

PEDIATRIC FEEDING DISORDER

FAMILY GUIDE





Letter to Families:

Dear Parent/Caregiver,

I am the 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. For me, my days were spent counting calories and desperately trying to get my son to drink and eat. I do not want any parent to feel the stress, exhaustion, and isolation that I felt.

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, capable, and know your child best. Nevertheless, you will greatly benefit by connecting with other families who are on this journey because they are in the unique position to understand what you are feeling.

This 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 entire guide focuses on such help and support available to you, and I am sure you will find it very useful. Please contact Feeding Matters at the number given below for any questions you may have after reading the guide.

Sincerely,

Heidi Van der Molen

Program Manager

Phone: 623.242.5234 ext. 303

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INTRODUCTION

When your child is struggling with feeding, it can be frightening, isolating, overwhelming, and exhausting. You do not have to face this alone.

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 healthcare professionals, and advocates. Feeding Matters works with these individuals to improve care for children with PFD and educate other healthcare professionals about PFD.

Chapter One of this guide will define and explain pediatric feeding disorder, often referred to as PFD, in more detail.

No matter where you are on this journey, this guide will give you the knowledge, tools, and resources necessary to help your child.

**This guide will be updated periodically to incorporate the latest knowledge and research in the field.*

Next Steps

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:

1

Fill out the Feeding Matters Infant and Child Feeding Questionnaire.

2

Next, schedule an appointment with your child's doctor. Take the completed Infant and Child Feeding Questionnaire to your appointment.

3

Find a qualified provider using Feeding Matters' Provider Directory.

4

Get support through Feeding Matters' Power of Two program or ask your child's doctor about local support groups.

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CHAPTER 1

WHAT IS PEDIATRIC FEEDING DISORDER (PFD)?

Pediatric feeding disorder (PFD) is defined as impaired oral intake that is not age-appropriate, lasts at least 2 weeks, and is associated with medical, nutritional, feeding skill, and/or social-emotional challenges.¹



In other words, a child may have PFD if they cannot eat the types of foods or the quantities of foods that other kids their age can eat. As a result of this, they may have medical, nutritional, skill, or behavioral problems.

If parents are facing difficulty when feeding their child, there is a direct and dramatic impact on the whole family, which can often result in considerable family stress or feelings of failure. This may lead everyone in the family dreading mealtimes, with interactions between the child and either or both parents becoming difficult, and a daily schedule that focuses heavily on the child's feeding. In addition, many of these children forego traditional experiences such as birthday parties, social opportunities, vacations, family outings, etc.

If you think your child has a feeding disorder, please refer to the [Infant and Child Feeding Questionnaire](#). This online screening tool will help you identify any red flags for PFD and understand typical feeding development, based on age. You can email or print the results and share it with your child's doctor to help you talk about your concerns. The questions below may also be a good place to start.

1. Does your baby/child let you know when he is 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/child's feeding? **Yes**/No

Answers in red present as possible red flags.

CHAPTER 2

FOUR DOMAINS OF PFD

Sometimes a child does not eat or drink the quantity or the variety they need to grow and be healthy. It's not just because they are being "picky eaters." There is usually an underlying reason. These reasons can often be understood by looking at specific areas, which are called domains. The four important domains that are related to PFD are medical, nutritional, feeding skills, and psychosocial. A problem in one domain can lead to problems in any of the other domains. Below, we have defined each of these domains and how they are related to PFD.



The Medical Domain:

The act of eating is a complex task that involves the entire body working as one coordinated unit. It takes 26 muscles and 6 cranial nerves working in perfect harmony to move food and liquid through the body.² This process takes only seconds but is the single most complex and physically demanding task an infant will complete for the first few weeks, and even months, of life.

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. For example, many infants have trouble timing their breathing with their swallowing, which makes them choke.

Possible Signs:

- ✓ choking, gagging, or coughing while eating or drinking
- ✓ vomiting
- ✓ poor weight gain
- ✓ fatigue during or following feeding

Who can help assess and treat?

Primary care doctors are generally the first person responsible for identifying PFD and can make a

referral to other specialists who will be most helpful for your child.

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If you feel like you are doing above and beyond what is typical with your child's feeding, talk to your child's doctor.

