ABUHB CAMHS

Sian Taylor CAMHS Dietitian ABUHB
Chair BDA ARFID subgroup

Aims of todays session

- What is restrictive eating including ARFID
- Links between autism, sensory process differences and eating
- Incidence and prevalence
- How school environments and lunchtime can impact eating
- Practical suggestions for reasonable adjustments
- Tips on things to avoid or proceed with caution
- Working together
- Reflection and questions

Voice of Experience (Joe's Story, from BEAT EDAW Resources)

In a world bursting with flavours our plates are full of challenges, not choices. There's so much we want to tell you about how ARFID affects and impacts our whole lives. We're not fussy. We don't choose to avoid or restrict food. Some of us can't stomach tastes and textures. Some of us are afraid we might choke. Other people seem to enjoy the build up to a meal. We can't think of anything worse. Food is a battle that extends way past the dining table. It can follow us everywhere, from the supermarket to work or school.

For us, every bite can be a battle

We are not being fussy.

Neophobic/ refusal?

14 months old-

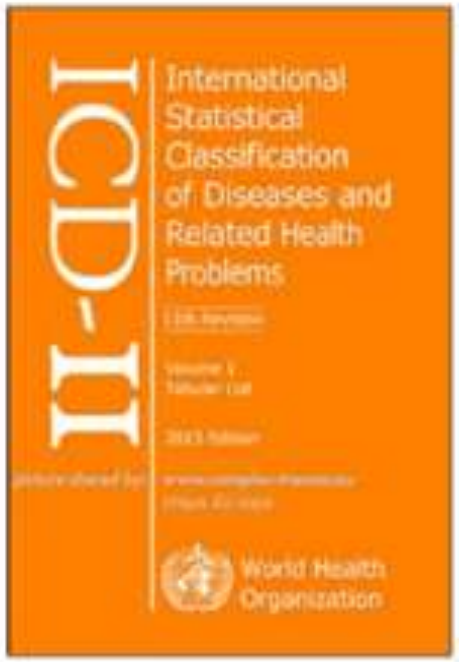
Rejection of food

20 months-8 years!-

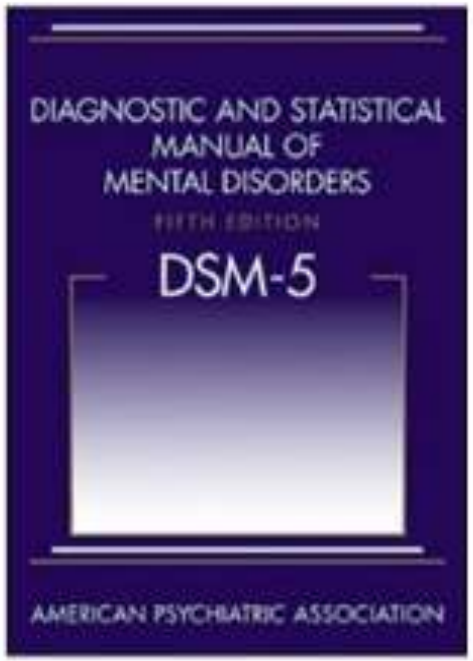
Neophobic response

What is ARFID?

- Avoidant Restrictive Food Intake Disorder
- Recognised eating disorder
- Previously known as SED/EDNOS
- DSM-IV Criteria *Copyright © 2013. American Psychiatric Association*
- ICD11 WHO



