

Finding an Appropriate Treatment Program for Children with Feeding Difficulties

A Guide for Parents

As parents, there comes a time when we realize that our child's feeding issues have gotten to the point where we need professional help beyond our pediatrician's recommendations and/or the "helpful" advice we get from family and friends. We may already be at a place where we want to change or increase our existing feeding therapy services. Mealtimes have become emotionally charged, confusing and time-consuming as we watch our children refuse or struggle to drink or eat. We've tried a thousand different "remedies" . . . entertainment, bribery, screaming, or ignoring to get our children to eat. We've switched formulas, nipples, bottles, and cups; we eliminate foods; we read about and purchase all-natural or super junk foods; we buy every spoon or straw on the market, most of which go untouched or make little difference at all. We cruise grocery store aisles and surf the entire Internet to see what we can read or buy. We beg our doctors and therapists for answers.

These feelings of helplessness and being overwhelmed are all very normal. But by becoming fixated on what WE can do to get our child to eat, we forget that ultimately it is the child who learns to eat and guides his own eating. It is important to stop and focus on or revisit the critical questions of WHY our child is having feeding problems. What is getting in the way of their ability and natural desire to eat? There are no easy answers. No single approach, medicine, surgery, formula, food or utensil is going to be the magic cure-all no matter how much we wish it were that simple.

If we are connected with other parents whose children have feeding issues, we may begin to question the services we are receiving. We may increase our stress through doubting the choices we have made. We worry about our child's feeding issues as well as our ability to seek the best medical and therapy services. It is essential to remember that we are doing the best we can with the available resources we have. We are our child's best advocate in negotiating the maze of treatment services and options. This article offers some ideas to give you the confidence and tools for finding the best professional(s) to partner with on your feeding journey.

Preparing for Intervention Services

When seeking therapeutic or medical services, organize and offer as much information as possible about your child's health and feeding history. This will optimize your conversation and time with any health professional. There are several ways to do this.

Compile a succinct **Medical History** (one to three pages) that includes, diagnostic testing procedures, dates of surgeries, previous and current medications and therapy interventions in addition to a current growth chart. There are many benefits to keeping track of (or recalling and reconstructing) these pieces of information about your child. It helps to identify

the components and key issues related to your child's current feeding problems. Medical professionals appreciate these summaries because they are much easier to read and digest than detailed piles of medical records. It is particularly beneficial for early intervention therapists and doctors when you are seeking a second or third opinion.

To organize as much information as possible about your child's feeding history, keep a **Feeding "Journal"** as a way to document your child's past and present feeding/mealtime patterns. Entries might be as simple as "Wow, ate a Cheerio without gagging today"; "finished 4oz bottle in 30 minutes"; "Aagh major stress at lunch—we both screamed and cried. Didn't eat a bite." Also include your child's food types and/or amounts, reflux or vomiting episodes, and mealtime behaviors and interactions as part of the journal.

Children can be quite inconsistent and unpredictable in their willingness and ability to eat in a new setting or with unfamiliar people. **Film your child at home** during a regular mealtime and share this "true picture" of your child with the health professional(s). This way they can actually see actual skills and deficits as well as other issues that are present (i.e., a vomiting episode or strong sensory responses). Ultimately, a **30-Minute Videotape** capturing your child's typical responses to food and to mealtimes is an ideal way to give a specialist or a feeding team a total understanding of your child's mealtimes at home. If applicable, include an example of a tube feeding on your tape. It is also wonderful to show a segment of your child at play.

And lastly, regardless of whether your child has previously received feeding therapy services, **learn as much as possible about eating and drinking** as you prepare to talk to new therapists or other experts. This allows you a deeper understanding of how children learn to eat and drink and the many medical, developmental, learning and psychological areas that could influence your child's comfort, skills and confidence with those functions. There are a number of books, articles and Internet websites available that are excellent sources of information. See the end of this article for a partial listing of these resources.

Document What You Know About Yourself and Your Child

Looking at or revisiting the critical questions of WHY your child is having feeding problems and what interests and skills are already present; is an important step to finding appropriate intervention services. There are a series of questions that are included below to help focus your attention and guide your thinking about your child's feeding issues. We hope that these will enable you to gather important information, to think "out of the box" and explore areas about your personal beliefs, your wants and your child's unique characteristics. Documenting your own analysis can be extremely helpful to further your own understanding of factors that contribute to how your child approaches eating and mealtimes, and ultimately to discover what will benefit them most. Jot down some of your thoughts and specific questions as you consider the following:

Children are extremely sensitive to our feelings and actions. They learn to adopt our attitudes and incorporate them into their own responses to mealtime. If we are feeling stressed, they often experience more stress. If we are anxious or worried, they feel less secure and less relaxed at mealtimes. When we push them to eat, they often push back.

