feeding matters

FAMILY GUIDE

Navigating the Pediatric Feeding Disorder Journey

DEAR PARENTS & CAREGIVERS

I am the senior program manager at Feeding Matters. I am also a mother to my son, Hadyn, who has struggled with pediatric feeding disorder (PFD) since birth. I want you to know that I understand what you are going through. No parent ever imagines that their child will struggle with feeding. My days were spent counting calories and desperately trying to get my son to drink and eat. I was scared and I don't want any parent to feel the way I did.

As you work your way through this world of PFD, my best advice to you is to trust in yourself and your child. You are strong and capable, and you know your child best. Nevertheless, you will greatly benefit from connecting with other families who are on this journey because they are in the unique position to understand what you are feeling.

PFD may not be what you had hoped for your child. However, I would like you to know that you don't have to fight this battle alone and that there are many people and organizations around you to help you get through this. This guide focuses on such help and support available to you, and I am sure you will find it useful. Please contact Feeding Matters at the number below with any questions you may have after reading this guide or submit your questions here.

Heidi Van der Molen
Senior Program Manager

feeding matters

INTRODUCTION

When your child is struggling with feeding, it can be scary and tiring. But you are not alone in this journey.

Established in 2006, Feeding Matters, a 501 (c)(3) nonprofit organization, is the first of its kind in the world that connects the concerns of families with leading doctors, researchers, allied health care professionals, and advocates. Feeding Matters works with these individuals to improve care for children with pediatric feeding disorder (PFD) and educate health care professionals about PFD.

This guide will define and explain PFD in more detail. No matter where you are on this journey, this guide will give you the information necessary to help your child. This guide will be updated periodically to incorporate the latest knowledge and research in the field.

After reading this guide, if you feel your child is at risk of having or may already have PFD, there are a few steps you can take:

CAREGIVER CHECKLIST

- ✓ Fill out the Feeding Matters Infant and Child Feeding Questionnaire
- ✓ Schedule an appointment with your child’s doctor. Take the completed Infant and Child Feeding Questionnaire to your appointment.
- ✓ Finda a qualified provider using the Feeding Matters Provider Directory.
- ✓ Get support through the Feeding Matters Power of Two program or ask your child’s doctor about local support groups.

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Pediatric feeding disorder (PFD) is defined as impaired oral intake that is not age-appropriate and is associated with medical, nutritional, feeding skill, and/or social–emotional challenges.

CHAPTER 1

WHAT IS PEDIATRIC FEEDING DISORDER?

A child may have PFD if they cannot drink or eat the types of foods or the quantities of foods that other children their age can eat. It's not just because they are being picky eaters. There is usually an underlying reason. This reason can be better understood by looking at specific areas, or domains, of PFD. The four domains that are related to PFD are medical, nutritional, feeding skill, and psychosocial (relating to the mind and to interacting with people). A problem in one domain can lead to problems in another domain. In Chapters 3–6, we have defined each of these domains and how they are related to PFD.

If mealtimes are difficult, there is a direct and dramatic impact on the whole family, which can result in considerable stress or feelings of failure. This may leave everyone in the family dreading mealtimes, with interactions between the child and either or both parents becoming strained and a daily schedule that focuses on the child's feeding. PFD may affect the child's everyday activities such as family outings, school participation, or social events.

If you think your child has a feeding disorder, please answer the questions below. These questions are often used to screen for infant and child feeding concerns. If two or more questions are warning signs please share with your child's doctor.

1. Does your baby/child let you know when they are hungry? Yes/**No**

2. Do you think your baby/child eats enough? Yes/**No**

3. How long does it usually take to feed your baby/child? **Less than 5 minutes**/5–30 minutes/**More than 30 minutes**

4. Do you often have to do anything special to help your baby/child eat? **Yes**/No

5. Does your baby/child let you know when they are full? Yes/**No**

6. Based on the questions above, do you have concerns about your baby's/child's feeding? **Yes**/No

Answers in red present as possible warning signs for PFD.

For a more in-depth screening tool, you may complete the full Infant and Child Feeding Questionnaire. You can email or print the results and share them with your primary care provider to help you talk about your concerns. If possible, take a video of you feeding your child or of your child during a meal to help your provider get a clear picture of mealtimes.

If an evaluation or feeding therapy is recommended, you can search the Feeding Matters Provider Directory to find a qualified provider.

You don't have to face this journey alone. Get support through Feeding Matters' Power of Two parent-to-parent mentoring program or ask your child's doctor about local support groups.

MYTHS OF PEDIATRIC FEEDING DISORDER

CHAPTER 2

TOP 8 MYTHS OF PEDIATRIC FEEDING DISORDER

1. **They will eat when they are hungry.**

   There are many reasons that a child with PFD might not eat even when they're hungry. For example, if eating or drinking is painful, the child may begin to link feeding with discomfort. They may avoid eating to avoid pain, despite being physically hungry. Similarly, a child with problems of the mouth muscles may want to eat but be unable to coordinate the process of sucking from a bottle or chewing and swallowing.

2. **It's just a phase—they'll grow out of it.**

   Often this advice comes from well-meaning professionals or family and friends. Unfortunately, it is not always true that a child will grow out of a feeding problem without help. Undiagnosed feeding difficulties may cause serious problems for the child and lead to family stress.

3. **My child is following their growth curve, so there is no concern.**

   Some children may follow their growth curve but still show signs of PFD. If you have to take extra measures to get your child to eat, there may be a concern.

4. **Babies are born knowing how to eat.**

   Eating is not instinctive for all babies. Some babies may require support from medical professionals.

feeding **matters tip**

Don't let others place expectations on you that you cannot handle. Find a plan that works best for you, your child, and your family. Understand that your plan may need to change throughout this journey.

TOP 8 MYTHS OF PEDIATRIC FEEDING DISORDER

5. **It’s just picky eating or a power struggle between the parent and child.**

Picky eating can occur in the first 5 years of a child's life, particularly in the toddler years. However, sometimes this pickiness expands to a feeding problem that affects the child and family. Similarly, if a child is not eating at any age, it is not the parent’s fault. The child is likely communicating that something about eating is challenging for them.

