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Gastrostomy feeding versus oral feeding alone for children with cerebral palsy (Review)

Gantasala S, Sullivan PB, Thomas AG

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[Intervention Review]

Gastrostomy feeding versus oral feeding alone for children with cerebral palsy

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ABSTRACT

Background

Children with cerebral palsy can be significantly disabled in terms of their ability to suck, chew and swallow. This can lead to significant impairment in feeding and, eventually, to undernutrition. It can also result in aspiration of food into the lungs. Length of feeding time may be considerably increased and, instead of being an enjoyable experience, mealtimes may be distressing for both child and carer. For children unable to maintain a normal nutritional state feeding by mouth, gastrostomy or jejunostomy tubes are increasingly being used to provide the digestive system with nutrients. A gastrostomy tube is a feeding tube inserted surgically through the abdominal wall directly into the stomach. A jejunostomy feeding tube is inserted into the jejunum, part of the small intestine, either directly or via a previous gastrostomy. Although gastrostomy or jejunostomy placement may greatly facilitate the feeding of children with cerebral palsy, many carers find it very emotionally difficult to accept this intervention. Moreover, the intervention is costly and there is the possibility of complications. The effectiveness and safety of the treatment requires further assessment. This review is an update of one previously published in 2004.

Objectives

To assess the effects of nutritional supplementation given via gastrostomy or jejunostomy to children with feeding difficulties due to cerebral palsy.

Search methods

For this update, we searched the following databases in July 2012: CENTRAL, MEDLINE , Embase, CINAHL, Science Citation Index, Conference Proceedings Citation Index, LILACS and Zetoc. We searched for trials in ICTRP and Clinicaltrials.gov, and for theses in WorldCat and Proquest Index to Theses. We also contacted other researchers and experts in this field.

Selection criteria

We looked for randomised controlled trials that compared delivery of nutrition via a gastrostomy or jejunostomy tube compared with oral feeding alone for children up to the age of 16 years.

Data collection and analysis

Screening of search results was undertaken independently by two review authors. No data extraction was possible as there were no included studies.

Main results

No trials were identified that met the inclusion criteria for this review.

Authors' conclusions

Considerable uncertainty about the effects of gastrostomy for children with cerebral palsy remains. A well designed and conducted randomised controlled trial should be undertaken to resolve the current uncertainties about medical management for children with cerebral palsy and physical difficulties in eating.

PLAIN LANGUAGE SUMMARY

Feeding by tube into the stomach or intestine versus feeding by mouth for children with cerebral palsy

Children with cerebral palsy can have problems with sucking, chewing and swallowing. This can make it difficult to eat and lead eventually to undernutrition or problems caused by food going down the wrong way and getting into the lungs. Mealtimes may be long and distressing for the child and for their carer. Increasingly, feeding by a surgically-inserted tube into the stomach (gastrostomy) or via a tube inserted into the middle of the small intestine (jejunostomy) is used to provide such children with nutrition. These processes can be costly, as well as being emotionally difficult for families, and complications are possible. We searched 12 databases in July 2012 but did not find any studies that randomly put children into two groups to investigate the effects of tube feeding via gastrostomy (or jejunostomy) compared to feeding by mouth only. Well-designed studies are needed to help medical professionals and families make difficult decisions about how to treat children with cerebral palsy and physical difficulties in eating.

BACKGROUND

Description of the condition

Children with cerebral palsy (CP) can be significantly disabled in terms of their ability to move. This disability may affect not only walking and hand function but also speech and the ability to suck, chew and swallow. This can lead to significant impairment in feeding ability and, eventually, to undernutrition. It can also result in food going down the wrong way (aspiration) and getting into the lungs. Feeding time may be considerably increased and, instead of being an enjoyable experience, mealtimes may be distressing for both the child and the carer. The only alternative, at present, to feeding by mouth is to deliver nutrients by a tube inserted into the stomach. This can be via a tube passed through the nose (nasogastric or 'NG' tube). The NG route is still used for long-term nutritional support in some circumstances but now it is generally recommended that tube feeding via gastrostomy (or jejunostomy) should be considered if non-oral feeding is likely to be required for longer than six weeks (Lloyd 1996).

Description of the intervention

Increasingly, for children with cerebral palsy who have very severe difficulties in eating and who are therefore unable to maintain a normal nutritional state feeding by mouth alone, gastrostomy or jejunostomy tubes are being used to provide nutrients (Shapiro 1986; Rempel 1988; Corwin 1996; Darwish 1999; Smith 1999; Sullivan 2005). A gastrostomy tube is a feeding tube inserted surgically through the abdominal wall directly into the stomach. A jejunostomy feeding tube is inserted into the jejunum (a part of the small intestine), either directly or via a previous gastrostomy. The surgical technique used may vary according to the specific needs of each child. Sometimes it is necessary to open the abdomen to insert the tube and this is usually the case when an additional procedure (a fundoplication) is required to treat vomiting. More commonly, the gastrostomy tube is placed using a fibreoptic endoscope inserted through the mouth and this procedure (a percutaneous endoscopic gastrostomy or 'PEG') avoids open abdominal surgery. Although gastrostomy or jejunostomy placement may greatly facilitate feeding of children with cerebral palsy, many carers find it very difficult to accept this intervention (Spalding 1998; Petersen 2006). Because eating (by mouth) is seen as normal and delivering food to one's child via a hole in the stomach is seen as abnormal, the decision to place a gastrostomy often involves deep emotions for parents (Thorne 1997; Spalding 1998; Nicholls-Sleigh 2000).

