

**MC
CA
ED**

Maudsley Centre for
Child and Adolescent
Eating Disorders

NHS

South London
and Maudsley
NHS Foundation Trust

Food avoidance, restricted eating and ARFID: an introduction for parents and carers

Lavender for Neurodiverse Girls Online Event
10 May 2021



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<https://mccaed.slam.nhs.uk/young-person-and-families/>

Hello!



Plan for talk

- What is ARFID?
- ARFID and neurodiversity
- What to look out for and when to be concerned
- What can I do?
- Time for some of your questions



What is ARFID?

“sensory processing disorder”

Fussy eating

“selective eating disorder”

A lifelong condition

What you get
with poor
parenting

My fault

Picky eating

Made up
nonsense!

A feeding disorder

Autistic eating

Faddy eating

A treatable condition

Never heard of it

Not a ‘proper’
eating disorder

An eating disorder

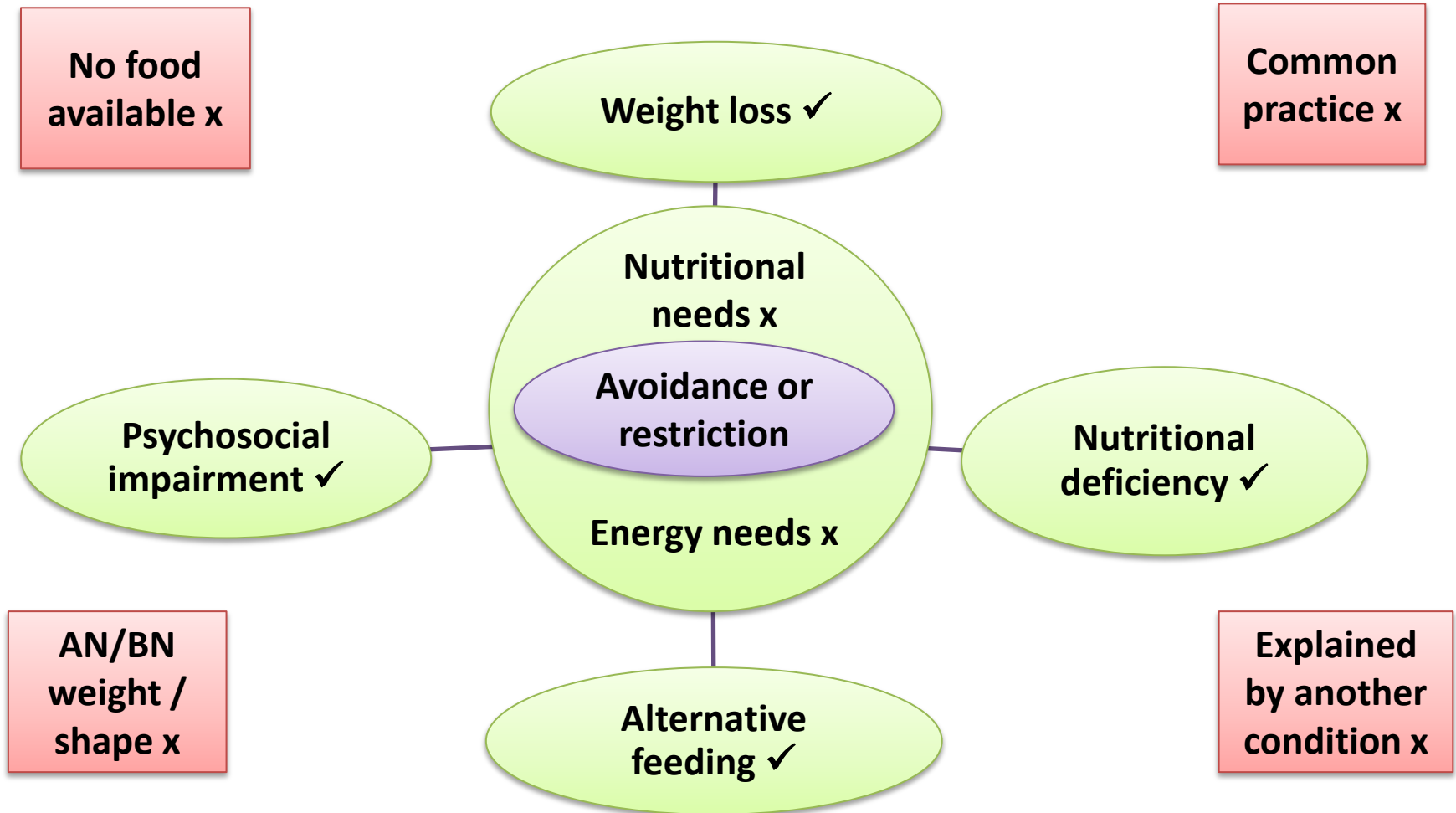
Nothing to worry about

A nightmare!!!

ARFID