6. **Placing a feeding tube is a sign of failure on the parent’s part.**

Regardless of the efforts of parents, sometimes children need a feeding tube to grow and develop. If a feeding tube is being recommended for your child, contact Feeding Matters for support. Through Feeding Matters’ Power of Two parent-to-parent mentoring program, you can talk to other parents who have experience with placing a feeding tube for their child, parents who have chosen not to place a feeding tube, and parents who have weaned their child off a feeding tube. For more information on feeding tubes, please visit The Oley Foundation.

7. **PFD is an eating disorder.**

PFD is not the same as an eating disorder such as anorexia. Body image does not play a role in PFD and should not be considered solely a mental health disorder.

PFD can be co-diagnosed or turn into ARFID, which is classified as an eating and a feeding disorder but is still different from traditional eating disorders because both exclude body-image disturbance.

8. **My child will always have PFD.**

Although PFD may be a lifelong journey for some children, many can develop functional and safe eating skills with proper treatment and therapy.

feeding **matters tip**

Surround yourself with others who have gone through a similar journey.

THE MEDICAL DOMAIN

> *“When our doctor said, ‘Here is what I think, but what do you think and what will work for your WHOLE family?’ That is when things changed; that was when we were brought to the table, treated with respect, and our voice finally mattered. A true partnership makes all the difference.” —Elizabeth B.*

CHAPTER 3

THE MEDICAL DOMAIN

The act of eating is a complex task that involves the entire body working as one coordinated unit. Considering there are so many muscles and body parts working together, it is possible that your child is having trouble eating or swallowing because of a medical issue. In some cases, children with PFD have medical factors that contribute or are the cause of their feeding disorder. This could be reflux, which can cause pain when eating, or it could be an airway and lung disorder, which may affect the suck-swallow-breathe coordination in babies. Medical conditions can cause problems in other areas, such as feeding skills or nutrition.

Possible Signs and Symptoms of a Medical Feeding Issue

- Labored breathing with or without feeding
- Color changes in the lips, around the mouth, or to the face when eating or drinking
- Sweating when eating or drinking
- Gurgling or squeaking sounds with or without feeding
- Recurring upper respiratory infections
- Crying, arching, coughing, or grimacing when eating or drinking
- Suspected food allergies
- Multiple formula changes
- Vomiting
- Never seeming hungry
- Physical discomfort when eating or drinking

Who Can Help Assess and Treat?

Primary care doctors, such as pediatricians, are generally the first people responsible for identifying PFD and can make referrals to specialists who will be most helpful for your child.

These specialists can include allergists/immunologists, cardiologists, dentists, developmental pediatricians, endocrinologists, gastroenterologists, geneticists, lactation consultants, neurologists, nurse practitioners, occupational therapists (OTs), otolaryngologists, pulmonologists, radiologists, speech-language pathologists (SLPs), or surgeons. Learn more about each of these specialists on the Feeding Matters website.

Note: Advanced education in PFD is recommended for all professionals who work with children and families who struggle to eat. Although a multidisciplinary certification pathway has yet to be established, Feeding Matters continues to advocate for knowledge and advancement in evidence-based practice and collaboration across all four domains.

Common Tests and Procedures that Specialists May Suggest May Include the Following:

- Allergy testing
- Chest X-ray
- Clinical evaluation of swallowing and feeding
- Endoscopy
- Fiberoptic endoscopic evaluation of swallowing (FEES)
- Modified barium swallow study/videofluoroscopic swallow study
- Gastric-emptying scan
- Genetic testing
- Upper GI series

We understand that medical tests can feel scary but they can also provide valuable information that helps guide your child's care. These tests can also help identify what is causing the problem or rule out problems, leading to the most appropriate care for your child.

THE MEDICAL DOMAIN | FAQ

How should I address medical concerns with doctors?

If you have concerns about your child's feeding, try not to wait until the next wellness checkup to address them. Make an appointment with your child's doctor to discuss your concerns as soon as possible. Try to keep a food journal of your child's eating and mealtime behavior(s) to share with your doctor. Bring a video of you feeding your child or of your child during mealtimes. You can also fill out the Infant and Child Feeding Questionnaire on the Feeding Matters website and either print it out or email it to your child's doctor.

Which medical tests are necessary for my child?

Recommended tests are based on each child's individual needs. Your child's medical team will advise you on which tests are necessary for your child.

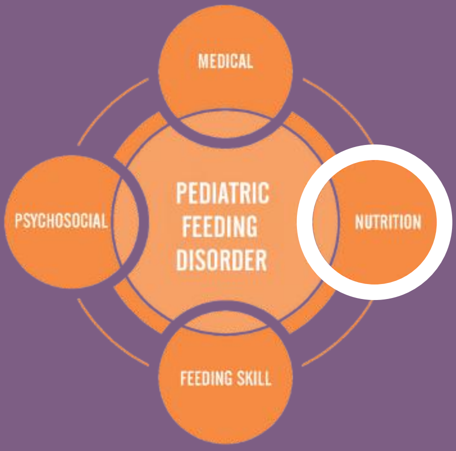
Which doctors or specialists will my child need to see?

Your child's primary care doctor (pediatrician) can help direct you to the specialists that are necessary for your child's care. Feeding Matters' Coordinated Care Model focuses on the four domains that affect a child's well-being. Ideally, you will want a multidisciplinary team that involves a specialist from each of the four domains of PFD.

Will my child need a feeding tube?

Making the decision to get a feeding tube can be difficult and scary. For some children and families, placing a feeding tube may be the best decision for many reasons. Don't be afraid to talk to your child's medical team about all of your options and concerns. Placing a feeding tube is always a team decision and should not be made without your input and agreement. This doesn't mean you failed your child, it simply means you care enough to give your child every tool possible to help them receive nutrition that is good enough.