World Health Organization



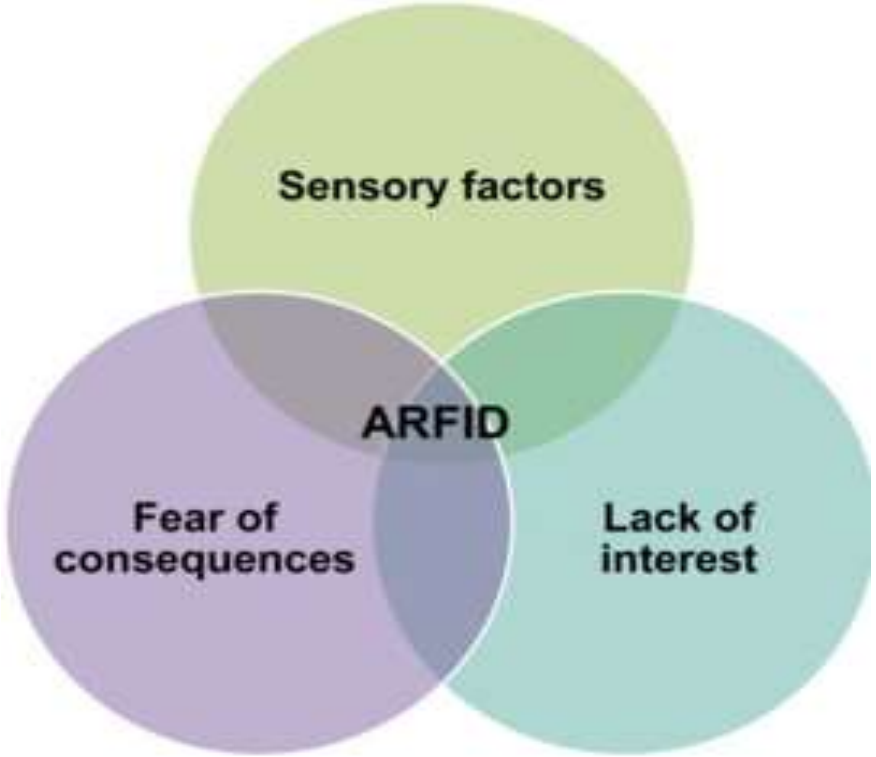
AMERICAN PSYCHIATRIC ASSOCIATION

What wouldn't be considered ARFID?

- Temporary changes in eating
- Concerns about body shape/weight
- Children who are not eating due to a medical condition that interferes with their ability to eat, or a psychological condition
- Reduced eating due to religious practices
- Reduced eating due to availability of food

Diagnostic Criteria (DSM-5 TR (2022) & ICD11 (2019)

A persistent eating or feeding disturbance associated with one (or more) of the following:



- Faltering growth/growth delay or obesity
- Significant nutritional deficiency
- Dependence on enteral feeding (supplements or tube feeds)
- Significant psycho-social distress/impairment due to food avoidance

The eating disturbance is not attributable to a concurrent medical condition or not better explained by another mental disorder. When the eating disturbance occurs in the context of another mental disorder, the severity of the eating disturbance exceeds that routinely associated with the condition or disorder and warrants additional clinical attention. The disturbance is not better explained by lack of available food or by an associated culturally sanctioned practice. The eating disturbance does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way in which one's body weight or shape is experienced.

