

# Temporary feeding tube placement in infancy and early childhood: tube maintenance and tube exit plan\*

## INTRODUCTION

This handout offers information for parents on the placement of a temporary feeding tube. We hope to contribute to your understanding and help you discuss and consent to the decision to be made. A feeding tube is a thin plastic device placed into one nostril (Nasogastric tube) or directly into the stomach (Gastrostomy) or gut (Jejunal tube). The aim is to provide sufficient nutrition to support growth and development. At this point the medical team in charge believes that tube placement will not be a permanent measure for your child, but a temporary one which might last for a few weeks or months. In most cases your child's individual medical history, its growth and developmental status and the need for sufficient nutritional intake will be the main reason for this consideration. As every intervention also has side effects, it is important for you to be well informed about all possible aspects of this intervention so as to help your child have the best possible benefit of this therapeutic measure.

## TUBE PLACEMENT

The actual placement of the tube depends on the specific kind of tube chosen. Depending on which tube is chosen placement might need a short general anaesthesia, after which your baby will be able to receive additional nutrition by the tube. The tube itself does not hurt however there might be some irritation at first, which usually does not last very long. All additional details on the topic of feeding times, necessary amounts and the specific formula will be suggested to you by your medical team in charge. Please make sure you ask any questions you might have before the tube is placed so that you are well informed and ready to support your child well.

## TUBE MAINTENANCE

Your child's medical team should now include at least 2 professionals who will be responsible and in charge of your baby for the intended period of time and phase of tube feeding. This is usually your child's Paediatrician or GP AND a member of the paramedical team. You and your child should meet with them before tube placement to discuss a maintenance and tube exit plan. The physician will check the efficiency of tube feeding on a medical, nutritional and growth related level. Initially this will need to be done on a monthly basis. All functional effects on your child's underlying medical condition and possible necessary therapeutic measures will need to be considered carefully. If you notice any negative side effects like recurrent vomiting, gagging, skin irritation or pain you should report these as soon as possible. The second member of the tube-maintenance team will most probably be a speech therapist, occupational therapist, psychologist or nutritionist who will focus their clinical expertise and attention on developmental matters and make an individual support plan with you for your child. Most children may receive a small amount of fluids for taste stimulation or even some nutrition orally during the phase of tube feeding. This will depend on the underlying diagnosis and medical condition but needs to be discussed carefully. It will help keeping up oral activity and make your child experience a sense of self motivated action, positive sensation and make a link to feeling satiated even though being mainly tube fed.

## **TUBE WEANING**

When a feeding tube is not intended to be a permanent intervention, it is recommended to discuss the intended duration of tube feeding and define some goals and criteria for ending this measure for your child with your child's medical team. Ideally these goals and criteria should form part of the written Tube Maintenance and Exit plan. Depending on the goals and criteria to be met, a time will come when the medical reason for needing temporary tube feeds is completed and your baby will be allowed to make the transition back to full oral feeds. This phase should be supervised professionally as starting to eat and drink may or may not happen by itself. It is important to report symptoms such as food refusal or constant vomiting as they might have an impact on the tube weaning process and your child might need additional therapeutic support. The team involved with your baby will help you to support your baby to catch up with their eating development and learn the necessary milestones and oral skills of this process. Motivation to want to eat and sufficient opportunities and role models are important, but constant offering and any kind of intrusive feeding is counterproductive.

## **DEVELOPMENTAL AND PSYCHOLOGICAL ISSUES AND CONSIDERATIONS**

Any temporary feeding tube should be removed as early as possible and as late as necessary. If possible this should happen between the ages of 6-12 months. The older your child gets, the greater the risk of developing dependency on being tube fed. Most tube fed children will not just start to eat on their own. They will need some additional support and parents might also be in need of additional specific advice. Tube dependency is a rare and non intended condition whereby the child remains or seems to remain dependent on tube feeding in the absence of any medical reason for this. This can happen because the child has not started to experience any positive oral sensations, might suffer from constant satiety and therefore lacks motivation to want to taste, touch and have food. This can also happen because the child defines itself as being a tube fed child and links its feeling of identity and wellbeing to remaining tube fed. As children will not learn to eat because it is expected of them but only by self motivation and increase of their feeding skills, it is crucial to know how you can support your child in this process.

## **NEEDING SUPPORT AND HELP**

As tube feeding is not usual, it is important that you feel comfortable, well informed and involved in the decision for your child to receive a temporary feeding tube. The intervention should be helpful for the benefit of your child's future development, health and growth and all intended goals must be evaluated regularly to minimize possible negative side effects. Please feel confident to ask your professional team for help if you feel in need as it will also help your child receive the best possible benefit from the period of tube feeding.

For additional information you can also visit [www.notube.at](http://www.notube.at), a webpage developed specifically for parents. It offers additional information on the subject of tube dependency and an online medical coaching service which supports the parents of a child to be weaned off the tube at home in case local facilities cannot provide support.