> ***"A feeding tube is a lifeline. Extra special kids get two belly buttons. Feeding tubes provide hope." —Alex M.***



THE NUTRITION DOMAIN

> *“We worked with Marnie once a week, and the therapy sessions we had with her were a game changer! She taught us so many different techniques, showed us a variety of tricks and tools, and helped us build up my daughter’s confidence and overcome her oral aversions. We are forever grateful.” —Megan B.*

CHAPTER 4

THE NUTRITION DOMAIN

Good nutrition is the foundation for growth and development. It directly affects a child's brain activity and capabilities, fine and gross motor skill development, and overall health and wellness. The unique nutritional needs of a child may be met in several ways. A child may be able to eat all of the food they need by mouth. In some cases, it may be necessary for a child to also have a nutritional drink or be given food through a feeding tube.

Whether an infant or child eats by mouth or through a feeding tube, good nutrition is necessary to thrive. Regardless of how a child is fed, mealtimes should be pleasant for both the child and caregiver.

A shortage of nutrients can be difficult to know just by looking at a child. Some nutrient deficiencies may be due to other medical conditions such as celiac disease; food allergies; or feeding challenges, such as PFD.

It is important to have your child's diet evaluated by a professional in the nutrition domain to determine if there are any possible nutrients your child may be lacking in their diet.

Keep a detailed food diary before meeting with a dietitian, including types and amounts of foods eaten.

Possible Signs and Symptoms of a Nutrition Issue

- Unable to eat/drink enough to grow or stay hydrated
- Insufficient or too rapid of a change in weight or height
- Lack of a certain nutrient (e.g., iron, calcium)
- Need for nutritional supplements
- Reliance on a particular food for nutrition
- Need for enteral feeds for nutrition-NG, GT, TPN (see Glossary)
- Constipation
- Limited dietary variety for age
  - Too few fruits, vegetables, or both
  - Limited or no protein source
  - Too few foods eaten regularly

Who Can Help Assess and Treat?

A registered dietitian nutritionist (RDN) is the most qualified specialist to discuss a child's growth and nutritional needs. RDNs are food and nutrition experts who look at a child's diet. An RDN may do the following:

- Determine if your child is eating the right quantity and kinds of food needed based on their needs and conditions.
- Work with you to create a nutrition plan that will support both you and your child.
- Work with your child's medical team to decide the best diet for your child.

> ***"We went to see that nutritionist on Monday, and it was so amazing. She understood. She understood not only the nutrition side of things but the REALISTIC side of things." —Paula B.***

THE NUTRITION DOMAIN

A Note About Hydration

Our body is made up of nearly 80% water, and so much of what our body does requires water. Proper hydration is essential for the growing brains and bodies of children.

Some forms of hydration are better than others. Look for options without added sugar. Water is the best choice, but there are many other options and some that even provide additional helpful nutrients and calories.

- Water
- Milk or milk alternatives such as almond milk, oat milk, and soy milk
- Fruits and vegetables
- 100% fruit juice—limit amount if possible

Possible Signs of Dehydration

- Fatigue or dizziness
- Decreased urination
- Dark yellow urine
- Dry lips, mouth, and skin
- No tears when crying
- Nausea or headaches
- Sunken eyes
- Irritableness

A Note About Breastfeeding

Although we know that breastfeeding has many benefits, it doesn't come naturally for everyone, nor does everyone want to breastfeed, and some caregivers aren't physically capable of breastfeeding.

- What works best for you and your baby is what matters most, and that may look different among children in the same family.
- As a caregiver during the newborn stage, it may be difficult to identify challenges with breast or bottle feeding on your own, and problems are frequently missed, even by health care professionals.
- If you have any concern, reach out to your primary care doctor, a certified lactation consultant (CLC), or an international board-certified lactation consultant (IBCLC) for additional information.

A Note About Feeding Tubes

Getting a feeding tube may be a short-term solution for some children to help them receive the nutrition they need, or it may be a lifelong support. In any case, it's important to talk about any concerns you have regarding a feeding tube with your child's team.

There is support available, whether you want to learn more about the different types of feeding tubes, which formulas can be used, or how to wean your child off their feeding tube when they are medically stable.

THE NUTRITION DOMAIN | FAQ

How do I know if my child is eating enough?

Your child's primary care doctor will track their growth at each wellness checkup. If you are worried about the quantity or type of food your child is eating, contact your child's primary care doctor to discuss your concerns. They may offer, or you can ask for, a referral to an RDN if you still have concerns.

Should I be worried if my child has a limited diet?

It's natural to feel anxious if your child only eats a few foods. If your child is refusing to try new foods or will only eat certain foods, try not to force-feed them. Listen to your child's cues. The most important thing you can do is to provide a positive environment for your child at mealtimes. Seek the help of your child's primary care doctor. They may refer you to an RDN, SLP, or OT to talk about your child's needs.

Does my child need a multivitamin?

A dietitian can help determine if a multivitamin is necessary by identifying any potential nutritional gaps in your child's diet. Supplements such as multivitamins are not regulated by the U.S. Food and Drug Administration. If your child's health care provider recommends any form of vitamin supplementation, look for a brand that is third-party tested to make sure the product matches what is on the label.

Will an RDN be able to work with my family's cultural preferences/dietary restrictions (e.g., vegetarian, kosher)?

Yes, an RDN should look at your family culture and work with you based on what your goals are, keeping in mind your cultural preferences, dietary restrictions, and the foods your family enjoys.

Do I have to feed my child formula through the feeding tube?

No, formula is not the only option for tube feeding. Based on the type of feeding tube and your child's nutritional needs or allergies, there are many options. For example, you could make homemade food in a blender or use a commercial product made from whole foods. Many of these products are covered by insurance. Discuss your options with your child's gastroenterologist, RDN, or both.

Will an RDN be covered by my insurance?

Nutrition services are often a covered benefit through your child's health insurance. It is a good idea to call your insurance provider to confirm your benefits. They can also help you find an in-network provider.