These specialists include allergists/immunologists, cardiologists, dentists, developmental pediatricians, endocrinologists, gastroenterologists, geneticists, lactation

consultants, neurologists, nurse practitioners, occupational therapists, otolaryngologists (ENTs), pulmonologists, radiologists, speech language pathologists, and surgeons. Learn more about each of these specialists on the [Feeding Matters website](#).

Common tests and procedures performed or suggested by specialists are as follows:

- ✓ Modified barium swallow study/videofluoroscopic swallow study (VFSS)
- ✓ Fiberoptic endoscopic evaluation of swallowing (FEES)
- ✓ Endoscopy
- ✓ Allergy testing
- ✓ Genetic testing
- ✓ Upper GI series
- ✓ Gastric Emptying Scan
- ✓ Chest X-ray



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.

While it can be frightening to think about putting your child through different medical tests, they can help you and your doctor make an appropriate plan for your child. The tests can also help identify what is causing the problem or rule out problems, so that you can get the appropriate care for your

child.

Frequently Asked Questions:

How should medical concerns be addressed with doctors?

If you have concerns about your child's feeding, try not to wait until the next wellness checkup to bring them up. Make an appointment with your child's doctor to discuss your concerns as soon as possible. If you keep a food journal of your child's eating and mealtime behavior to share with your doctor, it can help them direct you to the appropriate first referral. 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 the 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 can help direct you to the specialists that are necessary for your child's care.



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.

Will my child need a feeding tube?

Making the decision to get a feeding tube can be difficult and scary. However, for some children and families, this may be the best choice because it will ensure a child's growth and development. 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.

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

FEEDING MATTERS TIP

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

they need by mouth. In some cases, it may be necessary for a child to also drink a nutritional supplement

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

Possible Signs:

- ✓ lack of energy
- ✓ poor weight gain
- ✓ dehydration

Who can help assess and treat?

A registered dietitian nutritionist (RDN) is the most qualified specialist to discuss a child's growth and nutrition 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.
- ✓ Collaborate with your child's medical team to decide the best diet for your child.

A Note about Feeding Tubes

It may be that getting a feeding tube is a short-term solution to helping your child 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. In addition, do continue to work on feeding therapy. You should only wean your child from the feeding tube when they are medically ready, not because of fears about the feeding tube.

For more information on feeding tubes, please visit [Feeding Tube Awareness Foundation](#).

Frequently Asked Questions:

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 them 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, do not force-feed them. This may end up causing a negative mealtime experience for both you and your child. Seek out the help of your child's primary care doctor. They may refer you to an RDN, speech language pathologist, and/or occupational therapist to talk about your child's needs.

Will an RDN be able to work with my family's cultural preferences and dietary restrictions such as Kosher,

vegetarian, etc.?

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 and dietary restrictions.

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 and/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 GI Doctor and/or RDN.



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.

The Feeding Skill Domain:

Learning to eat skillfully and comfortably requires the development of sensory integration and motor coordination which makes it possible for an infant or child to suck, swallow, bite, and chew.³

Parents and caregivers play an important part at mealtimes. Mealtimes are a social time and

FEEDING MATTERS TIP

Trust in your child and trust that you know your child best.

parents and caregivers help the infant or child learn to communicate their needs. They also recognize feeding readiness skills. 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:

- ✓ difficulty chewing or swallowing
- ✓ getting tired during feedings
- ✓ limited food choices
- ✓ dependence on feeding tube

Who can help assess and treat?

Several different types of specialists receive training in feeding and development. The main ones are occupational therapists (OTs) and speech language pathologists (SLPs). Feeding specialists may do the following:

- ✓ Occupational therapists, physical therapists, and speech therapists look at motor strength and coordination, muscle tone, perception, and understanding related to feeding skills.
- ✓ Physical therapists and occupational therapists can look at body positioning and posture and recommend equipment to make feeding easier.
- ✓ Occupational therapists will help increase tolerance to sensory experiences, such as how different foods feel in the mouth, and help improve oral motor and swallowing skills.
- ✓ Speech therapists will provide strategies to improve communication and oral motor and swallowing skills that affect feeding.

The location of feeding therapy, along with how often you attend and how long it lasts, will depend on the child's medical needs, feeding challenges, and the child's and family's readiness for intervention.

