



INTRODUCTION

Hi and welcome to the Cerebral Palsy Foundation's ParentWise Podcast series. I'm Robyn Cummins.

Eating and socializing together is important for people in all cultures.

Sometimes, chewing and swallowing can be hard for children with cerebral palsy. At some point, non-oral ways of feeding might be suggested by your child's therapist, doctor or dietitian. Parents will often have different thoughts and feelings about this option and may find it a challenging decision to make.

In this podcast, consultant speech pathologist, Leigha Dark, explains the various tube feeding options with some tips to help guide you when making the decision.

WHAT IS NON ORAL FEEDING?

For some children with cerebral palsy, eating and drinking can be difficult. This can result in mealtimes which are lengthy, unpleasant for the child and the family, and even unsafe.

Various strategies such as mealtime management plans, improved positioning, and feeding techniques, can be used to make mealtimes safer and more enjoyable.

At times, however, these strategies are not successful and some type of non-oral feeding, or a combination of oral and non-oral feeding, may need to be considered.

Non-oral feeding can take many forms. Two of the common types of non-oral feeding are naso-gastric tube feeding and gastrostomy. With naso-gastric tube feeding, a tube is placed into the stomach via the nose. Naso-gastric tube feeding is considered when non-oral feeding is more a short-term option.

Gastrostomy is a form of tube feeding where a feeding tube is placed directly through the wall of the stomach.

In situations where a child needs to be tube fed for longer periods of time (or even permanently) a gastrostomy is used. The gastrostomy tube is usually placed directly into the child's stomach, and the child is fed through this tube, bypassing the mouth.

The doctor who places this tube often uses an instrument called an endoscope and so the procedure is called a percutaneous endoscopic gastrostomy or PEG.

MAKING A DECISION ABOUT NON ORAL FEEDING

A child may need to be tube fed for a variety of reasons. It may supplement an inadequate oral diet or totally replace oral feeding because of difficulty swallowing (known as dysphagia) or because food or fluid is accidentally inhaled into the airway (called aspiration).

Tube feeding does not mean that aspiration cannot occur, however with good care the risks can be minimised.

For people with cerebral palsy and their families, the decision to choose a non-oral feeding method can be fraught with difficulty and distress.

Many parents initially feel that their children will be isolated or ostracised if they begin using a non-oral feeding option such as gastrostomy. Parents may feel anxious about their child undergoing another medical procedure, and worry about the risks associated with tube feeding. These are natural concerns and parents who have made decisions about tube feeding for their children, report that one of the most helpful things is to find out as much information as possible.

Sourcing accurate information from a variety of professionals, support groups such as GISS (Gastrostomy Information Support Society), and from people who have personal experience of non-oral feeding, is important to assist in the decision-making process.

SUPPORT AND BENEFITS

A good interdisciplinary health team will give families and people with cerebral palsy the opportunity to talk about their thoughts and feelings in a non-judgmental and respectful manner.

The information your health care team provides should address your individual needs and concerns.

And it's not just the child's immediate family who need to be familiar with the tube feeding and nutrition plan.

Grandparents, aunts and uncles, babysitters and teachers, all need to be aware of the plan and how the gastrostomy works.

Having an extended support network can really help when making difficult decisions regarding gastrostomy or non-oral feeding.

Although it may be a difficult decision, research has shown that some of the benefits of gastrostomy include:

- Improved quality of life
- Decreased length of mealtimes
- Reduced stress related to mealtimes
- Improved nutrition and weight, and
- Improved health.

Research into how parents and caregivers feel about their decision to proceed with gastrostomy for their child, highlights that although many caregivers have initial reservations, they *are* satisfied with their decision.

Many families report that they may have made their decision earlier if they'd been aware of the beneficial outcomes for all involved.

It must also be pointed out that despite the overall benefits, some caregivers still report difficulties around mealtimes, and require continued support to address these difficulties. Some of these difficulties can relate to the care of the stoma - the area around where the tube is inserted into the stomach. This needs to be kept clean to reduce the risk of irritation or infection. Other areas of difficulty families report relate to getting the timing of mealtimes right using the gastrostomy tube.

Even though your child is not receiving food through the mouth, it is important to maintain good oral hygiene to reduce the risk of respiratory illness from germs (usually bacteria) found in the mouth.

All of these issues can be managed successfully with the help of your GP, dietitian, speech pathologist and gastroenterologist.

Whatever your final decision about gastrostomy for your child with cerebral palsy, it is essential to find out as much information as you can about non-oral feeding options and gather a supportive network of health professionals around you to help make an informed decision. You can contact the CP Helpline on 1300 30 29 20 or for more information or visit the GISS website at www.giss.org.au.

CLOSE

Thanks for listening. We hope you've found these strategies and ideas useful.

You can download or listen to more episodes in the ParentWise Podcast series at the Cerebral Palsy Foundation's website - www.cpfoundation.com.au