DIT	Diet Induced Thermogenesis
DLW	Doubly Labelled Water
EAR	Estimated Average Requirement
EB	Energy Balance
EBS	Energy Balance Study
ECW	Extracellular Water
FFM	Fat-free Mass
FFMI	Fat-free Mass Index
FM	Fat Mass
FMI	Fat Mass Index
GH	Growth Hormone
GMCS	Gross Motor Classification System
GMFM	Gross Motor Function Measure
GOR	Gastro-oesophageal Reflux
GS	Gastrostomy Study
G-tube	Gastrostomy-tube
H	Hydrogen
^{2}H	Deuterium
^{3}H	Tritium
HC	Head Circumference
HR	Heart Rate
HRQoL	Health Related Quality of Life
ICW	Intracellular Water
kcal	kilo-calorie
kg	kilo-grams
LLL	Lower Leg Length
MUAC	Mid Upper Arm Circumference
MUFA	Mono-unsaturated Fatty Acids
N	Number of participants
N	Total Body Water Pool
NG-tube	Naso-gastric tube

^{18}O	Enriched Oxygen
O_2	Oxygen
OBW	Original Body Weight
OHLS	Oxford Healthy Life Survey
OLLL	Original Lower Leg Length
OUAL	Original Upper Arm Length
PAL	Physical Activity Level
PC	Pearson Correlation
PEDI	Pediatric Evaluation Disability Inventory
PEG	Percutaneous Endoscopic Gastrostomy
ppm	Parts per million
PUFA	Poly-unsaturated Fatty Acids
QoL	Quality of Life
RDA	Recommended Daily Allowance
REE	Resting Energy Expenditure
RMR	Resting Metabolic Rate
RNI	Recommended Nutrient Intake
RQ	Respiratory Quotient
SD	Standard Deviation
SF-36	Short Form 36
SFA	Saturated Fatty Acids
SNS	Sympathetic Nervous System
SPSS	Statistics Package for the Social Sciences
SQCP	Spastic Quadriplegic Cerebral Palsy
TBW	Total Body Water
TEE	Total Energy Expenditure
TEF	Thermic Effect of Food
UAL	Upper Arm Length
VCO_2	Volume of Carbon Dioxide
VO_2	Volume of Oxygen
WHO	World Health Organization