WHAT IS PFD?

Paediatric Feeding Disorder: An Overview

Feeding is an intricate combination and coordination of skills. It is the single most complex and physically demanding task an infant will complete for the first few weeks, and even months, of life. A single swallow requires the use of 26 muscles and 6 cranial nerves working in perfect harmony to move food and liquid through the body. As infants get older, they have to learn how to eat new textures and flavours, and how to feed themselves. Like any other developmental milestone, learning to eat requires the co-ordination of multiple factors. When one or more pieces of the feeding puzzle are missing, out of order, or unclear, infants and children can have difficulty eating and drinking

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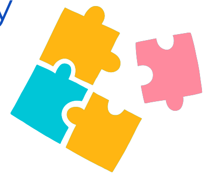


Paediatric Feeding Disorder (PFD) is a diagnosis in the World Health Organization's International Classification of Functioning, Disability and Health (ICF). It is defined as "impaired oral intake that is not age appropriate, and is associated with medical, nutritional, feeding skill and psychosocial dysfunction".

Essentially. PFD is difficulty learning to eat, due to challenges developing the necessary skills, often associated with medical factors, that results in nutritional and psychosocial consequences. For these children, mealtimes can be a difficult and sometimes painful experience. It's not that they won't eat, but that they can't. Research shows that across the world, 25% of children will have difficulty with feeding at some point in their life, and 10% of these will go onto have significant feeding difficulties. This figure rises for children with medical, developmental or learning differences.

PFD

A Framework for Describing Feeding Difficulties in Children

The **ICF** is a framework for describing functioning and ability in relation to a health condition. It provides a framework for describing how a person functions within their own environment. It shifts the focus away from negative connotations such as disability and places it on function and the positive abilities of the individual at the person level rather than an individual symptom level.

For **PFD**, this means looking at the skills and challenges related to feeding and eating (such as the development of sucking, swallowing, chewing, or self-feeding), the impact it has on the child (their overall development, growth, and participation in daily activities) and the family (the social and environmental consequences).

The PFD diagnosis provides a framework for describing the multiple symptoms that infants and children with feeding difficulties can experience. Understanding the drivers, or causes behind these symptoms is critical for helping to manage children's feeding challenges, improve their ability to participate in everyday activities and reduce the stress associated with supporting a child with feeding challenges.

THE FOUR DOMAINS

PFD is characterised by difficulties in the following four areas...

MEDICAL

There are a wide range of medical conditions that can contribute to children's feeding difficulties, and impact on their ability to eat and digest their food safely, effectively, and comfortably. Often presenting from birth/early infancy, research shows that children with **PFD** often have multiple co-occurring medical conditions. For example:

- Gastrointestinal conditions such reflux, constipation, food allergies and intolerances
- Congenital conditions such as cleft palate, down syndrome, heart and lung diseases
- Neurological conditions such as cerebral palsy, developmental delay and autism

Who can help?
Paediatricians, paediatric gastroenterologists, neurologists, ENT consultants.

What they do?
Effective and timely management of medical problems with active symptoms, such as reflux and food allergies. Support for complex and long term health problems, such as chronic lung disease or congenital heart disease.

NUTRITIONAL

Nutrition is the foundation for growth and development. Nutrition directly affects a child's brain activity, fine and gross motor skill development, overall health and energy levels. Not all children with **PFD** will present with weight loss or faltering growth. Some will follow typical growth centiles, but will often present with:

- Macro/micro nutrient deficiencies
- Reduced dietary diversity

Who can help?

A registered dietitian or nutritionist addresses growth and nutritional needs.

What they do?

- Assess a child's diet to determine nutritional intake and support with nutritional intake, vitamin and nutritional supplements.
- Work with a feeding specialists and family to explore foods that the child has the skills to eat.
- Support children with food allergies and intolerances.
- Help a child feed orally, by providing ongoing monitoring and assistance to increase oral intake and decrease supplement / enteral (tube) feed dependence, done in collaboration with the full paediatric feeding team.

SKILL BASED

Eating requires the co-ordination of multiple skills that are developed through sensory and movement experiences. Initially, children learn to suck, swallow, bite, then chew. They also require postural skills to sit up and feed themselves. Feeding skills and abilities include the social, communication, and interactive skills that integrate with mealtime skills. Underpinning all these skills is the ability for children to process and regulate the wealth of information that is sent to their brains from their senses, nerves and muscles. When too little or too much information is received ie children have under or over responsive sensory processing, they can be dysregulated at mealtimes, which makes it extremely challenging for them to learn new skills.

Who can help?

Therapists with specialised skills in paediatric feeding assessment and management often include speech-language therapists and occupational therapists.

What they do?