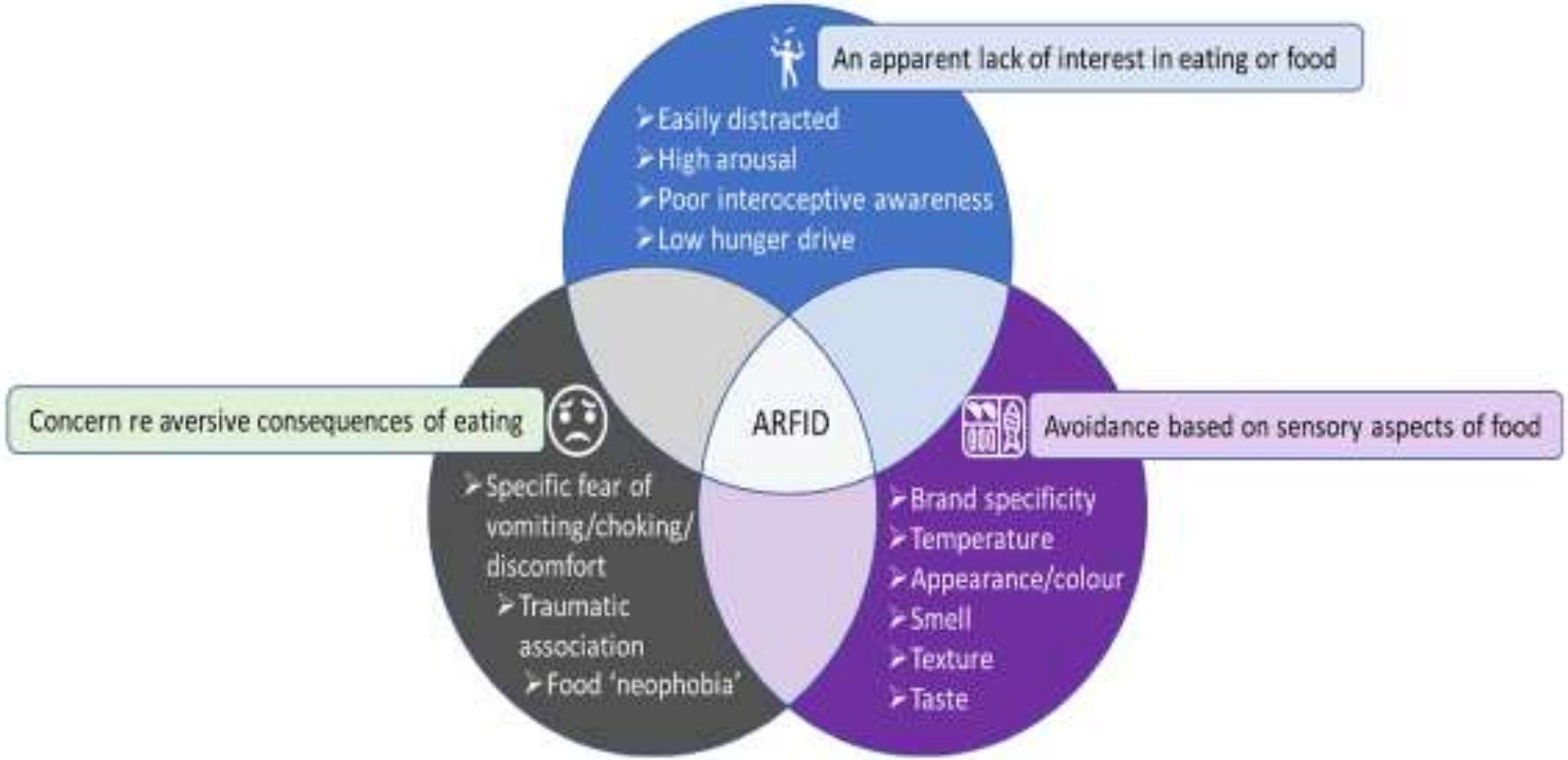
Incidence and Prevalence of ARFID

- Likely to be around 4.5-6% under 18 population
  - **Around 7500 under 18s in Gwent**
  - **Around 2475 Primary Age Children in Gwent**
- A systematic review published in 2022 indicated general population prevalence up to 15.5%
- **More common (up to 50%) in those with a diagnosis of autism**

Common factors in the developmental history (ARFID)

- Early history of reflux or food allergies
- Delayed weaning - or slow weaning progression
- Experience of choking- witness someone else
- Aversive experience of being fed - forced or coerced into eating
- Generalised anxiety
- Strong links with Autism (40%) ADHD and OCD

Drivers of ARFID – across domains of physical, nutritional, family impact and psychosocial



Archibald T, Bryant-Waugh R. Current evidence for avoidant restrictive food intake disorder: Implications for clinical practice and future directions. JCPP Adv 2023;3(2):e12160

Autism and eating

- 80% element of restrictive eating
- 95% resistant to try new foods
- Different is dangerous
- Emotional dysregulation
- Sensory needs
- Need for routine
- Predictability and repetition

Sensory needs
Interoceptic

Outside senses
- Tactile
- Visual
- Auditory
- Gustatory
- Olfactory

Inside senses
- Proprioception
- Vestibular
- Interoception

We all have unique interoception experiences

What is the disgust response?

When we see something we don't like, or smell something we find unpleasant, we become uncomfortable and display this through wrinkling out nose, gagging, retching, or even vomiting – this is known as the disgust response.

Some foods are so disgusting that the child, or adult, cannot even be near them or in the same room. This is also true of other people eating.

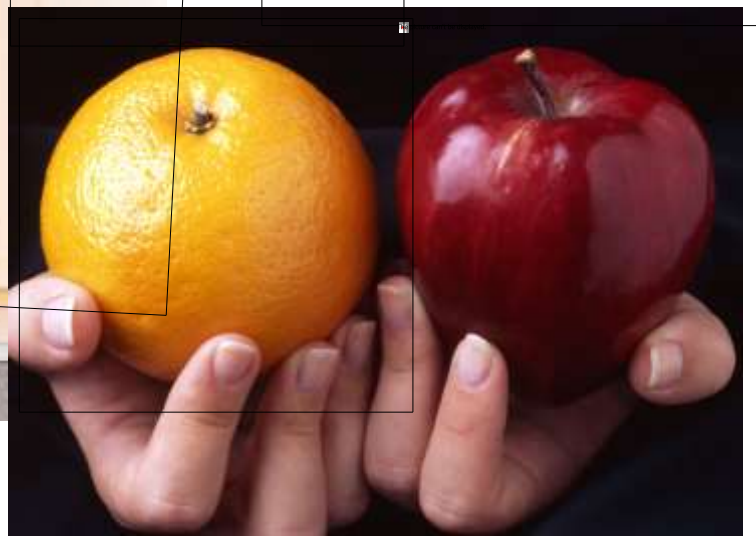
The more stress and anxiety there is around food and mealtimes, the more extreme the disgust response will be from your child.