Gastrostomy is not only used to provide nourishment for children with cerebral palsy; it is used for people of all ages, from infants to the elderly, and for a wide variety of medical conditions. These include situations of rehabilitation where full recovery of eating ability may be anticipated, such as after head injury; and in other extreme situations of terminal care for people with progressive disease where the underlying condition itself carries an increased risk of death. Therefore the underlying medical condition affects the outcome. Children with cerebral palsy have a non-progressive disorder but the physical disability, which results in the eating difficulties, persists. The relevance for children with cerebral palsy of findings from studies that include a majority of adults or a majority of children with disorders other than cerebral palsy is unclear.

How the intervention might work

In practice, paediatricians consider use of gastrostomy tube feeding as an intervention for children with neurological impairment even though high quality research on its effects is lacking (Canadian Paediatric Society 2009; NASPGHAN 2006). Two older systematic reviews (Samson-Fang 2003; Sleigh 2004), both including observational studies, reported severe methodological weaknesses in the studies they included. They concluded that implications for practice were therefore uncertain. The reviews highlighted specific gaps in knowledge about gastrostomy feeding for children with cerebral palsy.

Most children gain weight (Sullivan 2005) when tube feeding commences, but whether there are other benefits is less clear (Patrick 1986; Sleigh 2004). There are some reports of improved mood and less irritability in children fed by gastrostomy tube following tube insertion (retrospective comparison) (Sleigh 2004). While gaining weight makes the children look healthier (Thorne 1997; Nicholls-Sleigh 2000), however, the increased weight sometimes causes problems with handling and lifting (Nicholls-Sleigh 2000).

One cohort study (Strauss 1998) suggested that the risk of death was increased in children with cerebral palsy who were fed by gastrostomy tube, but other authors, reporting on case series studies, did not find any increased risk of mortality (Plioplys 1998; Smith 1999).

Another cohort study (Fung 2002) reported less chest (respiratory) illness in children with cerebral palsy who were fed by gastrostomy compared with children, also severely disabled with cerebral palsy, who took all their nourishment by mouth. Sullivan 2006 reiterated this. A possible explanation is that there was less gastroesophageal reflux (GOR) of acid stomach juices into the lungs following gastrostomy. However, a number of case studies have reported that GOR worsened following gastrostomy feeding (Heine 1995; Bachrach 1998; Sulaeman 1998).

A prospective study reported improved quality of life (using the SF-36 (Ware 1992)) for carers of disabled children following their child's gastrostomy (Sullivan 2002), while Fung 2002 reported that parental emotional well-being of the parents was lower in families feeding their child by gastrostomy compared with families whose children were fed by mouth. A more recent prospective longitudinal study of tube feeding in neurologically impaired children reported positive impact on the child's health but no improvement in quality of life for parents (Mahant 2009). Qualitative studies (Thorne 1997; Spalding 1998; Nicholls-Sleigh 2000) have described the emotional turmoil that families frequently undergo when faced with the decision about whether to accept gastrostomy feeding for their child. Qualitative studies have also suggested that the main benefit of gastrostomy for both children and families is the sense that pressure has been taken off oral feeding (Thorne 1997; Townsley 2000); however, new and unexpected problems may arise, such as mothers' reports of feeling less social support and finding it less easy to get out and about (Brotherson 1995; Spalding 1998; Townsley 2000).

While no formal economic evaluation has been carried out, gastrostomy feeding is costly: the costs of the operation, provision of equipment, the special commercially prepared 'feeds' and the cost of pre- and post-operative professional support that are

required, must be met. In the United Kingdom alone, there may be around 5000 children for whom this treatment is or could be applied (Sullivan 2002). With an estimated cost of between 3000 to 5000 GBP per child per annum, the annual cost of tube feeding disabled children could be between 15 million and 25 million GBP.

Why it is important to do this review

It is important to update this systematic review to see if it is possible to provide a stronger evidence base to guide families and their professional advisers through the difficult decision about feeding via a gastrostomy (O'Connell 2001; Sleigh 2004; Sleigh 2005; Mahant 2011).

OBJECTIVES

To assess the effects of nutritional supplementation given via gastrostomy or jejunostomy in children with feeding difficulties due to cerebral palsy.

METHODS

Criteria for considering studies for this review

Types of studies

Randomised controlled trials (RCTs).

Types of participants

Children up to the age of 16 years of age with cerebral palsy (as defined by trialists) and feeding difficulties and who were receiving nutrition solely by mouth prior to study entry.

We did not plan to include studies in which a majority of the children had feeding difficulties due to causes other than cerebral palsy, who had undernutrition for other reasons or who were already having nutrition by tube (for example, nasogastric or parenteral) prior to study entry or studies that included a majority (over 50%) of adults (over 16 years of age).

Types of interventions

Delivery of nutrition via a gastrostomy or jejunostomy tube compared with oral feeding alone. The intervention group could include children, who 1) also received some food by mouth; 2) had had surgical anti-reflux procedures performed; 3) were taking anti-reflux or other medication.

The control group could be children, as defined above, who were still being fed solely by mouth regardless of whether:

1) they received dietary supplements;
2) the texture of food was modified (for example, thickening liquids);
3) special interventions to enhance oral feeding were used (such as an oral appliance, oromotor therapy, etc);
4) an anti-reflux or other relevant surgical procedure had been performed;
5) anti-reflux or other medication had been given.

