



Information Sheet

Feeding your Child with CDH

Introduction

CDH children will rarely start life feeding like healthy babies do, and some will face feeding challenges for a number of years. While these challenges can be stressful for parents it is important to know that you are not alone. This information sheet is designed to give you some basic information about feeding your CDH child. You can obtain more detailed information from your child's healthcare professional.

Early Days

Prior to surgery, most CDH babies will receive their nutrients by total parenteral nutrition (TPN) delivered via an IV line. TPN consists of protein, carbohydrates, fats, vitamins, and minerals. Your baby may continue to receive their nutrients via TPN for some time following surgery or they may move on to milk quickly depending on how well they tolerate milk feeds.

After surgery you will have the opportunity to introduce milk to your baby, either in the form of expressed breast milk (EBM) or formula. No matter which method you choose to feed your baby, the feeding problems faces by babies with CDH will look similar. If you are breastfeeding, you should start expressing soon after birth. Often hospitals have breast pumps available for you to use in the hospital and will provide some storage facilities. If you have private health insurance, it is worth petitioning your insurance company to cover some of the cost of hiring or purchasing a breast pump.

When milk is introduced your baby will be fed via a nasogastric tube (NGT). Initially they will receive very small amounts of either EBM or formula. When your doctor believes your baby is ready, you will move on to feeding with a bottle or by breast.

Difficulties with Feeding and Development

While some babies progress smoothly with feeding, others have a slow start – he or she may take a long time to feed, tolerate only small amounts and experience reflux and vomiting. From here some babies start growing and feeding without too many problems and do very well. Other babies may have more complex feeding problems including severe reflux and vomiting and oral aversion (refusal to breast or bottle-fed).

There are a number of reasons that feeding problems arise in children with CDH. The longer a child is ventilated, along with the amount of suctioning required, the more at risk they are of having an oversensitive gag reflex, gastro oesophageal reflux disease (GORD) and oral motor developmental delays. These all contribute to negative associations for the baby with their mouth.

Babies who need frequent suctioning while ventilated, are ventilated for extended periods of time and/or experience pain while feeding as a result of having GORD, can develop an oral aversion that will result in feeding difficulties at differing levels. Some may be “fussy” feeders who take a lot of convincing to bottle or breastfeed, and others will refuse the bottle or breast altogether. The introduction of solids may also fail, as the baby is still very defensive when it comes to having something placed in its mouth.

In conjunction with being very defensive with feeding due to pain association, some babies may also have oral motor developmental delays that will impede on the baby’s ability to feed (bite, chew and swallow). A speech therapist experienced in feeding difficulties is needed to assess the baby’s oral motor development before effective strategies to overcome feeding difficulties can be implemented. Occupational therapy, clinical psychologists and dietetics, along with the babies’ doctor, can also help overcome feeding problems.

Some babies with CDH will have difficulty growing; studies have shown that more than 30% of babies are below the 5th percentile for height and weight during their first 12 months of life. Those with the most serious lung conditions are more likely to have problems growing as their calorie requirements are very high due to increased energy expenditure to breathe adequately.

Feeding Tubes

There are several reasons why feeding tubes may be necessary. Babies with CDH require more calories and may tire easily during a feed. In order to support appropriate growth and weight gain, your doctors may want you to fortify (add calories to) your EBM or breastmilk and “top up” your baby via a NGT at the end of the feed. In extreme cases, a baby will refuse to drink or eat altogether and will be totally reliant on a feeding tube for their sustenance. These problems may continue for months or even years.

Feeding tubes can be used in different ways depending on how well your baby can tolerate feeds and the type of feeding tube required. Most babies have trouble tolerating large feeds initially and need to have them introduced slowly. The baby’s stomach cannot tolerate the same amount of food as a healthy baby as their stomach may not be able to expand to the same degree. They become full very quickly and vomit easily.

Types of Feeding Tubes

The first tube used is a NGT. This is the same tube that your baby had inserted after birth. It is placed through the nose and ends in the baby’s stomach. They are easy to insert and can be replaced by the parents should they come out. There are short term and long term NGTs available. The long term one can stay in for up to six weeks before it needs replacing. Your baby can use a NGT until they are eating and drinking adequately.

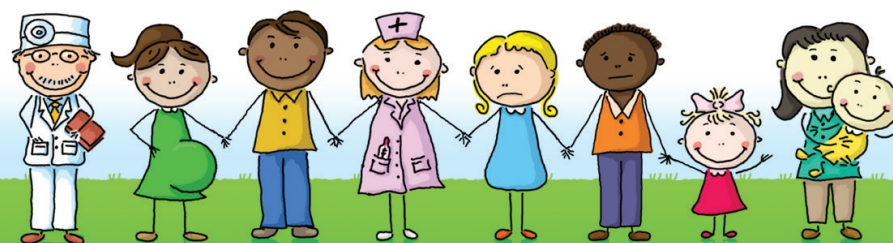
The other type of feeding tube that is inserted via the nose is a nasoduodenal (NDT) or nasojejunal (NJT) tube. These tubes need to be inserted by a radiologist under imaging. They are used when the stomach needs to be bypassed for feeding.

Sometimes it becomes necessary to change from a NGT/NDT/NJT to a tube that is placed surgically. These consist of gastrostomy tubes (PEG), gastro-jejunal tubes and jejunostomy tubes. The type of tube needed would depend on the babies feeding and digestion problems.

Intermittent (Bolus) versus Continuous Feeding

A bolus feed is where a certain volume is given over about 30 minutes, either via gravity and a syringe, or through a pump. Continuous feeds are used if the baby isn't tolerating bolus feeds or overnight to help 'catch-up' with your baby's daily calorie requirements. Sometimes a combination of both bolus and continuous feeds are used to ensure adequate growth of your baby.

NGT and PEG feeds can be both bolus or continuous. NDT and NJT feeds can only be given by a slow continuous feed because the stomach has been bypassed and the small intestine cannot tolerate large volumes quickly. Your baby would be on the feeds for 20/24 hours a day depending on their individual calorie requirements calculated by a dietician



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