

# ARFID Management in Children

A rapid summary of an underserved & vulnerable population



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Avoidant-restrictive food intake disorder (ARFID) has been a phenomena of the past decade, and an emerging dietetic area, especially in paediatrics, in need of much substantiation. This article aims to summarise key pieces of evidence from the literature on managing children with ARFID, but is not extensive. The opening sentence of almost every paragraph in this article should help to summarise and highlight the challenges of this underserved population.

## Definition of ARFID

Emerging formally in 2013, ARFID was added as part of the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders diagnostic criteria (DSM-V). It replaced an existing condition of Feeding Disorder in Early Infancy and Childhood (up to 6 years old), although ARFID diagnostic criteria is independent of age (see **Table 1**).<sup>1</sup> Although, in practice, age depends on access to care as some services do not accept referrals for young children with ARFID. A three-dimensional model has been put forward by Thomas *et al.* (2017), which helps to describe how various presentations of ARFID may exist, see: <https://bit.ly/ARFIDFig>.<sup>2</sup>

## Epidemiology of ARFID

Prevalence and incidence of children with ARFID is largely unknown. It is likely misrepresented in the literature due to a lack of large and homogenous studies, but also due to challenges in diagnosis (either not received or self-reported).<sup>3</sup> From a recent systematic scoping review amongst patients with eating disorders (all ages), ARFID may represent anywhere between 1.5-64% in clinical and <1-15.5% in non-clinical cohorts.<sup>4</sup>

From UK-specific estimates, a prospective surveillance study amongst caseloads belonging to paediatricians and child psychiatrists captured data between 2002-2006 to examine the incidence of restrictive eating disorders (not formally diagnosed but consistent with ARFID). Reports in this study were found between 25-34%.<sup>5</sup> Whereas more recent data from a tertiary paediatric feeding clinic in the UK reported 49% of children met the criteria for ARFID.<sup>6</sup>

## A link between ARFID and autistic spectrum disorder?

Farag *et al.* mentioned that ARFID in young children should raise suspicion for autistic spectrum disorder (ASD).<sup>6</sup> Food sensitivities, aversions and lack of interest are not mutually exclusive to children with ARFID, and are commonly reported in children with ASD. A recent scoping review identified a lack of evidence about ARFID and ASD specifically, but found food sensitivities were the most commonly cited issue in children with ASD and severe food restriction/selectivity.<sup>7</sup> Interestingly, presence of autistic traits

was examined in a small cohort of Japanese children with ARFID, which found 12.5% prevalence, suggesting a possible role in the contribution to ARFID.<sup>8</sup>

## Risk factors of ARFID

Generally, risk factors and determinants of ARFID are not well understood. Other co-morbidities, such as attention deficit hyperactivity disorder (ADHD) and anxiety disorders, have been commonly cited amongst individuals with ARFID. Features that have been particularly identified include cognitive inflexibility, need for control and rigidity, as well as preference for routine.<sup>4</sup> Characteristics of children with ARFID from a tertiary paediatric feeding clinic in the UK found that the majority were male, generally younger (aged 4-9 years), and had co-morbidities (including ASD in 61%).<sup>6</sup>

## Consequences of ARFID

Nutritional deficiency and weight loss form part of the criteria for ARFID (see **Table 1**), however some children may experience adequate growth, owing to the selective consumption of higher calorie food items.

Authors from a tertiary paediatric feeding clinic in the UK reported higher levels of inadequate nutritional status and/or supplementation in children with ARFID. Almost two thirds did not eat more than 10 food items, which increased the likelihood of nutritional inadequacy. Of these children, one third did not eat more than 5 food items and excluded whole food groups.<sup>6</sup> A comprehensive summary of food group restrictions and subsequent nutritional deficiencies and health consequences has been provided by Bialek-Dratwa *et al.* (see **Table 2**).<sup>9</sup>

Rates of nutritional deficiency disease have been estimated by a systematic review of case reports and series in children with ARFID symptoms associated with ASD. Scurvy was most commonly reported, followed by disorders of the eyes. It is important to note that cases were excluded where iron-deficiency was reported as the primary deficiency, or if deficiency was present without a diagnosis (e.g. low vitamin D without rickets). As such this report is likely underestimating inadequate nutrient intakes although vitamin A, B-12, C, D and thiamine were recorded.<sup>10</sup>