Therapy can occur in a variety of settings and by different delivery models including the following:

- ✓ Home-based
- ✓ School-based
- ✓ Clinic-based
- ✓ Outpatient intensive therapy
- ✓ Inpatient intensive therapy
- ✓ Teletherapy

Finding the right therapist for your family and child 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 and caregiver, and the expected outcomes for your child.

Frequently Asked Questions:

Why does my baby fall asleep during feeding?

Sleep may be a sign of satisfaction and relaxation. It may be the baby's natural way to end feeding. However, some babies may experience stress and discomfort with feeding. They fall asleep to avoid feeding or avoid pain caused by

FEEDING MATTERS TIP

Remind yourself that you are doing your best.

feeding. Moreover, some babies, especially those with medical conditions, do not have enough energy to finish a whole meal. They may fall asleep from fatigue. If your baby cannot stay

awake and enjoy their feedings, speak with your child's primary care doctor. Mealtimes 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 good gross motor skills, sitting, breathing, and swallowing can be challenging.



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.

My child does not chew food; it is swallowed whole. Is this a concern?

Yes, chewing skills prevent choking and help children safely eat foods with different textures. It is best to avoid foods that require chewing until the child has the needed skills. Work with a feeding therapist or talk to your child's primary care doctor if you think your child is having trouble chewing.

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

No, not at this time. 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 several times in a row, and give your child time to explore new foods at their own pace. If the introduction of new foods creates significant stress at mealtimes, speak with your child's primary care doctor.

The Psychosocial Domain:

When children exhibit challenging mealtime behaviors, they are showing that eating is unpleasant or difficult for them at that time. An increase in caregiver and child confidence results in mealtimes that are based on trust between parents and their children. Positive eating experiences build internal motivation, which in turn leads to long-term feeding success.

Possible Signs:

- ✓ child refusing to eat or drink
- ✓ difficulty eating in certain situations
- ✓ difficult behaviors, such as tantrums, during mealtimes
- ✓ parents and caregivers feeling stressed or overwhelmed

Who can help assess and treat?

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

An evaluation may include observing a mealtime at your home or in a clinic. The specialist may ask questions about your child's overall development, including motor, cognitive, language, and social skills. They may also ask about your child's moods, your stress level, cultural or family beliefs, when/where your child usually eats, and about your family dynamics.

Recommendations could include the following:

- ✓ Matching how and what you are feeding your child, with their skills.

- ✓ Finding activities to help regulate your child's emotions and behaviors before feeding.
- ✓ Practicing self-care for caregivers.
- ✓ Learning how to understand and respond to your child's cues around feeding.
- ✓ Exploring the best times and places to feed.
- ✓ Learning how to reduce distractions.
- ✓ Creating a consistent mealtime routine.
- ✓ Addressing 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 and 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.

Frequently Asked Questions:

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 meal times that stay the same each day can help create a routine.

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.

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.

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 keep the experience stress-free for both of you.

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. Children with PFD benefit from a multidisciplinary team to look at all four domains. When there is a problem in one of these domains, it can affect the others. It is important to have a team of specialists look at the medical, nutrition, feeding skill, and psychosocial domains.

If you want more information on any of these four domains, please read the consensus paper located [HERE](#)

FEEDING MATTERS TIP

You may have tried something before and it didn't work, but now it might.

CHAPTER 3

MYTHS AND SIGNS OF PFD



1. **They'll 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 and discomfort even though they are hungry. Similarly, a child with oral motor difficulties 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.**

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

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

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

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

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

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

Picky eating can occur throughout the first 5 years of a child's life. However, while picky eating is a phase that children often go through, if the child has PFD and it is left untreated, it can become a disability. If a child isn't eating, it does not mean that it is the parent's fault or that the child is trying to behave badly. Their behavior is most likely a form of communication or a way of adapting to earlier difficult experiences.

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 you can talk to other parents who have experience with placing a feeding tube for their child.

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

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

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

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



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.