Types of outcome measures

We planned to measure outcomes for both study participants (infant/child/teenager) and carers/family members.

Child outcomes

- Death
- Major medical complications of the surgery required to place the feeding tube (as defined by the trial authors); for example, peritonitis, cologastric fistula
- Other complications of the surgery
- Other complications related to the feeding tube
- Weight
- Other measures of nutritional status as defined by the authors
- Linear growth
- Type of feeding: oral, gastrostomy, jejunostomy or mixed
- Quality of life for child using a scale that has undergone formal psychometric testing or one that has been used in more than one study. Other criteria for judging the scale would be that the review authors judge it to be appropriate for children with cerebral palsy, responsive to change over time and to have a readily interpretable scoring system
- Functional assessment using a tool with properties as above; for example, the gross motor function classification system (Palisano 1997)
- Surgical procedures related to the feeding disorder
- Chest infections (as defined by the trial authors) requiring hospital admission
- Chest infections (as defined by the trial authors) treated at home
- Vomiting frequency
- Use of anti-reflux medication during trial author's specified follow-up period
- Use of anti-convulsant medication during trial author's specified follow-up period
- Frequency and/or severity of convulsions
- Time spent in feeding-related activities (as defined by trial authors) at the specified follow-up periods

Carer/family outcomes

- Physical health of principal carer using a tool that has undergone formal psychometric testing or has been used in more than one study and is judged by the review authors to be appropriate, is responsive to change over time and has a readily interpretable scoring system
- Psychosocial aspects for principal carer/family including carer/family stress, employment/financial issues and family relationships using an accepted measure as defined above

We planned to consider outcomes as short term (within six months - to reflect early effects related to surgery), medium term (within five years) and long term (more than five years from trial entry).

Search methods for identification of studies

Electronic searches

Searches for the original review were restricted to years post 1980. This is because the PEG was first described in 1980 and it is only since then that gastrostomy tube feeding has become widely used for children with cerebral palsy. For this update, we searched the following databases in July and August 2012. We limited the updated searches to the period following the publication of the original review (2004 onwards) unless the database had not been

searched previously, in which case we searched all available years. Details of the updated searches are in Appendix 1.

Cochrane Central Register of Controlled Trials (CENTRAL), part of the Cochrane Library 2012 Issue 7, searched 17 August 2012
Ovid MEDLINE(R) without Revisions, 1996 to August Week 2 2012, searched 17 August 2012
EMBASE, 1974 to 2012 August 16, searched 17 August 2012
CINAHL via NHS Evidence searched 17 August 2012
Science Citation Index (Web of Science), 1970 to 18 July 2012, searched 18 July 2012
Conference Proceedings Citation Index -Science (Web of Science), 1990 to 18 July 2012, searched 18 July 2012
ZETOC (limited to conference proceedings) searched 18 July 2012
Proquest Index to Theses (UK and Ireland) searched 19 July 2012
WorldCat (limited to theses and dissertations) searched 19 July 2012
ClinicalTrials.gov (www.clinicaltrials.gov/) searched 18 July 2012
WHO ICTRP (apps.who.int/trialsearch/) searched 18 July 2012

Language restrictions were not applied to the database searches. References of identified articles were searched for additional studies when these articles were directly on the topic, even if not reporting a randomised controlled trial (RCT).

Searching other resources

For the original review, Gillian Sleigh wrote to leading clinicians, researchers, manufacturers of relevant equipment (such as gastrostomy tubes, 'buttons', etc) and pharmaceutical companies that produce the 'feeds' and anti-reflux medication to ask whether they were aware of any studies not identified by the searches described above. None of these colleagues knew of any relevant RCTs.

In June 2013, we contacted several experts in the field by email to ask if they were aware of any randomised controlled trials, published or unpublished, that we might have missed. Those who replied did not know of any relevant RCTs.

Data collection and analysis

No trials were identified as meeting inclusion criteria for this review. See Table 1 for analysis methods to be used if relevant studies are identified in the future.

Selection of studies

For the original review, titles and abstracts of studies identified by searches of electronic databases were read independently by two review authors (GS and AT) to determine whether they might meet the inclusion criteria. Full copies of those possibly meeting these criteria found either on electronic searching or other methods were assessed by two independent review authors (PS and AT). Differences of opinion about suitability for inclusion were resolved by discussion. A third review author (GS) was available for arbitration if required. For the update, SG took the lead role in screening the search results.

RESULTS

Description of studies

No studies were found that met the inclusion criteria for this systematic review.

Risk of bias in included studies

No studies were found that met the inclusion criteria for this systematic review.

Effects of interventions

No studies were found that met the inclusion criteria for this systematic review.

DISCUSSION

The objectives of this review were to assess the beneficial or harmful effects that may occur as a result of gastrostomy or jejunostomy tube feeding for children with cerebral palsy, when compared with oral feeding alone. No randomised controlled trials were identified that met the inclusion criteria. This does not imply that there are no benefits or hazards of such treatments, merely that there is no reliable evidence available from which to draw conclusions at present. The review says nothing about the relative risks and benefits of gastrostomy or oral feeding compared with nasogastric (NG) tube feeding. The main reason that NG feeding was not included in this review is that, although the NG route is still used for nutritional support in some circumstances, it is now unusual as a long-term strategy. It is generally recommended that tube feeding via gastrostomy (or jejunostomy) should be considered if non-oral feeding is likely to be required for longer than six weeks (Lloyd 1996).