## Diagnostic and screening tools for ARFID

No widely validated diagnostic tools for children with ARFID exist. PARDI-AR-Q is a structured interview framework for healthcare professionals based on the pica, ARFID and rumination disorder interview. PARDI-AR-Q has been specifically used to detect characteristics and severity of ARFID during the diagnosis in older children and adolescents, but requires further validation before wider adoption.<sup>11</sup> The EDE-ARFID (eating disorder examination-ARFID) is a self-reporting tool for children, adults and parents. Its validity has been explored in a small study between independent reviewers and child-parent reports (n=39), which found high levels of convergence, however further validation is also required.<sup>12</sup>

Similarly, no widely validated screening tools for children with ARFID exist. Two preliminary studies have explored the EDY-Q (eating disturbance in youth questionnaire), which is a self-reported tool for those aged 8-13 years to assess for ARFID. This tool has shown favourable use but requires further validation.<sup>13, 14</sup> The NIAS (nine-item ARFID screen) has been used in a small group (including children from the age of 10 years). However, the authors of one study recommended concomitant use with screening tools (such as Eating Disorder Examination-Questionnaire [EDE-Q]) to rule out other eating disorders after a positive NIAS result, which may not be practical in a clinical setting.<sup>15</sup>

## ARFID management strategies

Unfortunately, there are no clinical guidelines for the management of children with ARFID in the UK and beyond. This places children with ARFID and their families at high risk of inconsistent care standards. There is a lack of concrete evidence to guide practice, which explains the lack of guidelines in this area. Several types of interventions may be used in the management of children with ARFID, which have been reported in the literature to varying degrees.

Working within a multidisciplinary team (MDT) from assessment to the treatment process is desirable due to the complexities of ARFID. Some evidence has shown that MDT approaches are commonly used in the interventions for ARFID, which have demonstrated improved outcomes.<sup>4, 9</sup>

Ensuring sufficient calories and nutrient intake is core to dietetic management, with individualised and specific focus on the nuances within each presentation of ARFID. Food chaining is a common method used,

often based on safe foods to reduce anxiety and contribute to some level of security. Trust, cooperation and avoidance of pressure and expectations a child will eat by caregivers is important in the treatment process, as this may negatively affect their child's eating behaviour.<sup>9</sup>

Psychotherapy, including cognitive behavioural therapies, have been used in adolescents with ARFID to address the eating-associated anxiety and fears around food and have demonstrated some success.<sup>4</sup> Family-based ARFID therapies can specifically support caregivers by reducing guilt, externalising and increasing empowerment, to aid at home recovery in pre-adolescent children with ARFID.<sup>4, 16</sup>

## Practice challenges

Due to restrictive referral criteria for some services (e.g. tertiary feeding clinics or child and adolescent mental health services [CAMHS]), lack of clinical time (where there is no allocation of funding for ARFID), or lack of skills in healthcare professionals, children with ARFID may not receive the best care. Dietitians are often the first port of call, which places an immense burden upon the profession, especially if not trained in the management of eating disorders, or within a MDT. The ARFID Specialist Interest Group of the British Dietetic Association have recently outlined the role of the dietitian in managing ARFID, which presents service recommendations. The statement highlights the importance of sufficient time for assessment, observations and dietary

analysis, as well as other considerations such as staffing levels and the roles within a MDT.<sup>17</sup>

## Research needs

Recommendations for guiding more research in ARFID have been well summarised by Bourne *et al.* (see **Table 3**).<sup>4</sup> These recommendations would help to synthesise evidence to better understand this population and inform practice and guidelines.

One of the key research recommendations is to '*go beyond the scope of the current evidence*'. In one of the few studies that has explored taste, supertasters were found to be significantly shorter in stature from a cohort of Caucasian preschool children in the UK.<sup>18</sup> Novel research in children with ARFID could help to explore lesser studied determinants, such as the drivers and perception of taste, and how this may impact dietary preferences and growth in this population.

## Summary

Children with ARFID are an underserved population due to lack of rigorous knowledge, guidelines and resources available. It is important to recognise ARFID is a rapidly emerging disorder of the past decade, and provision of support has not caught up with the demand in services. Healthcare professionals that cross the path of children with ARFID require more training, research and funding. Establishing validated screening and diagnostic tools, as well as effective treatment approaches for children with ARFID may help to detect and treat those most vulnerable.