- **Avoidant Restrictive Food Intake Disorder** is one of the six *Feeding and Eating Disorders* recognised by the World Health Organization
- It sits alongside anorexia nervosa, bulimia nervosa, binge eating disorder, rumination disorder, and pica, as a *clinically significant eating disturbance* in the ‘mental or behavioural disorders’ section
- ARFID involves significantly restricted eating behaviour in terms of the overall **amount** of food eaten and/or the **range** of foods eaten
- Unlike in anorexia nervosa, the avoidance or restriction is **not** due to body image disturbance or fear of weight gain

How is a diagnosis made?



What can drive the avoidance/restriction?

An **apparent lack of interest** in eating or food, e.g.:

- easily distracted
- high arousal
- poor interoceptive awareness
- low hunger drive

Avoidance based on **sensory** aspects of food, e.g.:

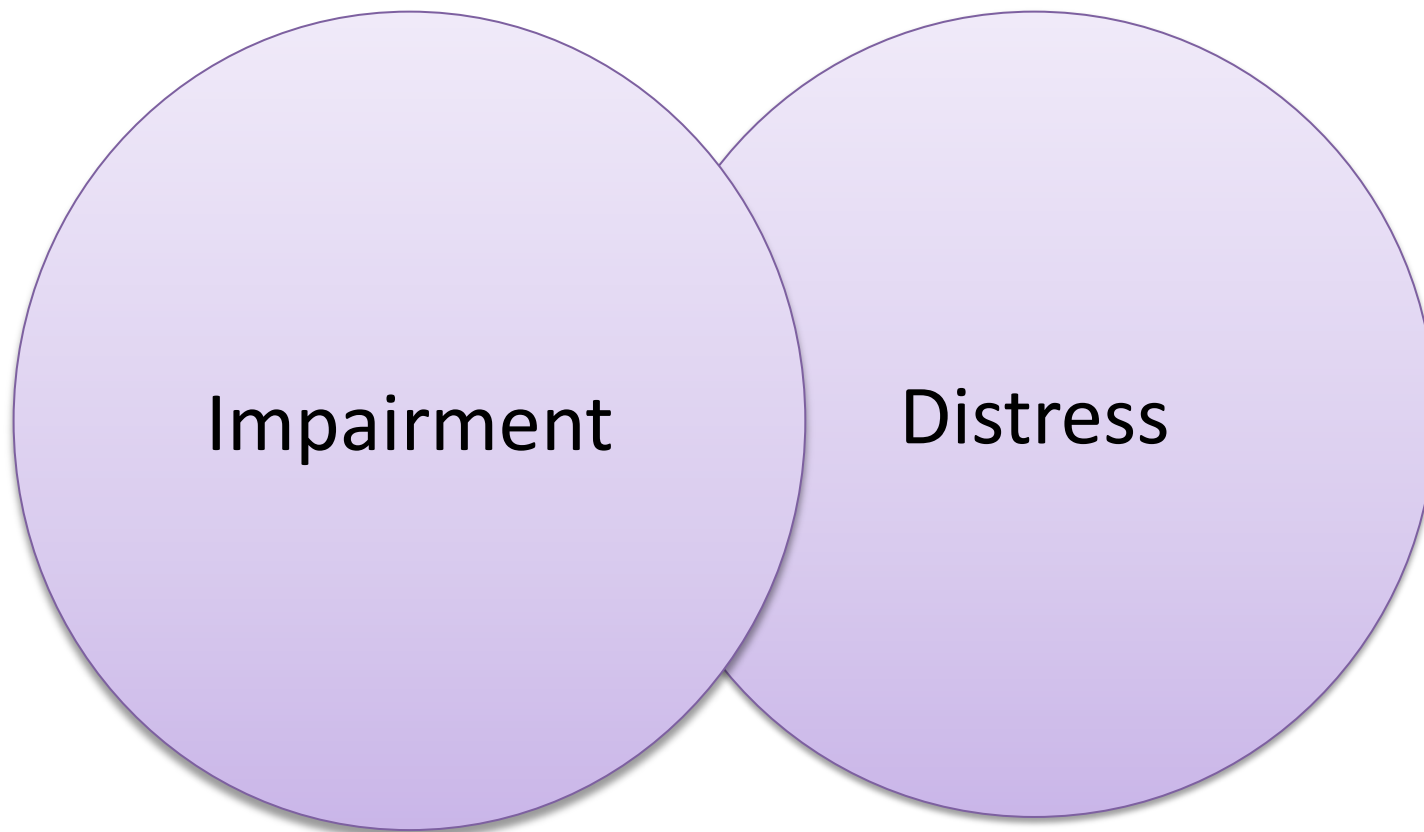
- temperature
- taste
- appearance/colour
- smell
- texture
- brand specificity