Becoming aware of our own emotions and behaviors can help our children to change.

- How do I feel about food and eating? Do I enjoy meals with my child?
- Do I feel worried, anxious, sad or unhappy about the way my child eats? Why or why not? What do I think would happen if I didn't feel this way?
- Do I feel stressed when I am feeding my child? Why or why not? How does my stress contribute to mealtimes with my child?
- Do I feel good about my child's eating and mealtimes (even if I would prefer a different type of eating or drinking)?
- Do I frequently remind my child to eat or to finish the food that is on the plate? Why? What would happen if I didn't remind my child to eat or drink?
- Do I serve only foods I know my child will eat? What might happen if I offer new foods?
- Do I offer special foods, favorite toys or videos to get my child to eat? Why? What do I believe would happen if I didn't offer these special rewards for eating?

Ongoing medical issues, physical coordination, oral-motor and sensory processing skills contribute strongly to children's comfort and skill with eating. To the best of your knowledge and experience:

- Does my child like to eat and drink? If not, why?
- Does my child associate pain and discomfort with food and eating?
- What specific GI issues (such as reflux, motility, gtube, etc.) am I aware of that affect my child's eating and drinking or have done so in the past? How might other medical issues be affecting my child's feeding issues? (cardiac issues, neurological, respiratory?)
- Does my child have motor-coordination issues that affect his/her ability to eat and drink comfortably? How do these have an impact?
- Does my child have adequate oral-motor skills? What are her strengths and weaknesses? Am I expecting more of my child than he/she is capable of, based on her skill level?
- Would my child experience less stress and fear at mealtimes if he had better oral-motor skills for drinking, chewing or swallowing?
- Do I push my child to eat faster or eat a larger amount of food than he can physically handle in a 30-45 minute mealtime?
- How are sensory issues affecting feeding choices and behaviors?
 - Has my child been evaluated for potential sensory integration issues?
 - Does my child dislike the feel of food on her hands, mouth or face? Does she have trouble with other "messy" textures such as sand or water?
 - Does my child experience discomfort related to sensory defensiveness or sensory overload? How can these be addressed so that my child is ready and comfortable when eating?
- Do I reduce overall stressors at mealtime before I deal with my child's oral motor skills for eating and drinking?

Some children communicate their distress and discomfort around mealtime in very unique ways. They may gag at the sight of food, resist coming to the table, scream when they are placed in their high chair, vomit, or refuse to open their mouths. If your child has this type

of reaction to food and mealtimes, you or therapists may have described your child as having “negative behaviors” or behavioral issues. Your challenge is to interpret the messages that your child is attempting to communicate.

Most children have developed these behaviors related to eating as a way of taking care of themselves. They have learned to compensate for the key issues that led to the current feeding difficulty. These issues must be evaluated and addressed in therapy or through a feeding program. If the child’s behavioral adaptations are treated in isolation, the child may fight adults who do not appear to understand that there is still an active problem that is influencing their ability to progress with eating. Comfort and skill development can become the foundation for developing your child’s inner desire to eat and the skills needed to do so. When children want to eat they eventually learn to regulate the amount and type of food that their bodies need. When children resist eating and parents push them too much, mealtime can become a battleground or the child becomes passive and dependent upon adults to let them know when, what and how much to eat. Consider the following questions:

- When, how and why did these behaviors start?
 - Did they begin as a coping mechanism?
 - Did they become more pronounced as mealtime became more stressful or as GI issues became more pronounced i.e. during an illness or when reflux medication was decreased?
- Did my child experience unrelated discomfort or pain that became associated with drinking or eating food?
- What types of behaviors does my child exhibit and in response to what situations? Are these behaviors based on: the person feeding the meal; the time or location of the meal; or the type of food being offered? Are these behaviors dependent largely on my child’s health and how well he is feeling at the time?
- Is my child afraid of:
 - choking or gagging on a bite of food?
 - dealing with uncomfortable textures and tastes?
 - being asked to eat foods that they are not comfortable with?
 - of being told how and when to take each bite?
- Has fear and distrust developed around feeding and mealtime? Why or how has this happened? How does my child demonstrate or communicate these feelings?
- Are my child’s behaviors developmentally appropriate/ “normal” for their age? Or are they extreme? Do I address these behaviors the same or differently than I would another child without serious feeding difficulties?
- When has my child experienced the “best” mealtimes? What factors contributed to these positive mealtime behaviors?