Types of presentations we see

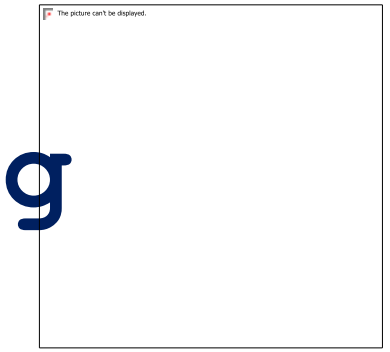
- Each child's RE will be unique to them
- Reliance on sameness/predictability of food and often in other areas of life
- Sensory hypersensitivity to properties of food and often in other areas of life
- Sensory profile of foods tends to be dry/crunchy/crispy or smooth and sweet and often processed – links to safety/disgust response/neophobia
- Mixed/wet textures tend not to be tolerated
- May be brand specific
- May be very sensitive to the ways in which food is presented
- May be unable to tolerate even accepted foods at different temperatures, or in different places

School environment

- Anxiety decreases appetite and willingness to try new foods.
- Anxiety increases sensory reactivity and decreases food intake.



Adjustments around eating



Allowing free choice from within foods typically on the menu, even if this results in a repetitive diet, or double desserts some days.

Ensuring foods are presented in a manner that doesn't trigger anxiety/disgust

- not touching
- on separate plates
- on plates from home
- without garnish or veg/salad

Ensuring foods are presented at an accepted (to the child) temperature

Making provision for school dinner items to be available at other times in the school day although routine of regular eating can be really helpful too

First line Advice

- Remove all pressure to eat new foods
- Always allow their preferred foods, and in difficult times offer only these
- Ensure they are comfortable in their environment, consider their sensory needs
- It is OK for them to eat away from the table if this is easier for them
- They may eat more/better with an iPad or watching television
- Encourage meals and snacks at regular times of the day
- Diet will usually improve long term (this can be very long term...i.e. late adolescence into early adulthood)
- Most important is for the patient to have adequate calorie intake, regardless of whether this is from snacky foods or "proper" meals, supplemented with multivitamins where necessary

Hints and Tips for Practical Management

- **Many widely held and traditional perspectives need to be suspended**
- For someone with ARFID/clinically significant restrictive eating, there are no good foods or bad foods, all food is a source of nutrition
- Eating away from the table/other children may be helpful
- Use of distraction/electronic devices may be helpful
- **Focus on developing a positive relationship with food**
- Healthy relationships are not characterised by fear, coercion, pressure, deceit, shame etc
- Don't with- hold or " starve" the child don't hide food