THE FEEDING SKILL DOMAIN

> *“Well-meaning friends and relatives offer advice that may have worked for their children but is totally ineffective or contraindicated for my daughter, such as, ‘She’ll eat when she’s hungry.’ With the support of my Feeding Matters Family Coach, I designed a research-based feeding program for my daughter. She’s now 4 years old and eating a wide range of foods!” —Amber H.*

CHAPTER 5

THE FEEDING SKILL DOMAIN

Learning to eat skillfully and safely requires the integration of many body systems. When a child demonstrates readiness skills, it makes it possible for them to suck, swallow, bite, and chew foods or liquids. This is a complex process that develops by building on previously learned skills to advance to additional skills.

Motor skills may include chewing different textures, lip closure to remove food off a utensil, or coordination of the tongue to swallow foods and liquids. Sensory processing examples may include intolerance to different food or liquid textures or temperature changes. Babies and children may develop sensory avoidance or defensive behaviors to foods and liquids due to prior negative experiences from eating such as choking or gagging.

Parents and caregivers play an important part during mealtimes because they help the infant or child learn to communicate their needs and wants. Feeding should be an enjoyable activity for the child and parent or caregiver; however, for children and families experiencing PFD, mealtimes can be a daily challenge. Medical complications, prematurity, or other health factors may be interfering with the development of feeding skills, and feeding therapy may be necessary. Therapy can increase your confidence in parenting a child with PFD.

Possible Signs and Symptoms of a Feeding Skill Issue

- Labored, noisy breathing or gasping
- Coughing, choking, gagging, or retching
- Gurgles or wet breaths
- Loud or hard swallows or gulping
- Inability to eat or drink enough for optimal growth
- Excessively short mealtimes (< 5 minutes)
- Excessively long mealtimes (> 30 minutes)
- Need for thickened liquids
- Need for special food or modified food texture
- Need for special strategies, positioning, or equipment
- Inability to latch to breast or bottle without help (12 months old or less)
- Weak suck (12 months old or less)
- Need for pacing, flow management, or rest breaks (12 months old or less)
- Need for special equipment to breast or bottle feed (12 months old or less)
- Often too tired to eat or quickly falls asleep when eating (12 months old or less)
- Breast or bottle feeds best when asleep (i.e., dream feeds; 12 months old or less)
- Inability to transition to solids (12 months old or less)
- Inability to wean from breast or bottle (12 months old or less)
- Grazing (eating) between scheduled mealtimes
- Refusal to eat, drink or swallow certain food textures
- Needs distractions to eat, such as screen time
- Needs excessive praise, threats, or bribes to eat
- Difficulty chewing age-appropriate foods
- Inability to eat in new or unfamiliar situations

THE FEEDING SKILL DOMAIN

Who Can Help Assess and Treat?

Developing an action plan to help your baby or child manage PFD should start with your primary care doctor. A team of providers may be needed to help manage PFD, and this team may change throughout the treatment and intervention process. During an evaluation, the provider and therapist may review your child's medical records, ask for a food journal and assess motor and sensory processing skills through a questionnaire, observation, or both.

Feeding therapy providers; SLPs; OTs with specialized training; and, in some areas, physical therapists, may do the following:

- Look at motor strength.
- Evaluate body positioning.
- Increase sensory tolerance.
- SLPs and OTs may evaluate swallowing (dysphagia) concerns, including improving oral motor skills and providing food and liquid modifications when indicated.

Therapy can occur in a variety of settings and through different delivery models:
Home-based | School-based | Clinic-based | Outpatient intensive therapy | Inpatient intensive therapy | Teletherapy

A Note About Transitioning to Solids

A child with PFD may struggle with the transition from liquid to solid foods. This transition is important because it sets a good foundation for solid-food mealtimes. When transitioning your child to solid foods, no matter what their age, you can try the following tips to facilitate a smooth transition:

- Follow a responsive approach: This means that you follow your child's communication cues about whether they are ready or interested in eating solid foods at that mealtime. They may show you they are done eating by turning their head away from food, swatting the spoon, telling you "no," or removing themselves from the table. They may show you they are interested by leaning forward for a spoon, opening their mouth when offered food, or picking up food.
- Avoid pressuring your child to eat solid foods. Subtle forms of pressure can include asking them to take a bite after they clearly said no, putting the spoon into their mouth if their lips are closed, trying to sneak in a bite of food while they are distracted, or trying to convince them to take a bite ("If you eat this bite, you can have TV time.").
- Keep mealtimes positive and enjoyable. Offer foods without an expectation that they will be eaten, incorporate music or tell stories, and encourage your child for each small win they have—maybe they touched a new food today!
- Let mealtimes be messy. Learning to eat solid foods is a process. Try not to clean up your child during the meal and instead let them stay messy and clean up at the end, away from the table if possible.
- Get your child involved outside of the mealtime. Bring them to the grocery store or farmers market and involve them in meal preparation or cooking.

If you are feeling stressed or anxious about introducing solid foods and more advanced textures or you have concerns about how well your child is able to manage solid foods, reach out to an SLP or OT. You can find one near you in the Feeding Matters Provider Directory.

THE FEEDING SKILL DOMAIN | FAQ

Why does my baby fall asleep during feeding?

YSleep may be a sign of satisfaction and relaxation. It may be your baby's natural way to end a feeding. However, some babies may experience stress and discomfort with feeding. They fall asleep to avoid feeding or avoid pain caused by feeding. Moreover, some babies, especially those with medical conditions, do not have enough energy to finish a whole meal. They may fall asleep from being tired. If your baby cannot stay awake and enjoy their feedings, speak with your child's primary care doctor. Mealtime should be a time that everyone in the family can share and enjoy together.

If my child is meeting oral motor milestones, but not meeting gross motor milestones, are there any concerns?

Yes. Gross motor skills, such as sitting up alone, are a foundation for fine motor skills, such as feeding oneself, chewing, and swallowing. Without adequate gross motor skills, sitting, breathing, and swallowing can be challenging.

My child does not chew food; they swallow food whole. Is this a concern?