Signs to watch out for:

- ✓ Feeding resulting in choking, gagging, vomiting, and/or coughing
- ✓ Rigid food preferences
- ✓ Difficulty sustaining nutrition and/or hydration
- ✓ Dependence of tube feeding or oral supplements
- ✓ Difficulty chewing or swallowing
- ✓ Getting tired during feedings
- ✓ Child refusing to eat or drink
- ✓ Difficulty eating in certain situations
- ✓ Parents and caregivers feeling stressed or overwhelmed



CHAPTER 4

ADVOCACY

Advocating for your child and your family is important. This occurs by speaking up for your child's best interests, knowing your rights as a parent/caregiver, finding the right therapist/medical team, and finding family support.

Don't forget that you know your child best.



Some key elements to consider when advocating for your child are:

Find a therapist that advocates for you and your child. Get started by:

- ✓ Asking your child's primary care doctor or checking Feeding Matters' Provider Directory.
- ✓ Checking with your local school district/early intervention programs.
- ✓ Talking with other parents.
- ✓ Reviewing your insurance plan to see if they have preferred providers in your area.

Look for a provider/therapist who focuses on family-centered care.⁴ A family-centered care provider:

- ✓ Is willing to collaborate with other providers and shares 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.
- ✓ Demonstrates experience and expertise in pediatric feeding, eating, and swallowing.

Understand laws and policies to protect children:

- ✓ National and state-specific laws and policies exist so children and families can access medical insurance policies, community resources, and school services. However, understanding insurance benefits can be overwhelming when you have a child with PFD. To best advocate for your child, you may need to appeal denied insurance claims or work with your child's providers to prove medical necessity of certain services.

Managing a denied insurance claim:

You have the right to appeal an insurance claim that has been denied. Insurance denials may cause a lapse in service and/or leave you with an unexpected bill. Common reasons for insurance denials may include:

- ✓ Services are not a covered benefit,
- ✓ Service is not medically necessary,
- ✓ Services were experimental or investigative in nature,
- ✓ Your plan was not active at the time of service.

The insurance provider is required to let you know why the claim was denied and inform you about how to appeal

the denial. Check your insurance providers' handbook for the appeals process. Most are posted online. You may also use one of Feeding Matters' templates located in our [Resource Library](#). If your appeal is denied again, you can file an external audit appeal, consult a legislator, or contact a local advocacy agency. Don't give up!

FEEDING MATTERS TIP

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

Frequently Asked Questions:

What can I do if I don't agree with my child's doctor?

It is okay to speak up and advocate for you and your child. You have the right to a second opinion, to ask questions, to appeal a decision, and to advocate for your child.

Will my child need all therapies discussed above (occupational therapy, speech therapy, psychologist, etc.)?

This all depends on the needs of your child. Your child's primary care doctor will examine your child and provide recommendations. Together, you can advocate for the services you want for your child.

Should my child receive school-based therapy and outpatient therapy?

Some children will benefit from both school-based and outpatient therapy. School-based therapy focuses on educational needs/goals. Outpatient therapy, whether it's clinic or home-based, focuses on developmental or medical needs/goals.



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 everyday. -Jon L.

What if my child does not make any progress from therapy?

Children make better progress in therapy when they are medically stable and developmentally ready to progress. Sometimes a break from therapy allows the child opportunities to apply their current skills or newly acquired skills to a wide variety of situations. If you feel progress has slowed due to the type of intervention offered, talk to your current therapist or consider a new facility or therapist for the benefit of a new perspective.

CHAPTER 5

NAVIGATING THE JOURNEY

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



Early Intervention:

Every state has an early intervention program. They offer services and support to babies and young children up to three years of age who have developmental delays and disabilities. To determine if your child is eligible, please check your state's [Early Intervention Program](#) or discuss with your child's medical team of providers.

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 three years old.
- ✓ Contact the Special Education Department in your district for information on evaluations and services.

Some specific things that parents/guardians can do to help the school testing team determine eligibility for special education services are:

- ✓ 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 district team how your child eats at home including food preparation, positioning during family mealtimes, and special precautions.
- ✓ Inquire about how they plan to establish a safe feeding plan for your child, train classroom and cafeteria staff, and monitor safety during mealtimes.

If your child has an Individualized Family Service Plan (IFSP):

- ✓ Prior to your child's third birthday, an Individualized Education Plan (IEP) meeting will be held that will

include service providers from early intervention 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 the director of special education in your school district to discuss options.
- ✓ Discuss whether your child would benefit from a 504 Plan.