It is essential that children receive services that address *all* of the areas that are affecting their eating and drinking abilities. We are more likely to find the therapist or program that best fits our child’s needs if we are clear about what we want. Consider what priorities and wishes you have for your child as you ask yourself the following questions.

Trust what you already know and want for yourself as well as your child.

- How do I know when my child is ready for feeding therapy? When are my family and I most able to support my child with therapy interventions? How much therapy is too little, not enough or too much?
- What type of treatment services do I want to find for my child? What specific types of therapies will he/she benefit from most? What can I do at home as a natural part of our day?
- What are my main concerns for my child in his/her feeding journey? at this time and for the future? (It may be helpful to look at this partial list of skills and issues and prioritize the ones that are most important for you and your child.)
 - o diagnosis and treatment of medical issues that affect eating
 - o increasing gastrointestinal comfort- throughout the day, at mealtimes and with tube feedings
 - o decreasing gag reflex
 - o increasing sensory processing skills; decreasing tactile defensiveness; improving sensory integration function
 - o developing oral motor skills
 - o decreasing fear, anxiety and distrust at mealtimes
 - o increasing volume of food taken in by mouth
 - o reducing vomiting and nausea
 - o improving drinking skills, swallowing skills, chewing skills
 - o drinking from a cup, chewing solids, taking pureed foods
 - o refining his/her eating efficiency – getting adequate calories by mouth at meals
 - o acquiring self-feeding skills, or other age appropriate feeding skills
 - o establishing awareness of hunger and fullness
 - o gaining weight
 - o building a positive, healthy relationship with food
 - o enjoying quality mealtime experiences
 - o improving motor coordination to support efficient eating
 - o eliminating “negative” behaviors that are present at mealtimes
 - o increasing interest in food and initiating a desire and willingness to eat
 - o weaning from the gtube
 - o expanding dietary diversity through a wider variety of foods, tastes and textures
 - o improving nutritional intake of diet
 - o establishing structured mealtime expectations and guidelines for my child (based on his/her skills and behaviors)
- Which of these situations or skills should be addressed before examining other areas? In what areas does my child already have strengths and abilities?
- What are my priorities? Are they the same or different from my child, my spouse, the therapist, pediatrician, gastroenterologist, or feeding team?

Identifying Appropriate Feeding Resources

Choosing a doctor or therapist to work with your child can be a real challenge, and requires the same type of information search that you would make if you were considering buying a house or car. The comparison may not seem glamorous, but it helps avoid the consequences of working with someone whose professional background or personality doesn't fit.

Different professionals have different interests and skills. Some of these will match your child's needs; others will not. For example, a feeding therapist who works well with children who have coordination difficulties that affect eating may have little or no background with the challenges of sensory defensiveness or sensory overload. If your child has a sensory-based feeding problem, it is important to work with someone who has both understanding and experience with children who are uncomfortable with sensory aspects of eating or drinking. A psychologist may have excellent experience with learning skills and family dynamics that relate to eating. However, if your child also has active problems with sensory processing, movement coordination or gastrointestinal comfort, you would want to find out how the psychologist would address these problems in a therapy program.

Most often, children receive their first therapy treatments through statewide early intervention services that are provided through local health departments and school systems at no cost. The programs are targeted for children ages 0 –3 years and then 3-5 years who are identified as having a delay in specific areas of development. These nationally mandated programs are a lifeline for many families and can provide hours of critical early intervention services by very good therapists. Due to the multi-faceted issues surrounding feeding problems, be sure that your child is receiving services from a trained, experienced therapist. Otherwise, he/she may not be getting the most appropriate services that they need and deserve to address their feeding difficulties.

There is no certification or licensure board for therapists working specifically in the feeding area. Therapists are licensed in their professional area (i.e. Speech-Language Pathology or Occupational Therapy). University graduate programs in Communication Disorders and Occupational Therapy are still very inconsistent in the amount and type of background in feeding and swallowing (dysphagia) education that they offer to therapists. Almost all of the training or education for feeding and swallowing problems of infants and children is provided through adult continuing education courses. Children demonstrating oral motor problems should be evaluated by a licensed, American Speech-Language-Hearing Association (ASHA) certified Speech-Language Pathologist with specific expertise in oral motor, swallowing and feeding disorders. To find a therapist in your area, you can contact the National Organization at ASHA Action Center, at 1-800-638-TALK.