Yes. Chewing breaks down food to safely swallow and prevent choking. Presenting small tastes of purees and then slowly introducing textures as the child advances with their chewing skills is a developmental and sensory motor approach to learning chewing skills. Children need practice and time; however, if you do not feel your child is progressing, and choking or gagging is occurring, you may need to consult with a doctor or feeding therapist.

My 1 year old is picky and refuses new foods. Is this a concern?

No, not at this time. It takes time for children to develop their taste preferences, so offering the same food 10–14 times is typical for the child to develop their palate. Picky eating and refusing to eat some foods is common in young children as they try new foods and learn how to eat different kinds of foods. Slowly introduce new foods, offer new foods multiple times, and give your child time to explore new foods at their own pace. If the introduction of new foods creates significant stress at mealtimes or there is a history of challenging feedings, speak with your child's primary care doctor.

feeding **matters tip**

Try to stay in the present moment and focus on every small step toward progress. Celebrate the "inchstones."

THE FEEDING SKILL DOMAIN

Recommendations

Finding the right therapist for your child and family is important when looking for therapy services. It is a good idea to interview the therapists you are thinking of visiting. Ask questions to help you understand the skills or issues that will be addressed during therapy, your role as a parent or caregiver, and the expected outcomes for your child. Prior to meeting with a therapist, consider keeping a feeding log for a week to help the therapist understand the eating and drinking challenges.

To find a therapist who advocates for you and your child, do the following:

- Ask your child's primary care doctor, or check Feeding Matters' Provider Directory.
- Check with your local school district and early intervention programs.
- Talk with other parents (in moderation, so you are not getting overwhelmed)
- Review your insurance plan to see if there are preferred providers in your area.

Look for a provider or therapist who focuses on family-centered care.
A family-centered care provider:

- is willing to collaborate with other providers and share information with them and your family;
- demonstrates respect for your child, your family, and your culture;
- understands environmental factors in your home, school, lifestyle, and culture; and
- demonstrates experience and expertise in pediatric feeding, eating, and swallowing.

feeding **matters tip**

Do not push your child beyond their feeding capabilities just to get them off the tube.

DO WHAT
MAKES YOU
HAPPY

THE PSYCHOSOCIAL DOMAIN

> *“For so long it seemed like there was no real plan to help Terra. When I learned to do my own research, ask direct questions, and propose my own steps and ideas for treatment—that is when things really started to turn around for our family.” —Loran E.*

CHAPTER 6

THE PSYCHOSOCIAL DOMAIN

When children exhibit challenging mealtime behaviors, they are typically expressing that eating is unpleasant or difficult for them at that time.

Caregivers and families often feel confused and frustrated by these behaviors. The behavior affects not only the caregiver–child relationship but also the child's thoughts toward feeding.

Possible Signs and Symptoms of a Psychosocial Issue

- Inability to come to or stay with the family at meals
- Refusal to eat what is offered or to eat at all
- Disruptive mealtime behaviors
- Inability to eat with others present at mealtimes
- Child stress, worry, or fear during meals
- Caregiver stress, worry, or fear when feeding child
- Presence of bribes, threats, yelling at mealtimes
- Need for distraction, rewards for eating, or both
- Unpleasant mealtime interactions between caregiver and child

Who Can Help Assess and Treat?

Behavioral health specialists, including psychologists, social workers, and board-certified behavior analysts (BCBAs), can help identify and treat psychosocial concerns related to mealtimes. RDNs, OTs, and SLPs may also provide guidance and support for challenging mealtime behaviors.

Behavioral health specialists may conduct an extensive review of your child's medical record (when available); provide you with questionnaires to obtain as much information about your concerns as possible; and conduct an interview with you, your child, or both, based on the biopsychosocial perspective. The biopsychosocial approach can help explain how the various domains of PFD interact and influence treatment. It looks at how biological and genetic factors interact with psychological and cultural factors in the development of PFD. The specialist may ask questions about your child's overall development, including motor, cognitive, language, and social skills.

Feeding-specific questions may include gathering a history of your child's PFD (including any triggering events), your child's preferred and nonpreferred foods and fluids, and any food allergies. Behavioral health specialists will also ask about mealtime routines, including length of meals; how meals are structured (including enteral feeds); the timing of supplements; and if there is a primary feeder. An evaluation may also include observing a mealtime at your home or in a clinic.

THE PSYCHOSOCIAL DOMAIN | FAQ

When is the best time and place to feed my child?

This will depend on the feeding schedule that is most realistic and least stressful for your family. Having set mealtimes that stay the same each day can help create a routine. Cultural practices and preferences influence where meals occur, and your treatment team should incorporate these into your treatment plan.

Why are consistent mealtimes important?

Consistent mealtimes help your child know what to expect. It also helps keep their appetite regulated so they are hungry at mealtimes but not overly hungry. When children are allowed to graze on food and beverages between meals, they tend to consume less.

How can I help mealtimes be positive for both my child and me?

Working with a professional can help you understand how to model positive behaviors and reduce mealtime stress. Remember that the behaviors that caregivers react to and pay attention to are the behaviors that are likely to continue to be seen in the future. This includes appropriate and inappropriate behaviors.

My child has been diagnosed with ARFID? What does this mean?

Avoidant/restrictive food intake disorder (ARFID) goes beyond picky eating. It’s a complex psychological feeding and eating disorder that affects how you relate to food and mealtimes. ARFID is different from other eating disorders because it’s not about body image or wanting to lose weight. ARFID can show as follows:

- An intense anxiety or fear about eating certain foods
- The inability to try foods or eat a food because of texture, smell, or appearance
- A lack of hunger; eating may feel more like a chore than a necessity

Some people with ARFID may have had feeding challenges as children, such as PFD, which can persist into adulthood if unresolved. But ARFID can also develop later in life, even without prior feeding issues.

When ARFID is diagnosed in young children, the standard of care should involve a detailed workup that considers the four domains of PFD to ensure that skill or medical factors are not contributing to the child’s feeding struggles. If a child is in early elementary school and an ARFID diagnosis is given, a PFD diagnosis also needs to be given because they are still in the feeding development window. To learn more, please view our infographic here.