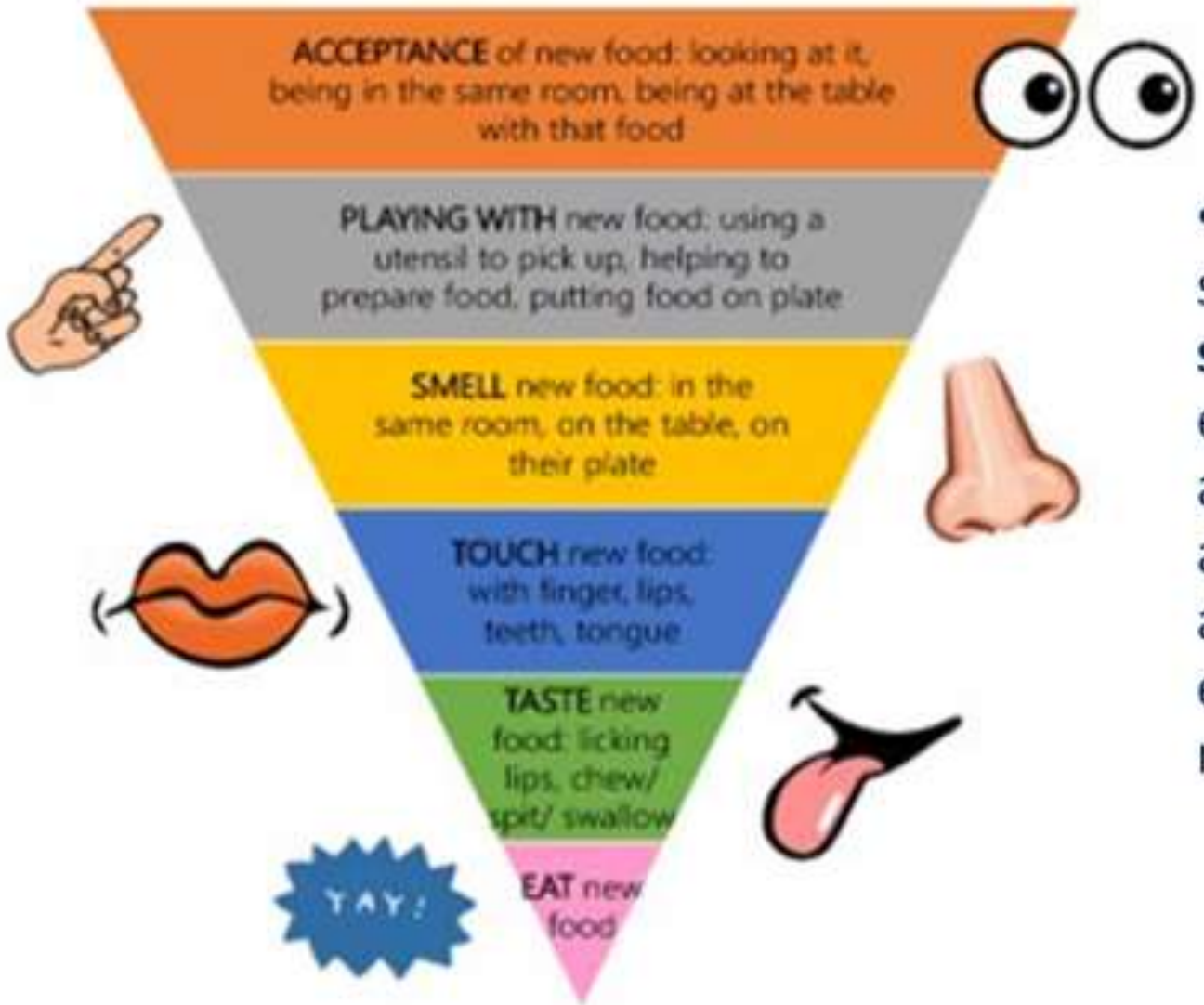
Exposing or introducing a new food

- Slooooooooooowly……
- Due to the disgust and anxiety response that seeing, smelling and trying a new food can bring any introduction of a new food needs to be done in a thoughtful and graded way that is led by the child and only when the time is right
- Approaches such as Steps to eating and food chaining can be helpful in planning how to introduce a new food

Example of pace with an adult

Comfortable now	Can eat now if I have to	Might try	Not ready to try yet
Orange juice with no bits		Pineapple juice with no bits	Fresh oranges
Apple juice with no bits	Cooked or tinned apple without skin, with custard or ice cream	Plain cooked apple Fresh apple without skin	Whole apples Pears (gritty texture)
Sieved strawberries and raspberries, on ice cream		Sieved peaches or apricots	
Cucumber without skin or pips		Cucumber slices with seeds, but no skin	Cucumber skin

Steps to Eating



- The model shown breaks down the stages into **accepting**, **playing with**, **smelling**, **touching**, **tasting**, and **finally** eating the new food. These stages allow for minimal pressure while being around the new food that should see anxiety slowly reduce, making eventually trying the new food seem much less scary for the child.

Fixed Choices

- One of the main strategies recommended for children with restrictive eating/ARFID
- Reduces anxiety and helps both the child and the caregiver feel a sense of control over their eating choices
- Reduces conflict
- Two questions never to ask:
  - "What do you want to eat?"
  - "Do you like it?"

Times to proceed with caution

Educational sessions which concentrate on healthy eating will cause a problem.