A stronger evidence base is required to guide families and their professional advisers through the difficult decision about feeding via a gastrostomy (O'Connell 2001; Sleigh 2004). An RCT to assess both benefits and harms of gastrostomy feeding versus oral feeding alone for children with cerebral palsy is essential.

AUTHORS' CONCLUSIONS

Implications for practice

As shown by this systematic review and those of Sleigh and Brocklehurst (Sleigh 2004) and Samson-Fang et al (Samson-Fang 2003), considerable uncertainty about the effects of gastrostomy for children with cerebral palsy remains. This makes it difficult for clinicians to guide parents when faced with the difficult decision about whether to accept or reject the offer of gastrostomy for a child who has cerebral palsy and difficulties with eating. Likewise, there are no reliable sources of information to which parents may be directed in order to find out information for themselves.

Implications for research

A well designed and conducted randomised controlled trial of gastrostomy feeding versus oral feeding for children with cerebral palsy should be undertaken to resolve the current uncertainties about medical management for children with cerebral palsy who have physical difficulties with eating. Barriers to such research include the complexity and costs of organising what would necessarily be a large multi-centre randomised controlled trial with power sufficient to detect moderate-sized treatment effects. In the continued absence of such a trial, a future update of this review may incorporate different study designs in order to analyse the available evidence.

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REFERENCES

Additional references

Bachrach 1998

Bachrach S, Melnychuk JO, Vinton NE, Davis M, Shaffer S, Mehta D, et al. Percutaneous endoscopic gastrostomy (PEG) tubes for enteral nutrition support (ENS) in neurologically impaired children. *Developmental Medicine and Child Neurology* 1998;**40 Suppl s78**:16.

Brotherson 1995

Brotherson MJ, Oakland MJ, Secrist-Mertz C, Litchfield R, Larson K. Quality of life issues for families who make the decision to use a feeding tube for their child with disabilities. *Journal for the Association for Persons with Severe Handicaps* 1995;**20**(3):202-12.

Canadian Paediatric Society 2009

Marchand V, Canadian Paediatric Society, Nutrition and Gastroenterology Committee. Nutrition in neurologically impaired children. Canadian Paediatric Society Position Statement. *Paediatric Child Health* 2009;**14**(6):395-401.

Corwin 1996

Corwin DS, Isaacs JS, Georgeson KE, Bartolucci AA, Cloud HH, Craig CB. Weight and length increases in children after gastrostomy placement. *Journal of the American Dietetic Association* 1996;**96**(9):874-9.

Darwish 1999

Darwish H. Living with cerebral palsy and tube feeding: easier to feed but at what cost?. *Journal of Pediatrics* 1999;**135**(3):272-3.

Egger 1997

Egger M, Davey Smith G, Schneider M, Minder C. Bias in meta-analysis detected by a simple, graphical test. *BMJ* 1997;**315**(7109):629-34.

Fung 2002

Fung EB, Samson-Fang L, Stallings VA, Conaway M, Liptak G, Henderson RC. Feeding dysfunction is associated with poor growth and health status in children with cerebral palsy. *Journal of the American Dietetic Association* 2002;**102**(3):361-8.

Heine 1995

Heine RG, Reddihough DS, Catto-Smith AG. Gastro-oesophageal reflux and feeding problems after gastrostomy in children with severe neurological impairment. *Developmental Medicine and Child Neurology* 1995;**37**(4):320-9.

Higgins 2002

Higgins JP, Thompson SG. Quantifying heterogeneity in a meta-analysis. *Statistics in Medicine* 2002;**21**(11):1539-58.

Higgins 2008

Higgins JPT, Green S (editors). Cochrane Handbook for Systematic Reviews of Interventions. Chicester: John Wiley & Sons, 2008.

Lloyd 1996

Lloyd DA, Pierro A. The therapeutic approach to the child with feeding difficulty: III Enteral feeding. In: Sullivan PB, Rosenbloom L editor(s). Feeding the Disabled Child. Cambridge: MacKeith Press, 1996:132-50.

Mahant 2009

Mahant S, Friedman JN, Connolly B, Goia C, Macarthur C. Tube feeding and quality of life in children with severe neurological impairment. *Archives of Disease in Childhood* 2009;**94**(9):668-73.

Mahant 2011

Mahant S, Jovcevska V, Cohen E. Decision-making around gastrostomy-feeding in children with neurologic disabilities. *Pediatrics* 2011;**127**(6):1471-81.

NASPGHAN 2006

Marchand V, Motil KJ, NASPGHAN Committee on Nutrition. Nutrition support for neurologically impaired children: a clinical report of the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition. *Journal of Pediatric Gastroenterology and Nutrition* 2006;**43**(1):123-35.

Nicholls-Sleigh 2000

Nicholls-Sleigh G. The Experience and Meaning of Feeding Children with Severe Dysphagia due to Cerebral Palsy: A Phenomenological Study [MSc dissertation]. Oxford: Kellogg College, 2000.

O'Connell 2001

O'Connell D, Glasziou P, Hill S, Sarunac J, Lowe J, Henry D. Results of clinical trials and systematic reviews: to whom do they apply?. In: Stevens A, Abrams K, Brazier J, Fitzpatrick R, Lilford R editor(s). The Advanced Handbook of Methods in Evidence Based Healthcare. London: Sage, 2001.

Palisano 1997

Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine and Child Neurology* 1997;**39**(4):214-23.