Concern re aversive consequences of eating, e.g.:

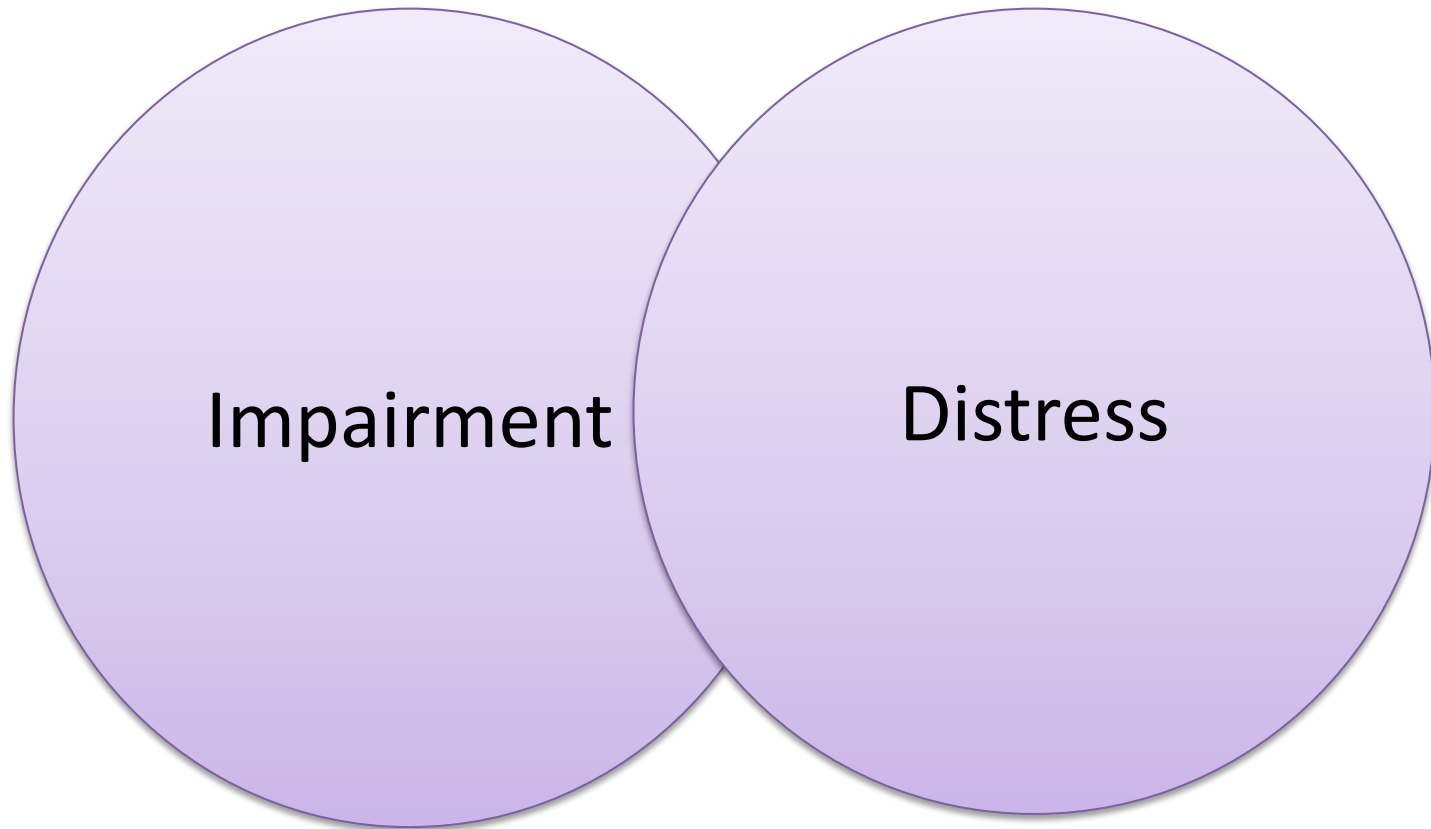
- specific fear of vomiting/choking/discomfort, etc.
- traumatic association
- food 'neophobia'

