

**Beat**  
Eating disorders

**AVOIDANT/  
RESTRICTIVE  
FOOD INTAKE  
DISORDER  
(ARFID)**

**Messaging for Eating  
Disorders Awareness Week**

**26 February - 3 March 2024**





# WHAT IS ARFID?

ARFID stands for **Avoidant/Restrictive Food Intake Disorder**. It is a little known and misunderstood condition that can have serious consequences for health if left untreated.

People with ARFID avoid certain foods or types of food, restrict the amount of food they eat, or both. It often presents in these ways:

- Some children and adults find certain textures, smells or tastes overwhelming or uncomfortable
- Some people worry that eating certain foods might make them choke or feel sick, this might be based on a previous difficult experience
- Some individuals may not eat as much or be interested in a variety of foods

ARFID is different from other feeding or eating disorders; in ARFID, beliefs about weight and shape do not contribute to the avoidance or restriction of food intake.

Although people with ARFID may lose weight or have low weight, this is not a criteria for ARFID. It can occur at any weight and varies in different people.

Anyone can have ARFID. It occurs in children, teenagers and adults.



# WHY ARFID?

We know ARFID is a little known and misunderstood condition, but one that can have a devastating impact on people's lives.

Too often, misconceptions about picky or fussy eating trivialise this serious condition and the stigma and fear of judgement can mean that those with ARFID and their carers suffer in silence. We want to promote a better understanding of ARFID, for people to be able to spot the signs of ARFID sooner and help more people get the support they deserve.

We have experienced an increase in calls to our Helpline from people affected by ARFID and our most visited web page is our **ARFID page**. We are hearing time and again that people affected by ARFID struggle to get help.

This is partly due to limited awareness of ARFID, limited research and a lack of standardised treatment pathways.

**Eating Disorders Awareness Week 2024** is all about tackling these misconceptions and raising awareness of this serious condition that can have fatal consequences if left untreated.



# LITERATURE REVIEW

To help ensure our messaging was informed by the latest evidence, academics from the University of Aberdeen, the University of Edinburgh and Cardiff University kindly produced a brief literature review of ARFID research for us.

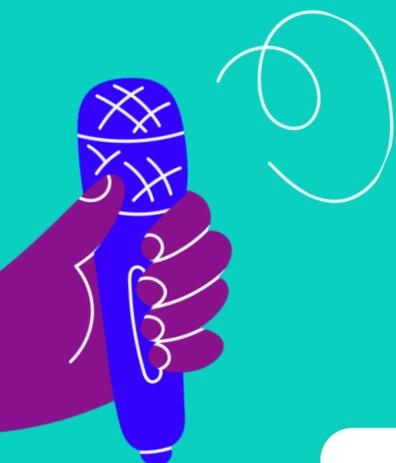
The key themes from the review were:

- There is a lot of uncertainty about the prevalence of ARFID, with estimates varying widely (between 0.3%-17.9%) across different studies
- ARFID is more common in autistic individuals and people with ADHD than in neurotypical people
- Typical age of onset is thought to be younger in those with ARFID relative to other eating disorders
- There has been relatively little research into ARFID treatment, which partly contributes to the variable service provision
- Consequences of ARFID can include weight loss, compromised growth, gastrointestinal problems, and significant malnutrition
- ARFID has serious impacts on social relationships, and engagement in education and/or employment
- Barriers to treatment include: lack of awareness and education, stigma, misconceptions around its severity, and lack of standardised care pathways. It is not known how long it typically takes to access diagnosis and treatment.



# CO-PRODUCTION

We asked the ARFID community to share their stories through a survey which ran in October 2023. This provided us with insight into the experiences of those affected by ARFID and helped shape our campaign messaging.



We also shared our campaign – as it developed – with lived experience volunteers for their feedback and input.

Our campaign theme was created from the experiences people shared through our survey – ARFID not being fussy eating was one of the key things that people wanted you to know about ARFID.