If you find that your local doctors and therapists do not have the education or experience in the feeding and swallowing disorders field, it may be better to travel a longer distance for an evaluation and consultation by trained experts. In partnership with these experienced professionals, you can develop a strong home-program that supports the needs of your child and may yield better results than more frequent contact with an unsuitable but closer therapist.

Here are a few more ways to identify professionals to consider for your child:

- Call local clinics, hospitals and universities to find therapists working with children with feeding problems.
- Talk to other parents and professionals who can give you personal insight into their experiences. Always ask if they know of anyone else who might have worked with therapists or professionals who might be right for your child. Broaden your search by asking for personal experiences and recommendations on various Internet listservs that focus on children with special needs, i.e. feeding disorders, sensory integration, reflux, prematurity or gtube groups.
- Identify workshops on feeding, swallowing, oral-motor development and sensory integration either through an Internet search or by asking professionals. Find out who the instructors are that teach longer, more intensive courses which tend to draw professionals who want a more in-depth understanding of the topic. Ask for the names of the therapists who participated from your area and for information about the subject matter and experiences that were provided in the workshop course.

The Initial Meeting – Important Questions

Once you have gotten a list of names and talked to people by phone or email, make an appointment to meet with the therapist(s) or program you are considering. From there you can get more information and decide whether this person fits for you and your child. During the initial meeting, it is important to share your knowledge and understanding of your child and to let the therapist or team know that you want to be a partner in the evaluation and therapy process. Use the medical history, feeding journal and videotape film to provide an overall picture of your child. If possible, arrange to send copies of these in advance. Present what you believe to be the key issues and your thoughts on “the problems”. What is their opinion? After considering your child’s individual feeding problem and history, ask the provider(s) if they feel they can address your child’s needs based on their training, skills and experience. If not, can they recommend another therapist(s)?

The following questions and their responses will enable you to gather information to help you decide whether you wish to schedule a more in-depth evaluation or therapy.

The Individual Therapist

- What training and education have you had to work with feeding and swallowing problems with children? What specific background do you have to address my child’s key issues? How long have you been working with children with feeding issues?
- What specific courses have you taken? Who have you studied with? What books or authors have you found helpful, as you’ve developed your own approach to children with feeding issues? What type of approach do you take with children?
- What type of overall assessment do you conduct to identify related medical issues (i.e. gastrointestinal, respiratory, cardiac, neurological, sensory, oral-motor) that might influence my child’s eating and drinking? What referrals do you make to other professionals or agencies for these evaluations?

- How do you or your program identify the skills that my child already has and work to enhance my child's existing abilities?
- How do you establish feeding goals and assess outcomes?
- How do you work with parents and other family members? How do you help parents incorporate therapy ideas at home? How do you work with parent feedback about the appropriateness of specific activities at home?
- How will you help me develop a positive mealtime experience so that my child develops a healthy relationship with food, wants to eat and enjoys food?
- How do you work with other professionals that are an important part of my child's feeding successes? (i.e. dietician, occupational therapist, pediatric gastroenterologist)

The Feeding Team

Some hospitals or clinics address the feeding issues of children and families through the coordinated evaluations and recommendations of a team of feeding professionals. A child might be evaluated by a core group of therapists and / or by a coordinated medical team that includes specialists in gastrointestinal, respiratory and neurological problems. Psychologists, dietitians and social workers are also included in many feeding teams. Theoretically this can be an efficient way of gaining an integrated treatment program that addresses a child's multiple issues. In reality, this is often not the case.

Programs, like individual therapists, can have strong biases about the best way to address feeding issues in children. Make sure you have a good program match based on your child's needs. Feeding problems can generally be divided into structural or physiological based feeding problems; motor based feeding problems; sensory-based feeding problems or experiential based feeding problems. There are different professionals and strategies that can be used to best address these various areas. For example, if the program does not consider the validity of sensory integration issues, an evaluation by an occupational therapist with training in sensory processing will not be included. Some programs set specific goals for the child to eat larger amounts or a wider variety of foods before addressing gastrointestinal issues such as reflux or poor gastric emptying. If gastrointestinal comfort and readiness for increasing the quantity of food are not present, a program to increase food intake can increase the physical pain and discomfort that a child associates with eating. The long-range impact can be seen in the child's increased resistance to eating.

Some feeding teams evaluate the child's abilities by having several team-members work simultaneously with the child. For example, the occupational therapist and speech-language pathologist might work together to explore how a child's seating system or self-feeding skills affect oral movement and the ability to eat or drink efficiently. Other programs rely on the individual assessments of team members. Teams also work in different ways to coordinate the information gathered by each individual. No single approach can be labeled the best way to function as a team.

