

PEG feeding and the child with ID

Feeding difficulties in children with an intellectual disability may indicate a need for PEG feeding. **Carmel Doyle** outlines the considerations

GOOD nutrition maintains health as well as enhancing normal growth and development. Children with an intellectual disability often require long-term nutritional support for a variety of reasons.

A child with severe cerebral palsy may have a problem with the ability to suck, chew and swallow without risk of aspiration. Important reflexes such as the cough and gag reflex may be limited.

Implications for feeding in conditions such as cerebral palsy, cleft lip and palate, and Pierre Rubin syndrome cannot be underestimated. Other underlying health conditions such as congenital heart disease and respiratory illness can also affect the child's ability to eat and drink.

Feeding problems for consideration also include the child's level of ability. Some may have very immature feeding skills, such as sucking food rather than attempting to chew it. Other children may be unable to take food from a spoon except by tongue thrust or licking movements. Therefore, some children are unable to manage food without incurring distress.

Such feeding difficulties are strongly linked to malnutrition and this in turn often necessitates the need for insertion of a PEG (percutaneous endoscopic gastrostomy) tube. Indications for PEG feeding a child with ID include:

- Anorexia
- Dysphagia
- Child unable to meet nutritional requirements
- Child unable to take sufficient food and dietary supplements
- Child unable to eat or drink.

PEG feeding involves an incision made in the abdominal wall. A permanent gastrostomy tube is fed into the stomach and pulled through the abdominal wall, thus creating an artificial tract that leads into the stomach.¹

Although widespread use of PEG feeds is a recent development in Ireland and the UK, in the US such approaches to nutritional support are more common. The PEG device is usually inserted for long-term use only.

The benefits of PEG feeding cannot be ignored when it has been argued that up to 80% of children with a profound ID are considered to be at risk of aspiration.²

The advantages and disadvantages of

Table 1

PEG feeding	
<p>Advantages</p> <ul style="list-style-type: none"> ■ May be used immediately or within hours of placement ■ May be used as long-term method of nutritional support ■ May be used in the presence of significant disease of the upper GI tract ■ Effective means of nutritional support ■ Ensures the child has adequate nutritional intake in a 24-hour period ■ Enables the child to take in orally whatever they wish without concerns about the amount to be taken in a 24-hour period 	<p>Disadvantages</p> <ul style="list-style-type: none"> ■ Insertion is an invasive procedure ■ Usually requires general anaesthesia ■ May be difficult to site in the presence of altered anatomy, tumours or severe obesity ■ Potential for wound infection ■ Unnatural method of feeding

Table 2

Caring for the PEG
<ul style="list-style-type: none"> ■ Good hand hygiene and skin care required at all times ■ Keep the site clean and dry ■ Observe for signs of leakage, excoriation or redness around the site ■ Avoid covering the PEG device with dressings or gauze as this may irritate the skin and cause infection ■ Clean under the external skin fixator ■ Always use equipment specific to the type of device being used ■ Only use the type and amount of feeds that are prescribed ■ The tube should be flushed before and after feeds ■ Bolus feeding should not be forced and gravity should be used ■ When continuous feeding is used, the correct pump and giving set is required

Table 3

Medications	
<p>Do</p> <ul style="list-style-type: none"> ■ Use liquid medication where possible ■ Check with pharmacist that medication can be crushed or capsules opened ■ Give medications one by one ■ Flush tube with 5ml-10ml water between medications ■ Check if medication should be given with or without feeds 	<p>Don't</p> <ul style="list-style-type: none"> ■ Give medications together ■ Put medication down balloon part of tube ■ Add medications to the formula/feed ■ Crush enteric coated or slow release tablets

adopting PEG feeding are outlined in Table 1.

However, the benefits of PEG feeding to the child with ID are often unclear.³ Therefore, a thorough nutritional assessment must be undertaken using a multi-disciplinary approach. This involves a multi-dimensional approach and cognisance must be taken of the value of the feeding process to the child.

Questions to be asked include:

- Does the child savour food?
- Is the sensory process of eating important to them?
- How will they cope with the effect of losing the feeding interaction that would usually occur at mealtimes?
- Will insertion of a PEG alter the child's quality of life?

The PEG device

There are a range of PEG tubes available:

- **Initial percutaneous endoscopic gastrostomy tube** – allows the stoma to develop properly. It comprises a disc on the inside, which stops the tube from falling out, and comes in a variety of sizes
- **Balloon tube** – may be first put in when the initial tube is placed. This has a balloon on the stomach end, which is inflated with water to keep the tube in place
- **Low profile button tube** – shorter tubes that sit flush with the skin on the abdomen and come in a variety of lengths. They have a flexible disk on the stomach end to hold the tube in place. Often called the MIC-KEY tube in Ireland, this is a popular choice for children.

Caring for the PEG

Gastrostomy care is straightforward and involves basic principles of care, regardless of the device being used (see Table 2). Additional guidelines relating to the specific device in place must also be adhered to and all manufacturers supply such information.

Guidelines that may assist when administering medications via a PEG are outlined in Table 3.

A long-term implication of PEG feeding is oral hygiene. Oral care for the child with ID who has a PEG feeding device is of great importance and especially when the child has no oral feeding. Teeth cleaning using toothbrush and toothpaste, dental swabs and lip care needs to be carried out regularly to ensure good oral hygiene.

Complications

The PEG involves some potential complications, including diarrhoea, constipation, nausea and vomiting. Rapid or excessive weight gain in a short period of time can occur. Difficulties may arise if the tube becomes obstructed and if the stoma site becomes infected, irritated or sore.

The decision to PEG feed a child with ID is one that should involve a lot of thought and information retrieval around the benefits of insertion for the child. Usually, the adoption of PEG feeding has had and continues to have a positive impact on the quality of life of a child with an intellectual disability.

Carmel Doyle is a lecturer in nursing at the School of Nursing and Midwifery Studies, TCD, Dublin

References

1. Jukes M. *Profound and Multiple Disabilities*. In: ed(s) Jukes M. *Nursing People with Profound Learning Disability*, Oxford: Blackwell Publishing (In Press) [Doyle C, Griffiths C.]
2. Gates B. *Learning Disabilities: Towards Inclusion*. 4th Edition. London: Churchill Livingstone. 2003
3. Todd V et al. *Percutaneous endoscopic gastrostomy (PEG): the role and perspective of nurses*. *J Clinical Nursing* 2005; 14: 187-194