ARFID

Understanding ARFID, the bigger picture of Paediatric Feeding Disorder, and the team who can help

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Arbour Vale School

WELCOME

A safe space, for you too

1. **No judgement**
   Feeding difficulties are never caused by parenting. Every family here is doing their best.

2. **Join in your way**
   Take part as much or as little as you like. It's fine to listen, jot notes or step out.

3. **Share what feels right**
   What's shared about families in the room stays in the room.

What we'll cover today

01 Welcome and getting started

02 What ARFID is, and what it isn't

03 The bigger picture: Paediatric Feeding Disorder

04 Signs that need a closer look

05 The diagnostic journey

06 Your multidisciplinary team (MDT)

07 Next steps, support and questions

ACTIVITY 1

The words we've heard

1. Turn to the person next to you.
2. What words have people used about your child's eating?
3. How did they land? Helpful, or hurtful?
4. What would you want people to say instead?

THINK ABOUT IT

The words we use shape how people see our children, and what help they get.

COMMON BELIEFS

ARFID myths

- ARFID is just very extreme picky eating
- Only autistic children get ARFID
- ARFID is caused by parenting
- A child has to be underweight to get help
- Children will always grow out of it
- You need a diagnosis before you can get support
- ARFID is about body image and weight
- It's just their autism, so nothing can be done
- A child who is a healthy weight can't have ARFID
- ARFID only affects teenagers

WHAT IS ARFID?

ARFID is more than picky eating, because of its impact

Significant impact

It affects growth, nutrition, energy or daily life for the child and family.

Not about body image

Food feels unsafe, uncomfortable or uninteresting. It isn't about weight or shape.

Often overlaps with autism

An autistic child can also have ARFID. It deserves its own support.

ARFID stands for Avoidant/Restrictive Food Intake Disorder. It's a recognised diagnosis (in DSM-5 and ICD-11), and it describes what a child is experiencing, never a failing of the child or the parent.

THREE PRESENTATIONS

ARFID can look different from child to child

Sensory sensitivity

Taste, texture, smell or look feels intense, so safe foods become very few.

Fear or aversion

After choking, vomiting or pain, eating feels dangerous, and worry starts early.

Low interest or appetite

Hunger cues are quiet, eating feels like effort, and fullness comes fast.

Many children show a mix of these, and the picture can shift over time. Spotting which one is leading helps the team decide what will help most.

The label describes the difficulty.

It never describes your child, and it never describes your parenting.

Paediatric Feeding Disorder (PFD): the bigger picture

Medical
reflux, allergies, swallowing safety

Nutritional
growth, deficiencies, supplements

Feeding skill
chewing, oral motor, self-feeding

Psychosocial
anxiety, mealtime stress, family life

PFD = eating that isn't age-appropriate for 2+ weeks, linked to one or more of these four areas

MAKING SENSE OF THE WORDS

How these terms fit together

Term	What it describes
PFD (Paediatric Feeding Disorder)	The umbrella: eating that isn't age-appropriate, linked to medical, nutritional, feeding skill or psychosocial areas
ARFID	A diagnosis within the mental health classification. Often sits in the psychosocial and nutritional areas of PFD
Dysphagia	Difficulty swallowing safely. Sits in the medical and feeding skill areas of PFD (see April's workshop)
Feeding skill difficulty	Chewing, moving food around the mouth or self-feeding is hard work, which can limit what a child eats
Typical fussy eating	Common and usually eases with time, without affecting growth, health or daily life (see September's workshop)

ACTIVITY 2

Which areas are involved?

In small groups, read each clue and decide which PFD areas it points to.

Coughs and goes red in the face during drinks	Area(s)...
Eats about 8 foods and has dropped a growth centile	Area(s)...
Can't chew lumpy foods and keeps food in the cheeks	Area(s)...
Panics at the table since choking on a sausage	Area(s)...
Meals take over an hour and the whole family is worn out	Area(s)...

SIGNS

Signs that may point to ARFID

Shrinking range

Foods drop off and don't come back, so the diet narrows over time.

Supplements

Relying on nutritional drinks, vitamins or a feeding tube.

Growth and weight

Weight loss, slow growth, or a drop across growth centiles.

Low appetite

Rarely hungry, fills up fast, forgets to eat, finds eating tiring.

Fear around eating

Panic or distress at the sight, smell or thought of food, often after a frightening event.

Life gets smaller

Avoids meals out, parties or school lunches because of food.

THE DIAGNOSTIC JOURNEY

What the pathway can look like

SPEAK UP

GP, health visitor, school nurse or SLT

REFERRAL

To a specialist team

ASSESSMENT

History, growth, mealtime, bloods

DIAGNOSIS

Named using agreed criteria

PLAN

One shared plan, home and school

You don't need a diagnosis to start getting support. Therapy, dietitian advice and school plans can begin while you wait.

Pathways, referral routes and waiting times vary by area, so ask your GP or school team what's available locally.

ASSESSMENT

What an assessment usually looks at

Mealtime observation

How food is offered, how your child responds, and how mealtimes feel.

Growth

Height and weight plotted over time, not just once.

Medical history

Illnesses, reflux, allergies, constipation and medication.

Nutrition

What is eaten across a week, and sometimes blood tests.

Feeding skills

Chewing, swallowing and self-feeding, and whether any is unsafe.

Wellbeing

Anxiety, fear, sensory needs and how eating affects family life.

DIAGNOSIS

What a diagnosis can, and can't, do

It can open doors

Access to specialist feeding teams, dietitians, psychology and school support.