Aruba
One Happy Island

THE PSYCHOSOCIAL DOMAIN | FAQ

I'm being told that my child's feeding issues are just behavioral; does this mean my child only needs to see a psychologist?

Not necessarily. Treatment for PFD is not typically provided by one discipline. Children with PFD benefit from a multidisciplinary team to look at all four domains. A problem in one of these domains can affect the others. It is important to have a team of specialists look at the interaction among the medical, nutritional, feeding skills, and psychosocial domains.

Will my behavior health specialist only talk about PFD?

No. Sometimes PFD co-occurs with other social, emotional, or behavioral concerns, such as medical trauma and struggles outside of feeding within the caregiver–child relationship.

Recommendations

- Match how and what you are feeding your child with their skills.
- Find activities to help regulate your child's emotions and behaviors before feeding.
- Manage caregiver burnout.
- Learn how to understand and respond to your child's cues around feeding.
- Eliminate distractions in the environment.
- Explore the best times and places to feed.
- Create a consistent mealtime routine.
- Address financial or social issues that affect how and what you are able to feed your child.

Remember, the best treatment plan is one that works for your family. Your child's doctor or therapist should work with you and any other caregivers to make a realistic, feasible plan for your family. Therapy is a group effort. Be open and honest about what works for your family and what doesn't. This will help your doctor or therapist meet your family's needs.

For more information on any of the four domains - Medical, Nutrition, Feeding Skill and Psychosocial - please read the consensus paper here.

feeding **matters tip**

If you keep doing the same thing and you keep getting the same response (not the one you want), then it's time to try something new.


feeding matters
I Love Someone with PFD
pediatric feeding disorder

NAVIGATING THE JOURNEY

> *“We are so thankful for Feeding Matters and the Power of Two. Before I connected with Robyn, I really felt alone. I was feeling extreme guilt that I was failing my son. I thought I did something during my pregnancy to cause my son to have his feeding issues; as a result, now as a mom, I couldn’t even feed my son. Others may say the same things that Robyn does; however, coming from a mom who has herself gone through similar issues with her son, her comments and suggestions to me have special value for me, and I appreciate them because I know she truly gets it.” —Pinali P.*

CHAPTER 7

NAVIGATING THE JOURNEY

Beginning the journey of caring for a child with PFD will vary depending on your child's age, needs, and the services available in your area. Your child's primary care doctor, therapists, or both, can help you get referrals to the following programs, if necessary.

Early Intervention

Once your child is discharged from the hospital setting, they may continue to need PFD services. Early Intervention (EI) services are available to children from 0 to 3 years old who qualify under federal IDEA Part C regulations. EI is a federal program in every state that offers services and support to babies and young children who have developmental delays and disabilities. A goal of the EI program is to enhance the capacity of families to meet the special needs of their babies and toddlers with disabilities (IDEA, Part C). These services are provided in the child's natural environment, such as the child's home, childcare center, or any other community setting typical for children aged birth to 36 months (3 years). EI services can include speech, occupational therapy, physical therapy, and special instruction by a teacher. To determine if your child is eligible, please check your state's EI Program or discuss with your child's medical team of providers.

When a child qualifies for EI services, an individual family service plan (IFSP) will be held that includes the parents and service providers. An IFSP is a legal document that guides parents' efforts to advance their child's development. At that meeting, the team of educators, therapists, parents, and so on work together to design a care plan. The goals and objectives for each service provider will be discussed and added to the plan. The plan also indicates the services that the child will receive, and the therapy model recommended.

If your child has an IFSP, a transition meeting must be held 3–6 months before your child's third birthday. The meeting is scheduled with the local school district and the child's parents or caregiver, where they learn about the services available to their child. This meeting is usually held at the child's school and is attended by the family, EI provider(s), district personnel, and the service coordinator. This team will develop an individualized education plan (IEP) that addresses the services your child will receive; the personnel providing the services; and the type of services that will be provided, including those that address your child's swallowing and feeding needs at school. Procedural safeguards, which are legal protections for parents and students with disabilities during the special education process, are usually given to parents at the IEP meeting. This meeting starts the 120-day referral timeline for completion of the child's IDEA eligibility evaluation.

If you have questions or concerns about the EI process or the outcome of the evaluation, each state has a parent advocacy group that will assist you:
https://www.parentcenterhub.org/find-your-center/#info.

> *"My days were consumed with my child's feeding. I was completely overwhelmed. Practicing self-care was a luxury I didn't think I deserved or had time for. Once I made the decision to take time for me, it got so much better." —Heidi G.*

NAVIGATING THE JOURNEY

Preschool and School-Based Services

When your child enters the public school system, you will need to know what services your district provides and how to access those services:

- Inquire about Child Find in your state prior to your child turning 3 years old.
- Contact the special education department in your district for information on screenings, evaluations, and services.

Specific things that parents and caregivers can do to help the school testing team determine eligibility for special education services are as follows:

- Share your child's medical and feeding history as well as feeding therapy interventions.
- Discuss your concerns regarding your child's mealtimes at school.
- Share with the team how your child eats at home, including food preparation, positioning during family mealtimes, and special precautions.
- Inquire about how the team plans to establish a safe feeding plan for your child, train classroom and cafeteria staff, and monitor safety during mealtimes.

If your child has an IFSP

- Prior to your child's third birthday, an IEP meeting will be held that will include service providers from EI and the schools. An IEP will be developed that may include feeding information.

If your child already has an IEP

- Inform the teacher who is setting up the annual IEP meeting that your child has been diagnosed with PFD, which will need to be addressed.

If your child does not qualify for special education services

- Consult with your child's medical team.
- Request a meeting with your school district's director of special education.
- Discuss whether your child would benefit from a 504 plan.

School districts and special education departments are responsible for educating students and strive toward providing safe, effective, and positive learning experiences. The IDEA and Act 504 of the Americans with Disabilities Act (ADA) are federal programs that require school districts to provide the services that students with disabilities need to be able to benefit from their academic program. Through IDEA and Act 504, school districts provide related services to help students with disabilities participate to their fullest potential academically and socially.