There are not 'subtypes' of ARFID

When is eating not OK?



When is eating not OK?



ARFID

- ARFID is therefore defined by a specific set of behaviours and circumstances that are known to have a significant negative impact on physical and mental health
- It has been shown that ARFID places individuals, families and relationships under strain and is often associated with considerable personal burden and negative impact on quality of life
- The majority of individuals with ARFID can be treated on an out-patient basis – the aim will usually be to:
 - Reduce risk
 - Improve everyday functioning in aspects affected by the eating
 - Help to lower stress and distress related to eating

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Main co-occurring conditions

- Autism spectrum disorders/conditions
- Attention deficit hyperactivity disorder
- Anxiety disorders
- Obsessive compulsive disorder
- Learning/intellectual disability
- Medical conditions (often gastrointestinal)



ARFID and ASC

- Eating problems are not an inevitable/fixed aspect of ASC– individual eating behaviours may or may not be distressing or impairing
- Autistic people with ARFID can be helped with appropriate input - even with very longstanding difficulties – the aim is to reduce risk and address impairment
- Common misconceptions in autistic CYP:
 - Eating difficulties characteristic of ARFID are ‘all part of autism’ or ‘autistic eating’ and so do not need diagnosis or treatment in their own right
 - Avoidance and restriction is always ‘sensory’

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Often enhanced in ASD/ADHD

P– an autistic YP with ARFID

"Having ARFID is surprisingly scary for me...because it is a literal 50/50 chance of being unable to eat...Some days I can't eat at all, because of my sensory going into a whole 'nother gear."

P's mum on the 'bitter cycle'

"If they don't eat, their mood goes. And then they don't eat. So it's me trying to stop the bitter cycle before it gets to the point where they are inconsolable because they're so hungry."

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Is this a problem?

- Foods are not allowed to touch on the plate....
- My child never eats or drinks at school.....
- My child smells everything before they eat it.....
- My child only eats grapes – no other fruit at all....
- I can't get my child to have milk on cereal – they'll only eat it dry....

**Only one of these is definitely a problem
But they may ALL be for any one individual**



What to look out for and when to be concerned

- Is your child/are you able to manage their preferences/needs and minimise distress and impairment without too much difficulty?
- Is it possible to request ‘reasonable adjustments’?
- What is the impact of your child’s eating behaviour?

Is it **directly** affecting:

- Their weight, growth or physical development?
- Their physical health and well-being?
- Their emotional well-being?
- Their ability to participate in social situations?
- Your life as a family in a way that is causing significant stress or distress?