It doesn't change your child

A diagnosis describes a difficulty with eating. It is not a judgement of your child or you.

It isn't a requirement

Support can begin before a diagnosis, and a diagnosis isn't always needed to get help.

Every area does this differently. It's fine to ask: who will make the assessment, what will it involve, and roughly how long will we wait?

BEFORE YOU GO

Getting ready for an appointment

Growth records

Your child's red book, or any weights and heights you have.

Foods list

Foods eaten now, and ones that have dropped off.

Food diary

3 to 5 days of food and drink. It doesn't need to be perfect.

Mealtime videos

A few short clips of real mealtimes, tricky bits included.

Existing reports

Autism assessment, SLT or OT reports and school notes.

Your questions

Jot down your worries and what you'd most like help with.

YOUR MDT (1 OF 2)

Medical and nutrition: who does what

GP

First point of contact. Checks health and growth, arranges tests, refers on.

Dietitian

Checks nutrition and advises on boosting foods, vitamins and supplements.

Paediatrician

Looks at the medical picture, treats medical causes and coordinates care.

Dentist

Checks teeth and gums. Dental pain can affect eating.

Gastro, allergy or ENT

Only if reflux, allergy, constipation or an airway issue is suspected.

Health visitor or school nurse

Monitors growth, signposts and helps you reach services.

YOUR MDT (2 OF 2)

Feeding, sensory and wellbeing

SLT

Assesses feeding skills and swallow safety, and supports communication.

School staff

Carry the plan into lunchtimes so home and school match.

Psychology or CAMHS

Supports anxiety and fear around food, adapted for autistic children.

You

The expert on your child. Your voice is central.

Feeding team

Some areas bring several of these roles together.

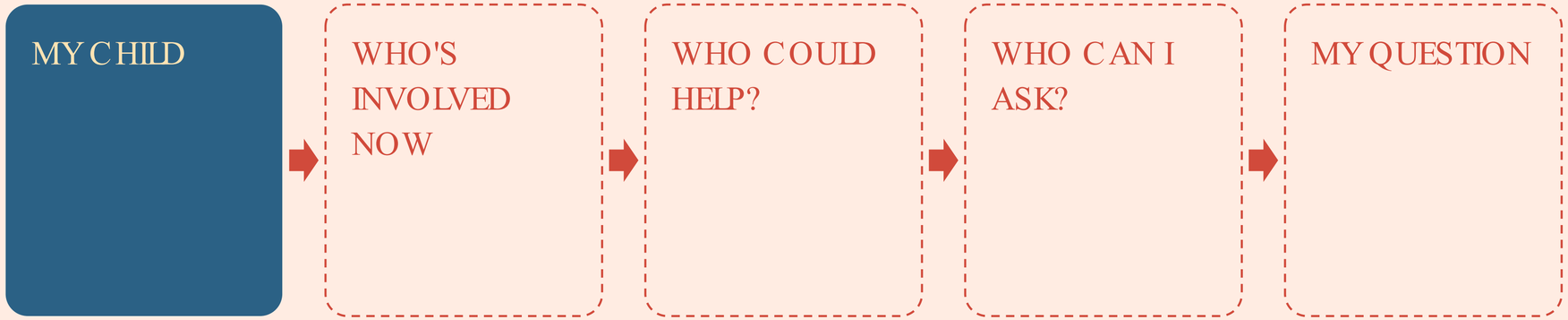
Occupational therapist

Looks at sensory processing, seating and self-feeding skills.

ACTIVITY 3

Map your team

1. Write your child's name in the centre box.
2. Fill in who is involved now, and who could help.
3. Choose one person you will ask for help or information.



You'll need: a team-map worksheet and a pen for each parent

WHILE YOU WAIT

While you wait for support

Keep safe foods safe

Keep accepted foods available, with the same brands where you can.

Share the plan

Tell school and other carers what helps and what doesn't.

Keep offering, gently

Offer other foods alongside safe ones, with no pressure to eat them.

Watch for change

If eating drops suddenly or your child seems unwell, see your GP.

Look after you

This is tiring. Share the load and tell the team how you are.

Keep a short record

Notes on weight and foods make appointments more useful.

WHEN TO ACT QUICKLY

Getting help at the right speed

Get help today	Ask for an appointment soon
Choking that doesn't clear, blue lips, or struggling to breathe (call 999)	Weight loss or growth slowing down
Drinking very little, fewer wees than usual, or unusually sleepy	Diet getting narrower over weeks
Refusing all food and drink for a day or more	Relying on supplement drinks
Vomiting that won't stop, or blood in vomit	Panic or distress around eating
Sudden big drop in eating, or your child seems really unwell	Coughing or a wet, gurgly voice at meals
Signs of dehydration or severe illness	Meals over 30 minutes or real family strain

Worried about your child's health or safety? Speak to your GP or NHS 111. In an emergency, such as choking that does not clear or difficulty breathing, call 999.

ACTIVITY 4

My next step

Choose one small thing you'll do this month. Take your card home.

ONE QUESTION I WILL ASK

e.g. who is coordinating my child's care?

ONE PERSON I WILL CONTACT

e.g. our GP, to ask about a growth check

ONE THING I WILL GATHER

e.g. a 3 day food diary and two short mealtime videos

Thank you

Questions?

1. **You don't need a diagnosis to ask for help**
2. **Feeding difficulties usually have more than one piece**
3. **Your team is bigger than you think**

Please complete the feedback form before you go.

Chelsea Ridge and Lucy Luff