School districts and special education departments are responsible for students having effective and positive learning experiences. Individuals with Disabilities Education Act (IDEA) and Americans with Disabilities Act (ADA) level the playing field for students with disabilities or special medical needs. They

allow them to participate to their fullest potential in the academic and social aspects of school.

School districts and special

education departments must follow IDEA and ADA guidelines and are responsible for making sure all students have positive learning experiences. Understanding some of the regulations that districts are bound by can help parents/guardians navigate the public school system throughout your child's education, including during mealtimes at school.

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Keep a medical log to track the dates of procedures, doctor visits, medications, and notes.

For more information on PFD and the school setting, please read the article written by Emily Homer CCC-SLP, ASHA Fellow, located in our [Resource Library](#).



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.

Feeding Matters' Resources:

Feeding Matters knows that families need support and our website has many resources for you. Below is a list of what you will find on our [website](#).

- ✓ **Power of Two:** one-on-one support with a family coach.
- ✓ **Provider Directory:** find a therapist or specialist.
- ✓ **Learning Center:** webinars, conferences.
- ✓ **Resource Library:** articles, educational handouts, products, books, and more.
- ✓ **Infant and Child Feeding Questionnaire:** online screening tool.



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.

Self-Care

Caring for a child with complex feeding needs can be isolating and overwhelming for you and your family. If you find yourself struggling with depression, do not feel bad. You are not alone. Self-care during this process is important to manage your stress in the best way you can and not reach the point of full burn-out. Some 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.
- ✓ Respite care resources can provide you with some “me” time. Organizations like Easter Seals have respite services and ARCH offers a [database](#).
- ✓ Move your body. This could be turning music on and dancing while you're doing housework, or taking five minutes to stretch during naptime.
- ✓ 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.
- ✓ Get outside! Natural light and fresh air can do wonders.

Sitting outside for five minutes, 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.

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.

GLOSSARY OF TERMS⁵



Allergist: A physician who manages disorders affecting the immune system such as allergies, eczema, or rhinitis.

Americans with Disabilities Act: Is a civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life, schools, transportation, as well as public and private places that are open to the general public.

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

Board-Certified Behavioral Analyst (BCBA): 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.

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

Dysphagia: A swallowing disorder in the mouth, pharynx, or esophagus.

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

Failure to Thrive: The inability to maintain or reach the 3rd percentile for weight.

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 (NG), Nasoduodenal (ND), Nasojejunal (NJ), Gastric or Gastrostomy (G), Gastrojejunal (GJ) or Transjejunal, and Jejunal (J) tubes

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

Gastroesophageal Reflux (GERD): 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 impacting health.

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 (IFSP): Special services for children with disabilities from birth through 3 years old. 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 Program (IEP): An individualized special education plan and related services provided by the school. The IEP is created by a team, including the child's parent(s)/caregiver(s), teachers, school administrators, related services personnel, and students (when appropriate) to meet that child's unique needs.

Individualized Healthcare Plan (IHP): A school nurse may initiate and develop an IHP for students whose healthcare needs require more complex management in the school setting.

Malnutrition: Insufficiencies or an imbalance of energy intake and/or nutritional intake that impacts growth, development, and health.

Multidisciplinary team: A group of healthcare professionals from different disciplines who provide specific services to a patient. They each treat independently.

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

Occupational Therapist (OT): A therapist who looks at daily living skills which include feeding, eating, and swallowing and focuses on physical, motor, sensory, and psychosocial development skills.

Otolaryngologist: An ear, nose, and throat (ENT) surgeon 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.

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

Psychologist⁶: A health care professional who helps individuals and families cope with life issues including mental and behavioral health concerns.

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

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

Registered Dietician Nutritionist (RDN)⁷: A health care professional who provides food and nutrition education to help individuals manage diets, maintain health, and prevent diseases.

Speech-Language Pathologist (SLP): A therapist who looks at feeding, eating, and swallowing disorders (oral and pharyngeal phases) while working on essential communication skills related to eating.

504 Plan⁸: A plan for how the school will provide support for any student with a disability. This plan details services and changes to the learning environment to ensure students can learn alongside their peers.

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