**Table 1: Diagnostic criteria for ARFID**

Based on the 5th edition of the Diagnostic and Statistical Manual of Mental Disorder (DSM-V)<sup>1</sup>

### Inclusion criteria

- An apparent lack of interest in food or eating
- Avoidance of foods because of their sensory characteristics and extreme sensitivity
- A concern about the aversive consequence of eating
- An inability to get adequate nutrients and/or energy into the body with food and links to at least one of the following:
  1. Significant weight loss (or lack of expected weight gain or growth in children)
  2. Significant nutritional deficiencies
  3. Dependence on enteral feeding or oral food supplements
  4. Disturbances in psychosocial functioning

### Exclusion criteria

- Not explained by lack of available food or by an associated culturally sanctioned practice
- Does not occur during the course of anorexia or bulimia nervosa
- No evidence for disturbance in the way in which one's body weight or shape is experienced
- Not attributable to concurrent medical condition or better explained by another mental disorder

Continued overleaf

**Table 2: Restricted food groups and subsequent nutrient deficiencies & health consequences by Bialek-Dratwa, et al.<sup>9</sup>**

Food group avoided	Nutrient deficiency	Health consequences
Cereal products	Carbohydrates	Hypotrophy
	Fibre	Atherosclerosis, gallstones, diverticulosis, colorectal cancer, breast cancer in women
Milk & milk products	Calcium	Rickets, hypocalciuria, reduced bone mineral density, osteopenia, bone weakness or fractures, osteoporosis.
Animal products & dairy products	Riboflavin/ vitamin B2	Low energy levels, poor growth, dry skin/skin problems, hair loss, dry cracked lips or cracks at the corners of the mouth, magenta tongue swelling, itchy and/or red eyes, sore throat, loss of lean body mass, anaemia, cataracts
	Total protein	Malnutrition, oedema
	Vitamin B12 Cobalamin	Hyperhomocysteinaemia, megaloblastic or macrocytic anaemia, low energy, weakness, numbness or tingling in hands or feet, difficulty walking or instability, constipation, anorexia, confusion, poor memory, mood changes, psychosis, mouth/tongue discomfort
	Iron	Microcytic anaemia, pallor, weakness, fatigue or drowsiness, irritability, poor concentration, learning, cognitive difficulties, mood changes, reduced exercise endurance, headaches, temperature intolerance, weakened immune system, reduced appetite due to mucosal changes (disappearance of tongue papillae with taste buds, reduced saliva production)
	Selenium	Oxidative stress
	Zinc	Oxidative stress, poor growth, and development, anorexia, weakened immune system, impaired night vision, taste and smell changes, hair loss, diarrhoea, poor wound healing
Fish	Omega-3 acids	Central nervous system disorders, cardiovascular disorders
	Vitamin D3	Rickets, osteomalacia, osteopenia
Vegetables & fruits	Folates	Hyperhomocysteinemia, megaloblastic or macrocytic anaemia, persistent fatigue, pallor, palpitations, dyspnoea, headache, mouth ulcers, increased risk of birth defects, poor concentration, increased irritability, weight loss
	Vitamin C	Microcytic anaemia, scurvy, petechiae, easy bruising, bleeding, and swollen gums, anorexia, anaemia, malaise, muscle, joint pains, corkscrew, perianal haemorrhage, wound healing disorders, hyperkeratosis, weakness, mood disorders
	Vitamin E	Oxidative stress
Animal & vegetable fats	Vitamin A	Hemeralopia, poor night vision/night blindness, weakened immune system, hyperkeratosis, impaired wound healing
	Vitamin K	Bruising and easy bleeding, prolonged prothrombin time
	Fat	Weight loss, absence of menstruation

Source: Bialek-Dratwa A, et al. (2022). ARFID-Strategies for Dietary Management in Children. *Nutrients*; <https://doi.org/10.3390/nu14091739>. This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license: <https://creativecommons.org/licenses/by/4.0>.

**Table 3: Summary of ARFID research recommendations by Bourne et al.<sup>4</sup>**

Exploring drivers of food avoidance	Researching beyond the 3 main drivers from the DSM-V criteria
Psychometric testing of assessment instruments	Testing in populations with a range of features and across the lifespan, in both clinical and non-clinical settings
More epidemiological data	Particular focus on the age of onset, impact of characteristics such as age, gender, sex and type of ARFID presentation
Going beyond the scope of current evidence	Exploring the psycho-biology of appetite and hedonic response to food

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