Patrick 1986

Patrick J, Boland M, Stoski D, Marray GE. Rapid correction of wasting in children with cerebral palsy. *Developmental Medicine and Child Neurology* 1986;**28**(6):734-9.

Petersen 2006

Petersen MC, Kedia S, Davis P, Newman L, Temple C. Eating and feeding are not the same: caregivers' perceptions of gastrostomy feeding for children with cerebral palsy. *Developmental Medicine and Child Neurology* 2006;**48**(9):713-7. [DOI: 10.1111/j.1469-8749.2006.tb01354.x]

Plioplys 1998

Plioplys AV, Kasnicka I, Lewis S, Moller D. Survival rates among children with severe neurologic disabilities. *Southern Medical Journal* 1998;**91**(2):161-72.

Rempel 1988

Rempel GR, Colwell SO, Nelson RP. Growth in children with cerebral palsy fed via gastrostomy. *Pediatrics* 1988;**82**(6):857-62.

Samson-Fang 2003

Samson-Fang L, Butler C, O'Donnell M. Effects of gastrostomy feeding in children with cerebral palsy: an AACPDM evidence report. *Developmental Medicine and Child Neurology* 2003;**45**(6):415-26.

Shapiro 1986

Shapiro BK, Green P, Krick J, Allen D, Capute AJ. Growth of severely impaired children: neurological versus nutritional factors. *Developmental Medicine and Child Neurology* 1986;**28**(6):729-33.

Sleigh 2004

Sleigh G, Brocklehurst P. Gastrostomy feeding in cerebral palsy: a systematic review. *Archives of Disease in Childhood* 2004;**89**(6):534-9.

Sleigh 2005

Sleigh G. Mothers' voice: a qualitative study on feeding children with cerebral palsy. *Child: Care, Health and Development* 2005;**31**(4):373-83.

Smith 1999

Smith SW, Camfield C, Camfield P. Living with cerebral palsy and tube feeding: a population-based follow-up study. *Journal of Pediatrics* 1999;**135**(3):3-10.

Spalding 1998

Spalding K, McKeever P. Mothers' experiences caring for children with disabilities who require a gastrostomy tube. *Journal of Pediatric Nursing* 1998;**13**(4):234-43.

Strauss 1998

Strauss DJ, Shavelle RM, Anderson TW. Life expectancy of children with cerebral palsy. *Pediatric Neurology* 1998;**18**(2):143-9.

Sulaeman 1998

Sulaeman E, Udall JN Jr, Brown RF, Mannick EE, Loe WA, Hill CB, et al. Gastroesophageal reflux and nissen fundoplication following percutaneous endoscopic gastrostomy in children. *Journal of Pediatric Gastroenterology and Nutrition* 1998;**26**(3):269-73.

Sullivan 2002

Sullivan PB, Thomas AG, Eltumi M, Grant H, Lambert B, McLean E, et al. Gastrostomy - tube feeding improves quality of life in caregivers of disabled children. *Archives of Disease in Childhood* 2002;**86 Suppl 1**:A61.

Sullivan 2005

Sullivan PB, Juszczak E, Bachlet AM, Lambert B, Vernon-Roberts A, Grant HW, et al. Gastrostomy tube feeding in children with cerebral palsy: a prospective longitudinal study. *Developmental Medicine and Child Neurology* 2005;**47**(2):77-85.

Sullivan 2006

Sullivan PB, Morrice JS, Vernon-Roberts A, Grant H, Eltumi M, Thomas AG. Does gastrostomy tube feeding in children with cerebral palsy increase the risk of respiratory morbidity?. *Archives of Disease in Childhood* 2006;**91**(6):478-82.

Thorne 1997

Thorne SE, Radford MJ, McCormick J. The multiple meanings of long-term gastrostomy in children with severe disability. *Journal of Pediatric Nursing* 1997;**12**(2):89-99.

Townsley 2000

Townsley R, Robinson C. Food for Thought? Effective Support for Families Caring for a Child who is Tube Fed. Bristol, UK: The Norah Frye Research Centre, 2000.

Ware 1992

Ware JJ, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Medical Care* 1992;**30**(6):473-83.

ADDITIONAL TABLES

Table 1. Additional methods for future updates

Issue	Method
Data extraction and management	It is planned to use paper data collection forms specially devised for use in this review to include information regarding study location, study quality, methods, participant characteristics at baseline (such as age, degree of disability and comorbidities), recruitment period, intervention, length of follow-up, loss to follow-up and outcome measures. The form will be piloted using one or two studies. Data extraction will be performed by two independent review authors for each study and will be scrutinised for disparity (Higgins 2008, section 7.2). Any differences will be resolved by discussion, contacting the authors of the study or independent arbitration as appropriate. Data will be entered into Review Manager software by one review author and checked by another.
Assessment of risk of bias	Included studies will be independently evaluated for risk of bias by two review authors, each of whom will independently assess each study at as high, low or unclear risk of bias using the categories and guidance of the *Cochrane Handbook for Systematic Reviews* (Higgins 2008). *Allocation concealment*