*"I would like more people to realise the difference between fussy eating and ARFID and know that people with ARFID don't have a choice, they don't choose not to eat, they physically can't."*

**- ARFID Carer**

*"It's not just 'picky eating'. It's a genuine medical condition that needs to be recognised as such. It's not easy for me to try new foods, so please don't pressure me to."*

**- Person with ARFID**



# MESSAGING

The campaign - **We're not being fussy** - was designed to help people with no knowledge of ARFID to understand the emotional difficulties of living with ARFID. It is written from the perspective of people affected by ARFID.

## WE ARE NOT BEING FUSSY



*"It's not picky eating, it's not having 'strong preferences', it is a real disorder that I didn't choose to have."*

*- Person in recovery from  
ARFID*

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.

Even after mealtimes, there isn't any respite because the fight for recognition and access to treatment is a long way from being won.

And then we're told that this could also seriously damage our health.

Avoiding the thing that's supposed to keep you alive isn't something people easily understand. So, we usually hide our struggles to avoid the judgement, stigma and the endless questions and suggestions.

For us, every bite can be a battle.

**#WeAreNotBeingFussy**

A man with long dark hair, wearing a red jacket, stands on a path in a green landscape, looking towards the right. The background shows rolling hills under a cloudy sky.

# JOE'S STORY

## #WeAreNotBeingFussy

Our main campaign messaging is supported by Joe's story. Joe has had ARFID for over 10 years and in our campaign video he describes how ARFID has affected his life.



The video launches on Monday 26 February via email, our social channels and the **Eating Disorders Awareness Week website**.

We have also worked with those affected by ARFID to produce 3 case studies and recorded some short video clips which will be shared on our social channels during the week.

# HOW BEAT CAN HELP

Treatment is not always easy to access, and eating disorder services may not be set-up to support those with ARFID effectively. But help is out there.

We have created support and training to help carers of those with ARFID develop the skills they need to support their loved one and themselves. These include:

- **POD** - our free e-learning platform for carers - provides carers with online modules, resources and spaces to talk with peers to help them better support their loved one.
- **Endeavour** - an 8 week programme for carers of young people aged 5-15. No diagnosis needed. Available in funded areas.
- And introducing... **Anchor** - our new 1-2-1 service for carers of young people aged 5-17. Currently being piloted in Kent and Essex.

Healthcare providers can contact us to find out how to commission our services in their area at [PublicSectorCommissioning@beateatingdisorders.org.uk](mailto:PublicSectorCommissioning@beateatingdisorders.org.uk)

Or if you are an individual who needs help now - our **HelpFinder** service can help you find support in your local area, and remember **our Helpline** is here to listen and support anyone affected by ARFID and disordered eating.





# WANT TO GET INVOLVED?



You can help spread the word about ARFID by:

- Sharing our videos, content and website on social or with friends and family
- Posting about **Eating Disorders Awareness Week** as we kick off on **26 February** – use one of our social assets to create your own post available at **[edaw.beateatingdisorders.org.uk](http://edaw.beateatingdisorders.org.uk)**
- Use our Hashtags **#WeAreNotBeingFussy #ARFID #EatingDisordersAwarenessWeek**
- Like, share and repost our content during the week
- **Fundraise Together** to help us raise awareness of ARFID and provide vital support such as our Helpline and Online Support Groups
- **Donate £25** to ensure we can be there when someone affected by ARFID needs us





## REMEMBER, THIS CAMPAIGN IS ABOUT...

- Raising awareness of ARFID
- Increasing understanding that this is not about being fussy or attention seeking, but is a condition with serious consequences for health
- Targeting carers – because ARFID can be an isolating experience, we're focusing the campaign towards those caring for someone who might have ARFID to help them spot the signs and seek help to support their loved one earlier
- Spreading the message that there is hope and help out there



# OUR RESOURCES

**Like, share or comment** on our video which will be launched on **Monday 26 February 2024.**

Visit our website to access social media assets in **English** and **Welsh**  
[edaw.beateatingdisorders.org.uk](http://edaw.beateatingdisorders.org.uk)

**#WeAreNotBeingFussy**



Scan the QR code to find out more



# Beat

Eating disorders

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