It is important for parents to be aware of the feeding team's priorities and to know what to expect from the evaluation or treatment recommendations. The following questions will help you to learn about the feeding team/program that you are considering and decide whether its approach best meets you and your child's needs.

- What is the philosophy of the overall program? How is the philosophy reflected in the way you will work with my child? How do you define or describe your "success rate" with children?
- When and how will you determine if my child is "ready" for this type of program?
- How are parents and other family members incorporated into your program? What types of parent education and parent support services are offered through your program?
- How will your feeding team diagnose and address my child's medical issues prior to setting specific eating goals? (i.e. reflux, poor motility, food allergies)
- How will you conduct an extensive multidisciplinary evaluation of my child in order to create and implement the most effective individualized treatment? Which professionals will take part in the evaluation of my child? In the treatment?
- Who establishes treatment priorities for my child prior to entering the program? How will these goals be set for my child? How and when will these goals be re-evaluated and modified? How will you measure my child's progress in the feeding program?
- How will your evaluation and treatment of my child take into consideration any present:
medical issues; motor coordination issues; sensory issues; oral motor issues; and/or experiential issues?
- How do you evaluate a child's readiness to transition from tube feedings to oral feedings?
- How much time per day will my child receive therapy? What type of therapy and related services will they receive? Who will be involved, to address:
 - o sensory processing skills?
 - o oral motor skills?
 - o experiential ("behavioral") issues?
- Who will be feeding my child his/her meals and in what setting? How many meals will my child receive per day and who is responsible for making food selections and meal preparation?
- What approaches will be used to help my child
 - o recognize hunger and fullness?
 - o increase the texture and variety of foods that my child learns to eat?
 - o experience positive mealtimes and establish a healthy relationship with food?
 - o increase their desire and willingness to eat and drink?
- What is the relative importance in your program of increasing the amount of oral intake of solids and liquids?
- What type of follow-up services do you offer to families in your program? How will you help me to incorporate at home what I learn in your program?

Making a Decision

Once you have explored why your child is having problems and what skills are already present, you can better evaluate which programs and/or therapists are best suited to value his special abilities, interests and needs in encouraging him to eat. You are the only one who can make the final decision about whether your child participates in a particular feeding program or receives specific therapy services. Professionals can answer questions, provide information about their services and make recommendations, but they *cannot* make the decision for you.

Opinions will vary, and hearing different views from equally qualified-sounding professionals can be confusing or even daunting. You will find that there are many diverse approaches and priorities in working with children who have feeding problems. Other parents or professionals views of a specific therapist or program are helpful; though bear in mind that their experiences and their child's experiences are very personal. Also, interactions between individuals are unique. If your style, beliefs and ways of approaching a challenge are radically different from those of the therapist or doctor, it may be difficult to work together.

Trust your gut-instinct about how well a therapist or feeding program will work for you and your child. It is just as important to honor your intuitive impressions, as it is to ask questions about specific aspects of the services they offer. Ultimately, you should process these perspectives and then choose your path with confidence.

Keep in mind, if the program or therapist is not meeting your child's needs or you disagree with aspects of your child's services, you have the right to voice your concerns. As a result, you may establish a better working relationship or you may wish to change therapists or programs. The bottom line is that it is all about learning and growing. We are always free to reconsider our choices and make new ones to reflect our current understanding of our child and ourselves. Reconsidering a choice that no longer fits for us does not have to be tied up with regrets and self-judgments. We have learned and grown in our understanding and we are free to change. Change is simply change. And positive change is present in every part of our lives.

About the Authors

Kris McNally has walked the feeding and mealtime journey with her son Seamus, who with her support has developed the comfort, skill and confidence to enjoy eating with his parents and brothers and sister. Kris is a Health Educator who is currently focusing on her role as the mother of 4 young children (including 5-year-old triplets). She is the founder and active leader of “Among F.R.I.E.N.D.S.” [Feeding Related Issues and Eating Disorders Support Group] in Severna Park MD.

Suzanne Evans Morris is a speech-language pathologist who specializes in the development of feeding programs for infants and young children. Suzanne maintains a professional practice that includes direct clinical work, continuing education workshops, development of clinical materials and clinical research. She is the director of New Visions, which sponsors innovative workshops for the teaching of feeding-related skills, and provides family-oriented clinical services. She is the coauthor of *Pre-Feeding Skills: A Comprehensive Resource for Feeding Development*, and the *Mealtime Participation Guide*.

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