Table 1. Additional methods for future updates *(Continued)*

	Low risk of bias indicates that the report gives a clear description of the method used for random allocation and i) the method was adequate to prevent both the person assessing eligibility for trial entry and the participant from knowing what the allocation would be (for example, through allocation by a central office unaware of the subject characteristics, or use of sequentially numbered, sealed, opaque envelopes); ii) the method was such that after assignment the allocation could not be altered and the decision about eligibility could not be changed. Unclear risk of bias indicates uncertainty about whether allocation was adequately concealed, for example the description of the method for allocation was not clearly described in the study report. If the concealment method is unclear, the authors of the study will be contacted to obtain precise information where possible. High risk of bias indicates that the description of the method for allocation was clearly described but the method was inadequate to guarantee allocation concealment (for example, open random number lists, or quasi-randomisation such as alternate days, odd/even days of birth or hospital numbers). *Blinding* We do not anticipate that blinding to the study intervention for participants (child and family and physician) will ever be possible for this intervention, and blinding is difficult even for the outcome assessor. This is because the intervention is a surgical procedure and the stoma through which the feeds are given and either jejunostomy tube, gastrostomy tube or 'button' (a device at skin level through which feeds are administered) cannot easily be concealed during physical assessment such as weighing. It also involves giving different types of food to the children in the intervention and control groups. The main source of nutrition for the intervention group would usually be commercially prepared 'feeds' whereas the control group would usually be eating ordinary food (even if pureed or commercially prepared baby foods). Thus it would be very difficult for many of the outcomes to guard against performance and detection bias. Use of reliable, valid assessment scales where possible would thus be particularly important (see above under outcome measures). Study quality for this review must therefore be assessed primarily on concealment allocation and analysis using an 'intention to treat' basis. If authors report attempts at assessment blinding this will be discussed. *Selective outcome reporting* We will locate the protocols of any included studies to assess whether all outcomes measured have been reported on and the plan for analysis has been followed. *Incomplete outcome data* Studies should be able to account for all participants at follow-up. If not clearly reported, an attempt will be made to contact the authors for further information. We will establish whether participants were analysed in the groups to which they were randomised, that is, on an intention-to-treat basis and on percentage loss to follow-up.
Measures of treatment effect	Where included studies have measured similar outcomes, we plan to conduct a meta-analysis. For continuous data, and where studies have used the same measure for the outcome, the mean difference and its 95% confidence interval (CI) will be calculated. Where a similar outcome has been measured using different instruments, the standardised mean difference with its 95% CI will be calculated, provided it is considered that combining these results makes clinical sense. For dichotomous data, the odds ratio and its 95% CI will be calculated.
Dealing with missing data	We will analyse data (where practical) on an intention-to-treat basis. Where insufficient data are reported, trialists will be contacted for further information.
Assessment of heterogeneity	Consistency of results will be assessed visually and by examining I^2 (Higgins 2002), a quantity which describes approximately the proportion of variation in point estimates that is due to heterogeneity rather than sampling error. This will be supplemented with a test of homogeneity, to determine the strength of evidence that the heterogeneity is genuine. If heterogeneity is suggested by a marked difference of effect shown on the plotted results or if there are differences in the method, population, intervention or outcomes chosen that suggest important heterogeneity, a random-effects

Table 1. Additional methods for future updates *(Continued)*

	model will be used in addition to a fixed-effect model. The possible reasons for heterogeneity will be explored by scrutinising the studies and, where appropriate, performing subgroup analyses.
Assessment of reporting biases	Should sufficient studies be identified in future, funnel plots will be drawn to investigate any relationship between effect size and study precision (closely related to sample size). Such a relationship could be due to publication bias, but may also be due to poor methodological quality of smaller studies or other systematic differences between small and large studies or may occur by chance (Egger 1997). If a relationship is found, clinical diversity of the studies will be further examined as a possible explanation.
Data synthesis	Assuming two or more studies that are suitable for inclusion are found in future, and assuming also that the study results are similar enough that they can be sensibly grouped together, a meta-analysis will be performed on the results. Both fixed-effect and a random-effects analyses will be performed as part of a sensitivity analysis.
Subgroup analysis and investigation of heterogeneity	Differences that might influence the effectiveness of gastrostomy feeding compared to oral feeding and that we will explore are: *age *presence of symptomatic gastroesophageal reflux or anti-reflux procedure *level of disability (including learning disability) *environmental factors
Sensitivity analysis	Sensitivity analysis will be conducted to determine the impact of risk of bias on outcome if studies of different quality are identified and included (for example, studies whose allocation concealment remains unclear after trying to contact the authors).

APPENDICES

Appendix 1. Search strategies 2012

Cochrane Central Database of Controlled Trials (CENTRAL) searched 17 August 2012

1MeSH descriptor Child explode all trees
#2child in Trials
#3infant in Trials
#4MeSH descriptor Infant explode all trees
#5baby or babies in Trials
#6"young adult*" in Trials
#7"young person*" in Trials
#8"young people" in Trials
#9teenag* in Trials
#10MeSH descriptor Adolescent explode all trees
#11MeSH descriptor Child, Preschool explode all trees
#12(#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11)
#13MeSH descriptor Enteral Nutrition explode all trees
#14tube* near feed* in Trials
#15enteral near feed* in Trials
#16MeSH descriptor Gastrostomy explode all trees
#17MeSH descriptor Jejunostomy explode all trees
#18jejunostom* in Trials
#19gastrojejunostom* in Trials
#20gastro-jejunostom* in Trials
#21(#13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20)
#22MeSH descriptor Cerebral Palsy explode all trees
#23MeSH descriptor Central Nervous System Diseases explode all trees
#24"little* disease" in Trials
#25spastic near/3 diplegia in Trials

