

Nutrition for Children with a Tracheostomy or on a Ventilator

Introduction:

Nutrition plays an important role for children with tracheostomy and children who depend on ventilators. Nutrition management is key to make sure they are growing appropriately. A nutritionist can manage these factors to make sure they are getting the right nutrition:

- Tolerance
- Calories
- Protein
- Vitamins and minerals

It is a key focus for these children because as they grow, their lungs grow, which can lead to better breathing. However, it is important to remember that all children grow at different rates and have different energy needs depending on their diagnosis and level of ventilator support. Nutrition goals are centered around providing enough nutrition while also balancing the ratio of weight and height.

Below we will discuss common nutrition issues and also factors that need to be addressed for discharge. These points are just a summary and your dietician will discuss further details, troubleshooting, and recommendations with you.

General points:

Oral Intake (Feeding by mouth)

It is common for children who depend on ventilators to have delayed abilities with their mouths. There are typically issues with reflux (liquid from the

stomach flows backward up the throat) and difficulty with feedings, which can contribute to sensitivity to anything being put in the mouth.

- Treatments include referring you to clinicians that help with feeding therapies such as Speech Language Pathology, Occupational Therapy and Behavioral Feeding Programs. Working with these services will be key to improving oral intake.

Enteral Intake (Tube feedings)

The majority of children require tube feedings due to their medical condition or until they are able to accept nutrition by mouth 100%. The tube types include the following:

- **Gastrostomy tube:** This tube is placed in the stomach. It is not permanent but it is the safest access for children unable to get their nutrition needs by mouth.
- **Jejunostomy tube:** This tube is placed in the small intestine and is needed when children can't tolerate feedings into the stomach despite multiple treatments.
- **NG tube:** This tube enters the body through the nose and runs down the esophagus (throat) and into the stomach. This is usually a temporary feeding tube and is not placed long term.
- **NJ tube:** This tube enters the body through the nose and passes through the stomach and into the second portion of the small intestine. It is typically placed when children are unable to tolerate feedings in the stomach.

It is important to remember tube feedings do not replace your progress working on oral intake. Tube placement provides a **safe way** for children to receive their nutrition while working on oral intake.

The Feeding Tube Awareness Foundation is dedicated to providing you with the information you need for day-to-day life with a child who is tube-fed. They

strive to raise awareness so that children who are tube-fed enjoy increased acceptance in society and parents have greater support in their care. They are not health care professionals, but parents who live it every day. Their goal is to make what is medically complicated, easier to understand.

<http://www.feedingtubeawareness.org>

Calorie Needs

Children on respiratory support have a lot of changes in their calorie needs depending on their medical condition and progress with breathing. Their calorie needs are typically lower than the standard recommendations for their age group. Your nutritionist will look at their specific condition to come up with an appropriate plan. It is also important to remember there are times your child won't need frequent feeding increases due to lower calorie needs and that is okay!

- **Formulas (some examples listed)**

- Standard: Enfamil Infant, Pediasure, Boost Kid Essentials, also high calorie available.
- Semi-Elemental: Nutramigen, Pregestimil, Alimentum, Pediasure Peptide, Peptamen Junior, also high calorie available.
- Elemental: Elecare, Neocate, Alfamino, Nutramigen AA, Vivonex Pediatric
- The chart below gives characteristics of each group:

Standard	Semi-elemental	Elemental
Designed for normal digestion. These formulas have completely intact milk protein, which requires the body to break them down to be able to use them. Options for low lactose or soy.	Protein is partially broken down; many are still milk proteins. May include more MCT fat.	These formulas contain 100% broken down proteins, they are designed to be as easy to digest and process as possible. This is the most allergy-friendly (hypoallergenic).

Troubleshooting common issues

Vomiting

It is very common that children with trachs and children who depend on ventilators have reflux or issues with vomiting. The key to management is discussing what is normal for the child and what is an issue that needs to be addressed. Your dietitian will discuss all of the following with you:

- How often? How much? What does it look like (formula or mucous)?
- Is the child constipated?
- Does the child typically do this during suctioning/trach changes/morning care/medications?
- Any consistent time of reflux and how close to feedings?

What do I do?

- Adjust the schedule, change times/volumes or slow down the pump rate.
- Change formula if you are unable to resolve by schedule or volume changes.
- Consider gut motility agents if needed (these medications help speed up digestion). We typically address this after all the schedule and formula changes have been addressed.
- Chimney venting system: Picture and description (appendix)

Constipation

This can be **very common** with children due to multiple reasons but the most common are **formula concentration or changes and the child's activity level**. Your dietitian will discuss all of the following with you:

- How long since the child's last stool?
- Is their stomach bloated?
- What have you tried so far?
- What is their current bowel treatment plan?

What do I do?

- Your dietitian will check your child's fluid needs first and increase water if needed.
- Try prune juice - discuss the dosing with your dietitian.
- Consider oil if prune juice doesn't work, it can be a natural laxative - discuss dosing with your dietitian.
- If your child is already on bowel treatment plan discuss with your team how to adjust it if needed. Or, your child may need to start a bowel regimen if we are unable to resolve with the treatments above.

Formula recipe

You will receive a formula recipe before discharge and it will be included in the packet.

Salt recipe

You will receive a salt recipe before discharge if your child is on salt supplement so that there is always a backup if a prescription not available.

What happens next?

Insurance and WIC:

DME (Durable Medical Equipment):

- This is a type of company that will provide all of your enteral (tube feeding) supplies as well as formula.

WIC = Women Infants and Children

- This is a program that provides formula and food packages to mothers with children under 5 years old. How much they provide is based on government guidelines.
- You can receive baby foods and infant cereal if your child is under 1 year old.

- You will need to set up your WIC account and appointment in your county and are required to go to the appointment, however your dietitian will provide a letter so that your child does not need to go with you.

Before discharge the team will send prescriptions to get the child's formula covered.

- The prescription is first sent to DME and WIC is provided as a supplemental program if you choose it.
- Standard formulas are automatically covered and some specialty formulas require a prior authorization (permission from your insurance company).
- Food based formulas are harder to get, your dietitian will discuss the process if needed.

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