School districts and special education departments must follow IDEA and ADA guidelines and are responsible for making sure all students are able to access their curriculum. Understanding the regulations that drive school districts can help you navigate the public school system throughout your child's education, including during mealtimes at school.

For more information on PFD and the school setting, please read the article written by Emily Homer in our Resource Library.

LA

NAVIGATING THE JOURNEY

Care for the Caregiver

The impact of trauma can take a toll on one's mental well-being and physical health. If you are feeling distressed either emotionally or in your body, here are some steps you can take:

- Recognize how you are feeling
- Acknowledge the feeling in your body
- Notice your breathing and see if you can breathe in a little more slowly and breathe out a little more slowly.
- Remind yourself that this is simply a reaction to a stressful experience, and it's normal.

Self-care during this process is important to manage your stress in the best way you can. Suggestions for self-care are listed below. Choose the ones that are realistic and helpful for you:

- Find support groups for parents in your area. Facebook groups are often used to connect with parents going through the same journey.
- Find professional support if that is feasible, such as a nearby therapist or one who can do teletherapy.
- Find respite care resources to gain some "me" time. Organizations such as Easter Seals have respite services and Access to Respite Care and Help (ARCH) offers a database: https://kidshealth.org/en/parents/respite-care.html.
- Move your body. This could be turning music on and dancing while you're doing housework or taking 5 minutes to stretch during your child's nap time.
- Tap into your village. Don't be afraid to ask for help with everyday tasks and tap into your community's talents. It is helpful for others if you are able to give them a specific request, such as asking your friend to bring a meal or your neighbor to pick up something you need on their next trip out.
- Consider journaling. Writing down the challenging and positive aspects of your days helps you get out the stress instead of keeping it to yourself.
- Get outside! Natural light and fresh air can do wonders. Sitting outside for 5 minutes, taking a quick walk around the block, or rolling down the windows while driving can be a quick boost.
- Engage in your spiritual practice, if you have one. Meditation, prayer, or whatever your spiritual practice is can help provide grounding.
- Trust your gut. Reading this guide means you are doing the best for your child.

Care for Siblings

Caring for a child with complex feeding needs affects the whole family, including siblings. Brothers and sisters may experience mixed feelings—from worry about their sibling to feeling left out or unsure of their role. Part of self-care includes nurturing a balanced family dynamic, so taking time to involve siblings, explain the feeding journey in age-appropriate ways, and carve out moments for one-on-one attention can help them feel included and valued. Simple actions, such as inviting siblings to help with small tasks or spending special time together, can foster a sense of connection and ease feelings of neglect. Feeding differences can be traumatic, for you and your family, especially if the pregnancy and birth did not go as planned.

ADVOCACY

> *"I have found that if I focus on the future and all the what-ifs, I just get stressed. Now I just try to not think about the future and focus on the fun of being her father every day." —Jon L.*

CHAPTER 8

ADVOCACY

Conservative estimates indicate that PFD affects more than 1 in 37 children under the age of 5 in the United States each year. Although PFD is more prevalent than autism or cerebral palsy, many medical providers and family members are unaware of the disorder and, therefore, may not recognize the early signs and symptoms. They may not realize or be able to understand what you are going through.

Speaking up for your child's best interests, knowing your rights as a parent or caregiver, finding and communicating with the right therapist and medical team, and getting family support are important parts of advocating. **Don't forget that you know your child best.**

You can do the following things to advocate for your child:

Learn as much as possible about PFD:
- Read the consensus paper, and share the diagnostic codes with your child's doctor, school personnel, or both.
  - R63.31 pediatric feeding disorder, acute (< than 3 months)
  - R63.32 pediatric feeding disorder, chronic (> than 3 months)

Build a care plan for your child:
- Add your child's medical history.
- Compile subspecialists notes and end-of-visit summaries.
- Include your goals and patterns of roles and relationships among family members that can help.
- Include food journals or videos of mealtimes with your child.

Look into laws and policies about special education and your child's rights:
- National and state-specific laws and policies exist so children and families can access medical insurance, community resources, and school services.
- Utilize Wrightslaw.com for reliable, up-to-date information about special education law and advocacy for children with disabilities.

Learn more about medical insurance laws and policies:
- Develop a relationship with your insurance case manager. They will help you navigate claims and denials.
- Utilize our medical necessity letter template here.
- Utilize our insurance appeal letter template here.

feeding **matters tip**

You may have tried something before and it didn't work, but now it might. Remind yourself that you are doing your best.

GLOSSARY OF TERMS

Allergist. A doctor who specializes in the diagnosis of asthma and other allergies. They may also be called immunologists.

Allergy testing. A method for determining to what substances a person is allergic, also known as skin-prick or blood testing. Top allergens involved in feeding and swallowing are milk, eggs, wheat, soy, peanuts, tree nuts, fish, shellfish, and sesame.

Americans with Disabilities Act. A civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life, schools, transportation, and public and private places.

Aspiration. When food or liquid enters the lungs, instead of entering the esophagus and going to the stomach.

Behavioral health specialists. Psychologists, social workers, licensed professional counselors, and board-certified behavior analysts can help identify and treat psychosocial concerns related to mealtimes. Sometimes, a psychiatrist (medical doctors who prescribe medication) may be involved to help manage anxiety and other mood concerns that may affect a child's ability to make progress in treatment. For more information on each specialist, click here.

Biopsychosocial Model. To understand and to adequately address a patient's needs, clinicians need to look at the interaction between the biological, psychological, and social dimensions of illness and symptoms.

Board-certified behavioral analyst. A specialist who looks at social and environmental changes to develop meaningful behaviors and social skills.

Cardiologist. A doctor who works with diseases and conditions of the heart and blood vessels and their treatments.

Certified lactation consultant. A health professional who specializes in breastfeeding and helps families nurse their children.

Chest X-ray. A radiographic X-ray image taken of a patient's upper body to evaluate for problems with the heart, lungs, and esophagus.