- Children with ARFID can usually only eat foods that others think of as unhealthy – snacks, biscuits, chocolate, crisps – because of the sensory properties of these foods.
- If the child starts to think of these foods as unhealthy then they will often stop eating them.
- These snack foods may well be the foods contributing to the child's adequate growth.

Reasonable adjustments will often need to be made to meet these children's sensory needs.

ARFID AWARENESS UK

A lot of people asked us if we could make one specifically for unchboxes, so here it is. Designed to help ARFID families navigate the complexities of 'healthy eating' policies, we hope that this makes life easier for our warrior children and young people.

ARFID Primary School Booklet

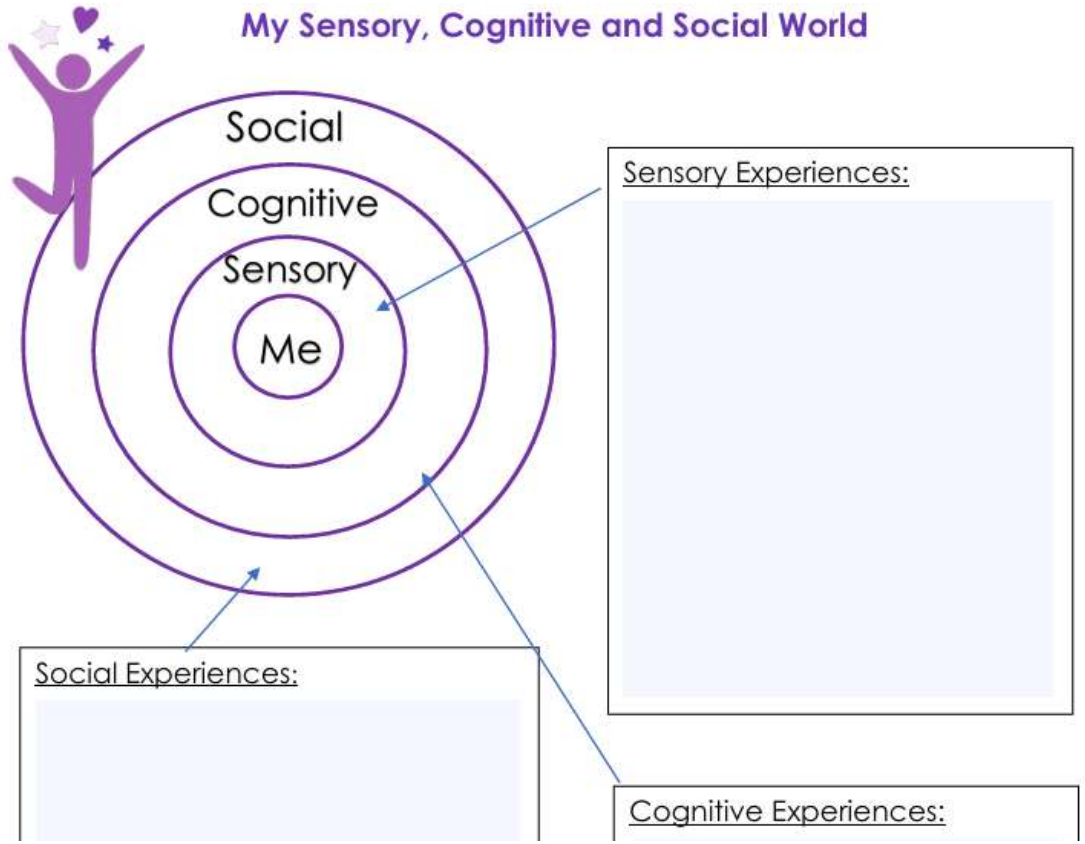
A booklet for primary schools explaining ARFID and how to support children and parents

Working together

- Child
- School staff
- Catering
- Health
- Parents

What is the need?

PEACE - Pathway
Eating disorders Autism
from Clinical Experience



Who is at fault?

NO-ONE!

The parents have not caused this problem by:

- Not offering foods; or
- Not providing the 'correct' diet at home.

Parents do not want their children to eat 'nothing but crisps and biscuits'.

Many of these children might have another condition which contributes to anxiety and pain around food, such as:

- Early reflux;
- Food allergies and intolerances.

They might have been very difficult to feed from early infancy.

