

Feeding Tube Dependency online support

By Feeding Tube Dependency Institute



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What is Feeding Tube Dependency?

Over the past thirty years, more and more infants and small children become feeding tube dependent. When infants go home with a feeding tube most parents expect that the feeding will improve over time. But evidence shows that the feeding situation gets worse and worse until the infant shows a total food refusal. Parents have to manage daily food refusal, vomiting and in some cases food aversion. Not all children show a massive food aversion. Some even take a certain percentage of food orally. But to move from a small oral intake to full oral feeding can be very challenging for you and your child. Early support is a key to reduce food aversion and to move from tube to oral feeding. If you want to start today our program, give you the opportunity. You reach out and we will schedule our first video consultation with you.

Feeding Tube Dependency online support

This program will allow you to stay at home and get support during the weaning phase via telemedical service. You don't have to travel, you don't risk infections during flights or a hospital stay, and you get assistance where you need it most: In your home feeding environment.

Preparation

In the first week we will prepare you and your child for the weaning period. We will have an initial video consultation with you and your child. We will give you advice how to handle the feeding situation as well as the feeding via tube. The first steps are sometimes small for us from an adult perspective but big steps for your child. Therefore, take time and being patient is very important. We will give you the support to feel calm and safe during this process.

Hunger Induction

You may have realized that your child is never hungry or thirsty. The feeding via tube blocks the natural hunger drive. Most children rather feel nauseous than hunger. Therefore, we will slowly decrease the amount of tube supply. Your child may re-experience hunger as well as thirst. This can be confusing and stressful for you and your child. We will be on your side and support you during the hunger induction.

Intensive Weaning Phase

Your child and you have gone through a phase of preparation and the hunger induction. Your child may feel hunger now, but maybe don't know what to do. Therefore, we will have daily videocall with you and your child. You will have many questions how to handle the situation and how to feed. *How can I see my child hungry? What do I do when my child seems hungry but doesn't want to eat or be fed? My child is losing weight, will there be an end? When can we pull the feeding tube? When will my child start to chew?* We will be on guard and giving you advice. If you have a challenging situation, make a short video. We will review it and come back to you.

Understanding Hunger and Thirst: You may have asked yourself if your child knows hunger. The answer is: Your child will know what hunger is but not what to do when is hungry. We will work with you to support your child regulate the hunger sensation.

Understand Food Refusal: Children do only what they are really motivated to do. Over the past 20 years we have learned from children that there are different motivations for food refusal, but there is always a motivation. What we do is trying to change this motivation from refusal to acceptance to enjoyment. Carefully, with a lot of heart and understanding, until your child feels safe to give up food refusal.

Think different: You tried very hard to get your child to eat. You spend hours with different spoons and different bottles, and nothing worked. And that frustrates you. You should know that it is neither you nor your child's fault. You need a fresh start for what comes next. We may have to change the situation, the handling, the food or the environment a little bit, to change your child's feeding behavior. Sometimes small changes can make a significant difference.

Follow-up

When we have successfully established oral feeding during the intensive treatment period, we will follow up with you for the next days. There will be questions regarding, food intake, textures, handling of infections, Weight gain and growth. You are welcome to send us your questions, concerns and your feeding videos. We will go through your question and come back to you. Usually the program ends after 30 days. But if you would like to proceed you can book us as long as you need us.

What is included in the program?

You may wonder what is included in our program and what to expect. The cost in US-\$ breakdown gives you an overview about what we charge you for and how we will support you.

	<i>Costs</i>
Readiness for wean screening	523 \$
30 days of online consultation	2010 \$
Up to 10 video calls with our treatment team	1370 \$
<i>Total</i>	<i>3803 \$</i>

Your next steps:

1. You will receive a questionnaire via email, please answer all the questions and return the questionnaire via email.
2. Please send us a short summary of your child's medical background
3. We will send you an invoice via email and with the transfer of the program fee, we will start with our support program.
4. Download the app Threema on your phone and send us your ID. You send us your ID and we will start your support group.
5. Now you can start to send us videos via this group, share your questions or concerns with us and we will come back to you.

What we do for you:

Thank you for setting-up the group, now we are ready to go. We will start with the feeding tube dependency assessment. You will get a report back in the next three days. You can ask any question at any time. We will come back to you for any question seven days per week.

Our Institute, your support team:

The institute for feeding tube dependency is one of the leading teams in the treatment of food aversion and feeding tube dependency. We are looking back on a history of 20 years of weaning experience. In several research studies we have shown that treatment with our team is successful in 90 % of all involved cases. Asking about our treatment approach we would answer: We are following the child's needs. When the child doesn't sense the hunger drive, we reduce calories. It could be a conflict with feeding, and we try to solve the conflict. It could be a different feeding environment and we will change the environment. Parents are often scared off withdrawing the feeding tube. They can't picture an eating child. We will give the families strength through support. We may know a lot about weaning with hundreds or even thousands of families we have spoken to. But you as a parent are the expert of your child, you know your child best. We listen to you and find a solution to conflicting situations which works for all of you.