- Assess a child's ability to swallow safely and efficiently.
- Improve skilled movement of the mouth that leads to safe and efficient eating and drinking, and ability to eat a wide range of different texture foods.
- Help develop speed, strength and coordination of motor skills that support postural control, feeding development and self-help skills.
- Determine if motor and/or sensory problems are contributing to a child's feeding difficulties.
- Assess sensory processing skills and develop strategies that support sensory regulation and the ability to incorporate all of a child's senses in an organised way for eating.

PSYCHOSOCIAL

Most of us look forward to eating, we enjoy mealtimes with friends and family. Social events, celebrations and festivals often involve food as a central part of the experience. But these experiences are very different for children and families effected by **PFD**. For the families, mealtimes and feeding their child becomes a constant, daily struggle. Concern about their child's nutritional intake leads to anxiety and frustration. For the child, mealtimes can be difficult and sometimes painful process. This can often present as behaviours of distress and difficulties participating in mealtimes at home, perceived as refusal by others, in the child's educational setting and in the community.

Who can help?

Occupational Therapists, Speech & Language Therapists, Psychologists

What they do?

Occupational Therapists can work with the child and family to improve sensory regulation at mealtimes and provide strategies to support participation in daily routines. A Speech and Language Therapist can work with the family to adapt communication around food and mealtimes, to develop confidence through positive interactions and develop children's ability to advocate for themselves and develop their self-esteem.

There can be trauma associated with feeding difficulties, and when anxiety and fear are significant issues, referral to a mental health specialist, such as a Psychologist or Psychiatrist may be helpful. Where anxiety and fear becomes the dominant driver for a child's refusal to eat, a mental health specialist may diagnose a child with the eating disorder ARFID and recommend psychological interventions, such as CBT.

PFD - FAQ

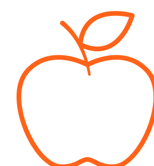
What are the signs of PFD?

Learning to eat is a complex developmental process. Children are instinctively driven to engage with food and mealtimes when their body systems are functioning effectively . A child is at risk for developing PFD when any system is not functioning properly. Often emerging in infancy, early identification of signs and symptoms is important for the long-term health and well-being of affected children, and their family.

Medical:

Gastro symptoms associated with eating/drinking (vomiting, constipation), food allergies, crying, arching, coughing, choking, sweating, breathing / colour changes when eating and /or drinking, physical discomfort when eating/drinking, recurring upper respiratory tract infections.

Nutritional:



Difficulty eating/drinking enough to grow and stay hydrated, nutritional deficiencies, need for nutritional supplements, limited dietary diversity.

Skill based:

Difficulty chewing food, gagging on food, difficulties self-feeding, only able to manage a limited range of textures, difficulties with postural control, need for special strategies, positioning or equipment, excessively long (> 30 minutes) or short meals (<5 minutes), difficulty managing the sensory properties of mealtimes (tastes, smells, sounds, feel, sight of food).

Psychosocial:

Difficulty with mealtime participation across all social contexts (home, nursery/school, restaurants, parties etc) , behaviours of distress at mealtimes, need for distraction or rewards for eating, feeding difficulties significantly impacting on family routines and activities.

PFD - FAQ

What age can PFD develop?

PFD emerges in infancy or early childhood but can persist beyond childhood.

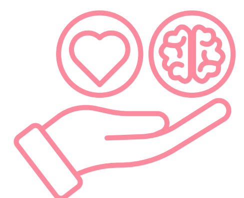
How common is PFD?

PFD is common. In one study, 1 in 37 children demonstrated symptoms of PFD. PFD is much more common in children with neurodevelopmental and learning differences.

Is PFD the same as fussy eating?

Most children go through a phase of fussy eating, known as the 'neophobic stage'. This is a typical part of development, usually occurring between 12 months-3 years old, where children become wary of new or different things. However, PFD often emerges earlier in infancy and is associated with medical and skill based challenges. Children do not not simply 'grow out' of PFD and it can make eating a difficult and at times painful experience.

What are the consequences of PFD?



PFD matters. It can affect social and emotional well-being as well as growth and nutrition. Left untreated, it can result in nutritional deficiencies, chronic fatigue, difficulties participating in everyday activities and mental health challenges.

Is there support?

Due to it's complex nature, children with PFD are always likely to have feeding differences. However, it is important to recognise it is a developmental condition, and therefore, with help and support, it can change. Feeding therapy should support the child's underlying skill, learning and sensory differences and support those around the child to adapt the environment, their communication & interaction styles.

PFD - Eating as Learning

Learning to eat requires the co-ordination of multiple skills, environmental & social factors. Effective support should take into account all these factors.

Oral motor & language skills

Sensory processing

Fine motor & self-help skills

Seating, posture & positioning

Medical & nutritional factors

Family routines & communication style

Sleeping & toileting routine

Social & emotional factors

Eating as Learning

We make mealtimes, good times.

Integrated Therapy Approach Diagram The Feeding Trust 2020 ©