Quite often children (and adults) with ARFID will also have a diagnosis of:

- Autism spectrum disorder (ASD), and/or-
- Attention deficit hyperactivity disorder (ADHD).

They will all have sensory processing difficulties; these are more likely to be seen in ASD and ADHD. They will also be rather anxious, especially in social situations.

ARFID Primary School Booklet

A booklet for primary schools explaining ARFID and how to support children and parents

Working with a child

This is a sensory based disorder, which will need **sensory desensitization.**

Foods are refused because of their **sensory properties** – taste, smell, appearance, texture.

They might:-

- Dislike getting food on their hands and face.
- Not want to get involved in messy play.
- Need to keep their hands clean, and frequently wiped.
- Not like food smells.
- Have problems with different food textures.

With younger children

- If you do try messy play – start from those things that the child can touch (usually dry textures) and gradually move on to the more difficult and wetter textures.
- See what the child is happy to handle but don't use foods to begin with, use non-foods that don't leave a residue (Play-Doh) .

With older children:

Take care with any food preparation or education sessions, they might find these difficult to tolerate – if they can take part in them.

- Use pictures of foods.
- Use packaged food for them to handle.
- Prepare food with them – but they might just want to watch at first.

Some children, however, might have problems with any session which involves food or food packets.

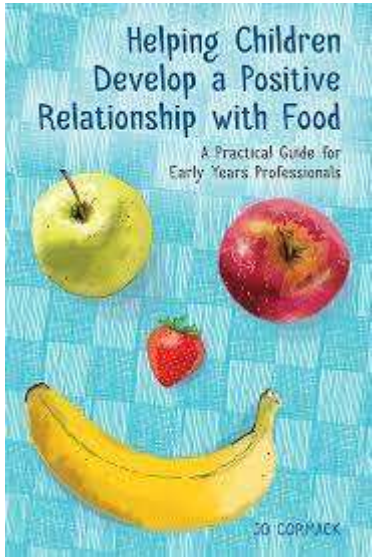
Resources

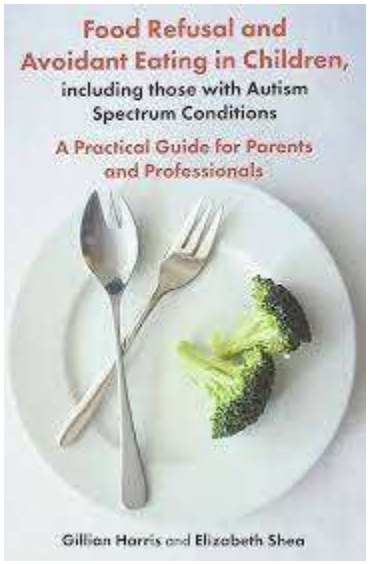
ARFID Awareness.UK
A charity supporting those with ARFID or those who think they or their child might show signs of ARFID
www.arfidawarenessuk.org

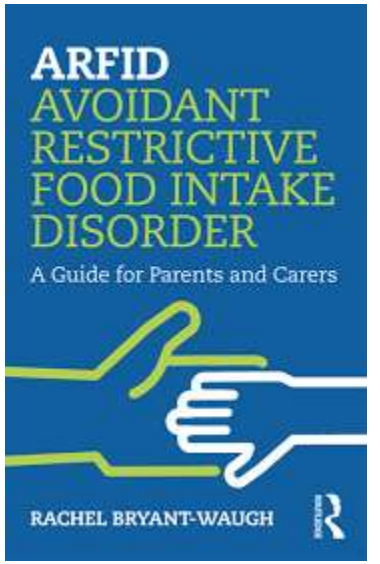
Learning from the tragic Death of 7 year old Alfie Nicholls - Concern

- **Awareness of ARFID to be increased all professionals**
- Strategies within and across health, education and social services to ensure effective identification and management.
- Normalisation of “poor diets” in autism
- EHCP - not holistic enough
- The role of the dietitian could be fundamental…..demands and limited understanding of how they could work to support ARFID nationally meant rarely regular input.
- **Action should be taken**

Resources/Signposting







- arfidawarenessuk.org

- beateatingdisorders.org.uk
- (ENDEAVOUR 8 week
- parent group)

- Support for Avoidant Restrictive F Disorder Cumbria cntw.nhs.uk

be body positive

NHS Building a positive relationship with food and your body

ARFID Awareness UK

Beat Eating disorders