Children's Health Insurance Program. A free or low-cost health and dental insurance program for children who do not have other health insurance coverage. Options are available through www.insurekidsnow.gov.

Clinical evaluation of swallowing and feeding. A procedure often conducted by a speech–language pathologist that considers the many factors that contribute to a child's ability to eat and drink: a child's medical history, anatomy, development, behavior, and skill level. The evaluation may also include imaging, such as an X-ray, or functional studies, such as a swallow study.

Dehydration. A dangerous loss of body fluid caused by illness, sweating, or inadequate intake.

Dysphagia. A swallowing disorder involving difficulty processing or moving liquid or food through the oral cavity, pharynx, esophagus, or gastroesophageal junction.

Endoscopy. A procedure that uses an endoscope to visually examine the inside of the throat, stomach, and the beginning of the small intestine (duodenum). An endoscope is a flexible tube with a tiny camera and light attached to it. An endoscopy is typically performed by a gastroenterologist (a doctor of the stomach and intestines) while the patient is asleep under anesthesia. During an endoscopy, the doctor may collect samples (biopsy) to test for certain conditions and examine for causes of swallowing dysfunction.

Endocrinologist. A doctor who works with internal endocrine glands, such as the adrenal and thyroid glands, which can be involved in diabetes and nutritional and metabolic disorders.

Failure to thrive. A term used to describe inadequate growth or the inability to maintain growth.

Feeding tube. A tube placed in the nose, stomach, or small intestine to supply nutrition when a person has trouble eating by mouth. Different types include nasogastric, nasoduodenal, nasojejunal, gastric or gastrostomy, gastrojejunal or transjejunal, and jejunal tubes.

Fiberoptic endoscopic evaluation of swallowing. A test of how a child is able to swallow food through their throat to their stomach using an endoscope, which is a tiny camera with a light attached to it. The endoscope passes through the nose and down the back of the throat to see if a child's swallowing function is normal.

Gastric emptying scan. A test that measures the time it takes for food to empty from the stomach and enter the small intestine. A small amount of tasteless radioactive material is added to formula, milk, or food and allows a special camera to create images for the radiologist to study.

Gastroenterologist. A doctor who looks at diseases of the digestive organs, including the esophagus, stomach, intestines, pancreas, liver, and gallbladder.

Gastroesophageal reflux disease. The flow of gastric secretions (stomach juice) from the stomach up into the esophagus, airway, or mouth.

Geneticist. A doctor who looks at the genetic makeup of the patient and the effect it has on disease, heredity changes, mutations, or deletions affecting health.

GLOSSARY OF TERMS

Genetic testing. The process of examining a person's DNA (genetic code), chromosomes, or proteins for changes that may indicate a genetic condition or disease.

Hydration. The process of replacing fluids lost through sweating, breathing, and eliminating waste.

Immunologist. A doctor who looks at the immune system, including bacterial and viral infections and their effect on health and wellness.

Individualized family service plan. A written document that outlines early intervention services for children from birth to age 3 who have disabilities or are at risk. It is part C of the IDEA, and its goals are family focused.

Individuals with Disabilities Education Act (IDEA). A law that makes a free and appropriate public education available to children with disabilities ages birth through 21 throughout the United States. It guarantees special education and related services for those children.

Individualized education plan. A legal document that details a child's special education needs, including related services and how those needs will be met. The plan is created by a team, including the child's parent(s)/caregiver(s), teachers, school administrators, related services personnel, and student (when appropriate) to meet that child's unique needs.

Interdisciplinary team. A group of health care professionals who work together to treat a patient.

International board-certified lactation consultant. The highest accredited health care professionals specializing in lactation.

Malnutrition. Insufficiencies or an imbalance of energy intake, nutritional intake, or both, that affects growth, development, and health.

Modified barium swallow study or videofluoroscopic swallow study. Widely used procedures to visualize a child's ability to swallow in real time. A radiology technologist will have your child swallow a variety of liquids and solids in front of an X-ray and will work with an SLP to interpret the results. Barium in the liquid or solid will allow the swallowing motion to be visible on the X-ray.

Multidisciplinary team. A group of health care professionals who come from different disciplines working together to provide specific services to a patient.

Neurologist. A doctor who looks at conditions related to the brain, nervous system, and muscular function.

Occupational therapist. A therapist who seeks to increase a person's independence in performing meaningful occupations through a holistic approach, including feeding, eating, and swallowing and focuses on physical, motor, sensory, and psychosocial development skills.

Otolaryngologist. An ear, nose, and throat doctor who looks at conditions of the head and neck to prevent and manage diseases; cancer; and deformities of the sinuses, nose, throat, ears, face, jaw, and upper airway.

Pediatric feeding disorder. Impaired oral intake that is not age-appropriate, and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction.

Physical therapist. A therapist who looks at gross motor skills needed for positioning, posture, and mobility related to eating and feeding (i.e., head control, sitting balance).

Pulmonologist. A doctor who looks at respiratory conditions related to the lungs and pulmonary system.

Radiologist. A doctor who uses imaging methods to diagnose and treat orthopedic, soft tissue, cardiac, or neurological conditions.

Registered dietitian nutritionist. A credentialed health care professional who applies evidence-based information about nutrition and diet to contribute to the health and wellness of individuals, groups, and communities.

Respite Care. A short-term care service that provides relief for primary caregivers.

Speech–language pathologist. A therapist who looks at feeding, eating, and swallowing disorders (oral and pharyngeal phases) while working on essential communication skills related to eating.

Total parenteral nutrition. A method of feeding that provides nutrients to the body intravenously, bypassing the usual process of eating and digestion.

Upper GI series. An X-ray examination of the esophagus, stomach, and the first part of the small intestine, the duodenum. The patient swallows a liquid containing barium, which coats the inside walls of the upper GI tract organs so that function and shape of these organs are visible on X-ray.

504 plan. A plan for students with disabilities that schools develop to provide accommodations to the learning environment that help meet their needs in the classroom. This plan covers any condition that limits daily life activity.

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