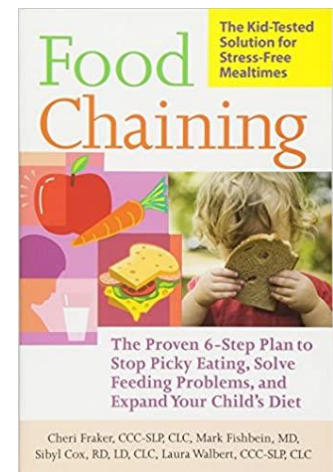
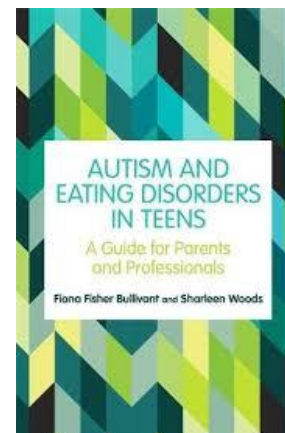
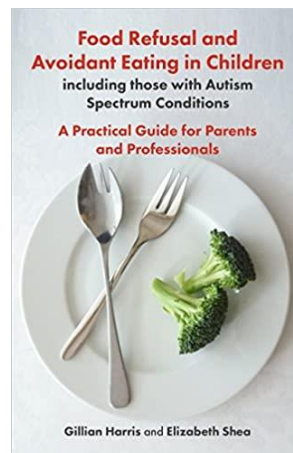
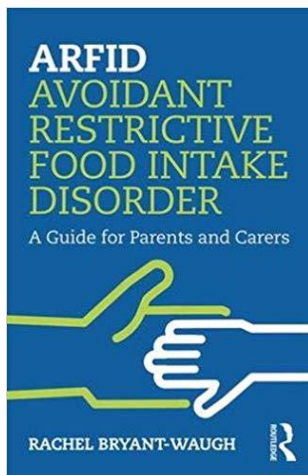
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What can I do?

- Access resources – useful pointers to early strategies that may be helpful in your situation
- Pick your battles around food and mealtimes and keep stress low
- Talk to others – your concerns are based on something!
- Seek help if you are concerned about physical/mental wellbeing



What can I do?

- Try to keep concerns in perspective
- Don't forget what you know about good parenting!
- If working with your child on eating be clear that consistency is important and communicate this to others—some accommodations may be needed/helpful
- Look after yourself

what do I need to worry about and what is OK?

Consistency, clear reasonable expectations, boundaries, encouragement

NO FAULT NO GUILT NO BLAME NO SHAME
NO FAULT NO GUILT NO BLAME NO SHAME



Working to change eating behaviour

- Work on one area at a time whenever possible
- Map out [modest] goals and steps to achieve them
- Think about what heightens and lowers arousal and consider the need to build in sensory/arousal management strategies
- Consider the eating environment – number of people, noise, light, smells, environmental stimuli may be too much or too little
- Consider time of day for meals/snacks and activities around them
- Be mindful of possible impact of place or people present

You may need to highlight reasonable adaptations to facilitate eating

Seeking help

- Do some preparation – what are you worried about and why? Take some notes with you
- If appropriate, say you think your child might have ARFID and ask about locally available treatment
- Be prepared to signpost professionals to information, e.g.:
 - BEAT website <https://www.beateatingdisorders.org.uk/types/arfid>
 - MCCAED website <https://mccaed.slam.nhs.uk/>



P's mum on seeking help

"Keep at it. Be the squeaky wheel. Be the advocate your child needs. It doesn't matter if you come off as the pushy mum or the noisy one. Keep going because there is help out there."

Back to P – on treatment

"I'm a lot happier to try new things because the amount of anxiety has gone down. It's allowed me to order and think 'OK, this is what's going through my head'. Not prevent it, but help it not give so much of an input. Not prevent it but help regulate it."

Moving forwards from here.....

- We need to keep the conversation going – awareness raising is key
- Positive progress relies on families and professionals working together
- More research is needed, including on understanding the experience and impact of ARFID from the individual's, parent/carers' and family members' perspectives
- In the meantime.....

Welcome focus on training and awareness raising about ARFID generally but also specifically about ARFID and neurodiversity

Growing body of clinical evidence that autistic people with ARFID can be supported to change their eating behaviours

The needs of neurodiverse individuals with ARFID are now actively being addressed at service, commissioning and policy level

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Plan for talk



**THANKS FOR
LISTENING!**

- **Time for some of your questions**