#26spastic near/3 quadriplegia in Trials
#27MeSH descriptor Nervous System Diseases explode all trees
#28"nervous system disorder*" in Trials
#29neuro* near disab* in Trials
#30neuro* near impair* in Trials
#31(#22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30)
#32(#12 AND #21 AND #31)
#33(#32), from 2004 to 2012

Ovid MEDLINE(R) without Revisions <1996 to August Week 2 2012> searched 17 August 2012

1 exp Child/ (648497)

2 child$.ti,ab. (464317)

3 exp Infant/ (367799)

4 infant$.ti,ab. (126195)

5 (baby or babies).ti,ab. (24869)

6 (young adj (adult$ or person$ or people)).ti,ab. (41535)

7 teenag$.ti,ab. (8266)

8 exp Adolescent/ (729245)

9 adolescen$.ti,ab. (97003)

10 exp Child, Preschool/ (319971)

11 exp Young Adult/ (225239)

12 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 (1435934)

13 enteral nutrition.mp. or exp Enteral Nutrition/ (9039)

14 (enteral adj (feed$ or nutrition)).ti,ab. (5363)

15 tube feed$.ti,ab. (1581)

16 gastrostomy.mp. or exp Gastrostomy/ (4738)

17 jejunostomy.mp. or exp Jejunostomy/ (2005)

18 jejunostom$.ti,ab. (1114)

19 gastrojejunostomy.mp. (868)

20 gastro-jejunostomy.ti,ab. (57)

21 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 (15424)

22 cerebral palsy.mp. or exp Cerebral Palsy/ (9029)

23 central nervous system diseases.mp. or exp Central Nervous System Diseases/ (550079)

24 little$ disease.ti,ab. (26)

25 (spastic adj3 diplegia).ti,ab. (456)

26 (spastic adj3 quadriplegia).ti,ab. (206)

27 exp Nervous System Diseases/ (973101)

28 nervous system disorder$.ti,ab. (984)

29 (neuro$ adj5 disab$).ti,ab. (3166)

30 (neuro$ adj5 impair$).ti,ab. (13550)

31 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 (980414)

32 12 and 21 and 31 (658)

33 limit 32 to yr="2004 - 2012" (379)

EMBASE <1974 to 2012 August 16> searched 17 August 2012

1 exp child/ (1681105)

2 child$.ti,ab. (1117253)

3 exp infant/ (509550)

4 infant$.ti,ab. (332273)

5 (baby or babies).ti,ab. (60506)

6 (young adj (adult$ or person$ or people)).ti,ab. (80293)

7 teenag$.ti,ab. (17271)

8 exp adolescent/ (1206189)

9 exp preschool child/ (479088)

10 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 (2793246)

11 exp enteric feeding/ (18054)

12 (enteral adj3 (feed$ or nutrition)).ti,ab. (13161)

13 (tube$ adj3 feed$).ti,ab. (6746)

14 tube fed.ti,ab. (490)

15 exp gastrostomy/ (6722)

16 exp jejunostomy/ (2874)

17 jejunostom$ {No Related Terms} (4452)

18 jejunostom$.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword] (4531)

19 exp gastrojejunostomy/ (2319)

20 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 (35800)

21 exp cerebral palsy/ (22395)

22 exp central nervous system disease/ (1640619)

23 little$ disease.ti,ab. (91)

24 (spastic adj3 diplegia).ti,ab. (944)

25 (spastic adj3 quadriplegia).ti,ab. (479)

26 exp neurologic disease/ (2265718)

27 nervous system disorder$.ti,ab. (1995)

28 (neuro$ adj5 disab$).ti,ab. (5992)

29 (neuro$ adj5 impair$).ti,ab. (24627)

30 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 (2276874)

31 10 and 20 and 30 (1247)

32 limit 31 to yr="2004 - 2013" (790)

CINAHL via NHS Evidence searched 17 August

1. CINAHL; CHILD/; 170307 results.
2. CINAHL; child*.ti,ab; 150333 results.
3. CINAHL; INFANT/; 66181 results.
4. CINAHL; infant*.ti,ab; 33651 results.
5. CINAHL; (baby OR babies).ti,ab; 12433 results.
7. CINAHL; teenag*.ti,ab; 4276 results.
8. CINAHL; ADOLESCENCE/; 167077 results.
9. CINAHL; adolescent*.ti,ab; 35149 results.
10. CINAHL; CHILD, PRESCHOOL/; 77372 results.
11. CINAHL; "young adult*".ti,ab; 7612 results.
12. CINAHL; "young person*".ti,ab; 544 results.
13. CINAHL; "young people".ti,ab; 5487 results.
14. CINAHL; 1 OR 2 OR 3 OR 4 OR 5 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13; 376101 results.
15. CINAHL; ENTERAL NUTRITION/; 4292 results.
16. CINAHL; "enteral feed*".ti,ab; 1016 results.
17. CINAHL; (tube* adj3 feed*).ti,ab; 1558 results.
18. CINAHL; GASTROSTOMY/; 664 results.
19. CINAHL; JEJUNOSTOMY/; 135 results.
20. CINAHL; gastrojejunostom*.ti,ab; 47 results.
21. CINAHL; gastro-jejunostom*.ti,ab; 1 results.
22. CINAHL; 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21; 5505 results.
23. CINAHL; CEREBRAL PALSY/; 4840 results.
24. CINAHL; CENTRAL NERVOUS SYSTEM DISEASES/; 775 results.
25. CINAHL; "little* disease".ti,ab; 2 results.
26. CINAHL; "spastic diplegia".ti,ab; 167 results.
27. CINAHL; "spastic quadriplegia".ti,ab; 58 results.
28. CINAHL; NERVOUS SYSTEM DISEASES/; 2562 results.
29. CINAHL; "nervous system disorder*".ti,ab; 103 results.
30. CINAHL; (neuro* adj5 disab*).ti,ab; 906 results.
31. CINAHL; (neuro* adj5 impair*).ti,ab; 2284 results.
32. CINAHL; 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31; 10995 results.
33. CINAHL; 14 AND 22 AND 32; 76 results.
34. CINAHL; RANDOMIZED CONTROLLED TRIALS/; 8205 results.
35. CINAHL; 33 AND 34; 2 results.

