

Homemade Blended Formula Handbook

Introduction

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Many families who are providing tube feedings for their children have asked, "Why can't I feed this child the nutrition I feed my other children?" or "What can I offer my child besides the same formula every day?" or "How would I go about providing real blended food through the tube?" or "Can I still use the commercial formula and just add a little food?" or "Where would I start"?

These families have often asked dietitians, pediatricians and other feeding team members these questions, only to have them admit to having little or no experience with blended foods in tube feedings. Much to the frustration of families, many of these professionals have asked them, "Why would you want to offer something besides commercial formula?" Some professionals have said, "Well, I've never had anyone ask that question, but let's learn together." This handbook is for them, all of them: the families who ask "why?" "how?" and "what?" and the professionals who have limited experiences and want to learn. It provides a starting point for making homemade blended formulas and a sharing of information, based on what we already know about feeding children. It incorporates what we know about mealtime experiences and what helps children grow. It combines this knowledge with the experiences of parents and other professionals who have written these chapters.

What is homemade blended formula? Historically, these types of tube feeding formulas have been called "blender feedings," "blenderized formula," or "blenderized tube feedings." We have added the word "homemade" to celebrate the personal and nurturing nature of the preparation. We define homemade blended formula as any formula that a parent makes that modifies a standard formula with "real" foods. It could be a commercial formula with a small amount of baby food fruit or vegetable added, or three meals a day of blended food with commercial formula at night, or a complete diet of homemade blended foods, or many options in between. We would have

preferred to title the book "Homemade Blended Meals" to remind readers that tube feedings are mealtimes too. However, "Homemade Blended Formula" clarifies that the book is directed towards the needs of parents and professionals who share the lives of tube-fed children.

Historical perspective Tube feedings have been around in some form for a long time. The use of gastrostomy tubes, knowledge of the digestive system and nutrition, and the technology of tube feedings has developed over centuries. In the 60s and early 70s, when many of us began supporting families of tube-fed children, there were far fewer tubes, so our experience with tube feedings was limited. Only the sickest children received supplemental feedings. Tubes were predominantly limited to larger catheter tubes. Infants received tube feedings with their infant formulas. However, as they grew, their parents added baby foods to the formula or pureed family foods and did the best they could to get the food through the tube. Our collective experience was predominantly "blenderized feedings."

By the mid 1970s, formula companies developed specialized tube formulas based on detailed nutritional research, which provided a better understanding of micronutrients and total nutritional daily requirements. Families moved from blending table foods to the use of commercial formulas. These formulas became an easier option for families. Dietitians and physicians supported the use of these formulas because they offered nutrition based on the newest research. They knew just how many calories, macronutrients and micronutrients the child was receiving. It was easily quantifiable, very portable, pasteurized and balanced. Families were sent home with cases of formula, a specific time schedule, and a prescribed number of ounces per feeding. Tube feedings often became just one more procedure required of parents when their medically fragile children returned home from the hospital. The tube feeding process and its vocabulary of doses and ounces and mls or ccs inadvertently emphasized the medical nature of nutrition and increased the separation from the family meal and the feeding relationship that parents dreamt of for their children.

Today, technology has greatly changed and made tube feedings much easier for children and their families. They're more portable, more efficient and less restrictive. We also have become a more health-conscious and better-informed society. We're learning daily from research literature and the

popular press about foods we should add or remove from our diets. We're increasing our understanding of the importance of diversified diets as the best way to provide the micronutrients needed for optimum health. Parents are rightfully asking if one formula, one diet or one recipe can provide all the nutritional variation needed to maximize nutrition, health and growth for their tube-fed children.

In addition many parents are asking about homemade blended formulas as a way to empower themselves in making personal choices about foods. Many parents report that preparing homemade blended formulas gives them more control in their children's growth and feeding, and allows them to nurture their tube-fed children with food as they would orally fed children.

In this handbook, we consider how to integrate the best of past technologies and concepts with the present, to create a new present and future for tube-fed children and their families. We'd like to help families and professionals think about the meaning of tube feedings and find ways to integrate them into the family mealtime.

Research Very few published articles describe the "hows" and "whys" of homemade blended formulas. By contrast, a great deal has been researched about healthy nutrition for orally fed children.

We have a large amount of information about what to feed children, how much to feed them at different ages, what nutrients are needed for optimal growth and how to interact with children at mealtimes. There's limited research into how to translate this information for tube-fed children and their nutrition, and it's dominated by information about commercial formulas and their benefits.

Commercial formula need not be the only option. Many parents are feeding their children homemade blended formula and have had very positive experiences. Instead of being written up in scientific journals, these positive experiences have been shared anecdotally through professional discussions and from parent to parent by phone, Internet mailing lists and online chat rooms. We need to encourage and support research about homemade blended formulas. Historically, good research is designed from a broad collection of personal and clinical experiences, which enables researchers to ask

meaningful questions.

We've seen the changes that homemade blended formulas have made for many children and their families. In this handbook, we've included input from families in the United States, Canada, England and Australia, obtained from professional clinical experiences, informal parent questionnaires and feeding support groups on the Internet. It's hoped that the experiences and questions raised in this handbook will inspire researchers to ask those meaningful questions.

Team Approach It's our belief and experience that supporting families in the decision-making process necessary for making homemade blended formulas requires a team approach. The parent is the leader of the team. We trust the instincts and knowledge of parents as they make everyday decisions about feeding their orally fed children. And we need to trust parents of tube-fed children to make nutritional decisions for their children.

The special considerations of tube feeding technology and special diets, and the translation of oral feeding knowledge to tube feeding, often requires additional team support. When parents are considering serving homemade blended formula, it's very important to work closely with their children's health care team, starting with the primary care physician.

To reflect that team support in this guide, in addition to our own years of clinical experiences as an occupational therapist and speech-language pathologist, we've compiled and edited articles from dietitians, physicians, nurses, and most importantly, parents. Parents have written articles and given input every step along the way. They've suggested topics, provided information, reviewed drafts and given feedback.

It's our intent to provide information about feeding children, education about homemade blended formulas, guidelines for introducing blended foods through the tube and some sample recipes. We'll share parent and professional experiences. But mealtimes are personal in nature, whether they're oral or tube mealtimes. What works for one family and one child may not work well for another family and child. We include guidelines for providing blended meals through a tube, but more importantly we share ways to listen to your child and move forward in offering food as your child

indicates readiness. Each child and family is different;

The choices families make in their journeys with tube feeding reflect their family circumstances and dynamics, and their children's specific nutritional needs. No equipment or diet defines what makes mealtimes work. The essence of the tube-feeding mealtime lies in the bigger picture. Positive and successful mealtimes are defined by how tube feedings are offered, how blended foods are introduced, how cues are read, and how we listen to children.

It's not our perspective that every child who receives tube feedings should be given a homemade blended formula. Rather, it's our intent to offer information so parents and professionals can make informed choices for feeding children who receive nutrition through a feeding tube.

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