LILACSsearched 18 July 2012

(cerebral palsy) or spastic or (cns disorder$) or (central nervous system disorder$) [Words] and enteral or feed$ or nutrition or gastrostom $ [Words]

Limited to PY 2004-2012

Science Citation Index and CPCI-S (Web of Science) searched 19 July 2012. All years searched as not searched previously

7 #6 AND #5
DocType=All document types; Language=All languages;
#6 TS=(child* or baby or babies or teen* or adolescen* or youth* or boy* or girl* or preschool* or infan*)
DocType=All document types; Language=All languages;
#5 #4 AND #3
DocType=All document types; Language=All languages;
#4 TS=(cerebral pals* OR spastic* OR "little* disease")
DocType=All document types; Language=All languages;
#3 #2 OR #1
DocType=All document types; Language=All languages;
#2 TS=(gastrostom* or jejunostom* or gastrojejunostom* or gastro-jejunostom*)
DocType=All document types; Language=All languages;

#1 TS= ((enteral* or tube*) Near/3 (feed* or nutrition*))
DocType=All document types; Language=All languages;

WorldCat (www.worldcat.org/) searched 19 July 2012

(kw:cerebral palsy OR spastic*) AND (kw: enteral*OR tube* OR gastrostom* OR jejunostom* OR gastrojejunostom* OR gastro-jejunostom*) > 'theses/dissertation'

Proquest Index to Theses (UK and Ireland) searched 19 July 2012

all(cerebral pals* OR spastic*) AND all(enteral*OR tube* OR gastrostom* OR jejunostom* OR gastrojejunostom* OR gastro-jejunostom*)

ZETOC (zetoc.mimas.ac.uk/) searched 18 July 2012

11 2 general: spastic* enteral*, 2004-2012
10 5 general: spastic* gastrostom*, 2004-2012
9 0 general: spastic* jejunostom*, 2004-2012
8 0 general: spastic* gastrojejunostom*, 2004-2012
7 0 general: spastic* gastro-jejunostom*, 2004-2012
6 0 general: "cerebral palsy" gastro-jejunostom*, 2004-2012
5 0 general: "cerebral palsy" gastrojejunostom*, 2004-2012
4 1 general: "cerebral palsy" jejunostom*, 2004-2012
3 11 general: "cerebral palsy" enteral*, 2004-2012
2 35 general: "cerebral palsy" gastrostom*, 2004-2012
1 40 general: "cerebral palsy" gastrostom*

WHO International Clinical Trials Registry Platform (ICTRP) (apps.who.int/trialsearch/) searched 18 July 2012

Advanced search:
Condition: Cerebral palsy OR spastic*
Intervention: enteral* OR tube* OR gastrostom* OR jejunostom* OR gastrojejunostom* OR gastro-jejunostom*

ClinicalTrials.gov (clinicaltrials.gov/) searched 18 July 2012

spastic OR cerebral palsy | enteral OR tube OR gastrostomy OR jejunostomy OR gastrojejunostomy OR gastro-jejunostomy

WHAT'S NEW

Date	Event	Description
7 January 2013	New citation required but conclusions have not changed	There are no relevant randomised controlled trials. No change to our conclusion that high quality research is needed
18 July 2012	New search has been performed	Search updated in July 2012

HISTORY

Protocol first published: Issue 4, 2002
Review first published: Issue 2, 2004

Date	Event	Description
15 September 2008	Amended	Converted to new review format.
30 January 2004	New citation required and conclusions have changed	Substantive amendment

CONTRIBUTIONS OF AUTHORS

For the original review, Gillian Sleigh developed the search strategy. Gillian Sleigh, Adrian Thomas and Peter Sullivan each contributed to the selection of trials and writing of the text of both the protocol and the review.

Sapthagiri Gantasala took the lead role in updating the review. I actively searched and screened all papers from 2004 to date for any RCT evidence.

Adrian Thomas has contributed to the writing and checked the manuscript of the updated review.

Peter Sullivan guided and supervised the process of the updated review and checked the manuscript.

DECLARATIONS OF INTEREST

Sapthagiri Gantasala - none known.

Peter Sullivan is a member of the Danone Scientific Advisory Board. His Institute received a Nutricia Research Grant for work carried out in the area of optimising nutrition to improve growth and reduce neurodisability in young children with cerebral palsy. McKeith Press provided royalties for work carried out on the subject of feeding and nutrition in children with neurodisabilities. Payment was received for the development of an educational presentation on cow milk intolerance from Mead Johnson Limited.

Adrian Thomas - none known.

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INDEX TERMS

Medical Subject Headings (MeSH)

*Eating; Cerebral Palsy [*complications]; Gastrostomy [adverse effects]; Nutrition Disorders [etiology] [*prevention & control]

MeSH check words

Adolescent; Child; Child, Preschool; Humans; Infant