BDA The Association of UK Dietitians

ARFID Mental Health Sub Group

Clinical Considerations for Gastrostomy Feeding in Patients with Avoidant Restrictive Food Intake Disorder (ARFID)

Authors note

This document has been written and developed by specialist dietitians including committee members of the British Dietetic Association (BDA) ARFID Sub-Group and the BDA Learning Disabilities Sub-Group. We have been supported in our peer review by expert clinicians from Great Ormond Street Hospital Feeding and Eating Disorders Service, the BDA Parenteral and Enteral Nutrition Group (PENG) and the BDA Paediatric Group. We would also like to extend our gratitude to Mr Alex Ruck Keene KC (Hon), Professor of Practice at the Dickson Poon School of Law, King's College London for writing the legal aspects of this piece.

Individuals with lived experience have significantly contributed to the direction and production of the document. This has included sharing their own gastrostomy feeding journeys to help shape our understanding through case studies. They have shared their stories with honesty, courage and reflection and their voices are poignant, impactful and essential to the conversation. We hope that all readers spend time understanding the lens of lived experience found on pages 23-31.

"Looking back, I wish we had the option of getting the (gastrostomy) tube back when (they) …only had one safe food left… it would have saved us years of anxiety and upset… which resulted in an extremely traumatic experience"

"Please, listen. No one expects a miracle. We are not looking for a cure. We don't expect you to wave a magic wand and make ARFID go away. What we want is empathy, understanding, support and honesty"

"It has been nine months since the procedure and it's like we have a new person".

Executive Summary

Significant regional variation exists in the timing and criteria for gastrostomy referral in individuals with Avoidant/Restrictive Food Intake Disorder (ARFID). Some services consider gastrostomy after only brief periods of nasogastric (NG) feeding, whereas others delay discussion for years. In certain areas, an NG feeding trial is treated as a prerequisite even when clinical indicators suggest it may be ineffective or potentially harmful. The reasons for these disparities remain unclear, but likely reflect differences in ARFID awareness, multidisciplinary perspectives, the consistency with which treatment pathways are explored, and operational pressures such as long waiting lists.

This document aims to promote more consistent, informed, and balanced decision-making regarding gastrostomy feeding. The overarching principle is to ensure timely, individualised care that avoids both unnecessary delays and premature escalation to invasive interventions.

Key Principles:

- **Assessment of ARFID should be comprehensive and multidisciplinary**, and in many cases, multiagency
- **The lived experience of the individual and their family must remain central to all discussions and decisions.**
- **Risk assessment should be structured and holistic**, addressing all four ARFID risk domains and considering short-, medium-, and long-term consequences, alongside procedural and post-operative risks.
- **Gastrostomy feeding should not be a first-line intervention**, but rather one option within a broader therapeutic framework for individuals of any age with ARFID. Individuals with ARFID should not face critical consequences of malnutrition and/or dehydration before gastrostomy feeding is considered.
- **Gastrostomy feeding can serve as a time-limited therapeutic tool**, supporting nutritional rehabilitation without necessarily representing a permanent solution.
- **Decision-making should be grounded in principles of human rights, equity, and fair access**, ensuring that clinical pathways do not inadvertently disadvantage particular groups

Aim

This document aims to inform and support the dietetic roles and responsibilities in the consideration of gastrostomy feeding for individuals with ARFID across the age range. These professional responsibilities are explored within the wider multi-disciplinary team (MDT) process, and informed by the current evidence base, current clinical practice and lived experience.

We hope that this document provides a helpful understanding about the role of gastrostomy feeding in the care and treatment of individuals with ARFID.

Introduction

ARFID is a relatively recent addition to the spectrum of eating disorders (American Psychiatric Association, 2013). Unlike other well-known eating disorders (such as anorexia nervosa or bulimia nervosa) ARFID is not driven by body image concerns or a fear of gaining weight. Instead, individuals with ARFID are typically driven by one, or a combination of three recognised subtypes (Sanchez-Cerezo *et al*., 2024). These include severe sensory differences, specific fears that arise from a concern of inadvertent consequences (such as a fear of choking or vomiting) and a disinterest in food and eating. Across all sub-type presentations is the same shared clinical risk: significant nutritional or physical health consequences (James *et al*., 2024) and/or clinically significant psycho-social impairment (Hay *et al*., 2017). Holistic treatment consists of a multidisciplinary approach where the interdisciplinary make-up should be determined by the individual clinical presentation, identified needs and psychological formulation.

Although ARFID is increasingly recognised across the lifespan, it is most diagnosed in children and adolescents (Norris et al., 2016). Though awareness is growing, ARFID remains relatively under-recognised and under-treated in clinical practice due to a lack of robust ARFID pathways and treatment teams within the NHS (Cucinotta *et al*., 2023). This is not inconsequential, given that at its most severe, ARFID can have fatal consequences in both adults and children (Judiciary, 2024; Judiciary, 2021).

This document is presented in response to the recommendations laid out in the prevention of future deaths reports (Judiciary 2026; Judiciary, 2024; Judiciary, 2021). The coroners' recommendations for health, social and education professionals locally and nationally include the role of the dietitian within assessment and treatment of ARFID. The document also recognises learning arising from the instances of life-changing nutritional-blindness resulting from untreated malnutrition (Schimansky *et al*., 2024) and the recognition that almost 25% of individuals with ARFID require hospital admission (Tsang *et al*., 2020).

Here, we outline the case for the identification and consideration of gastrostomy feeding. Gastrostomy feeding is indicated where a prolonged failure of oral feeding is expected (Choi and Cho, 2022) and although pre-diagnosis, the European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN) 2010 review (Braegger *et al*.,, 2010) cites 'inadequate food intake' secondary to 'food aversion' amongst the clinical situations for which enteral nutrition could be required (*table 2, page 112*). We assert that gastrostomy

feeding has an important role in supporting growth and development and preventing mortality and morbidity within the ARFID population. We explore the impact that gastrostomy feeding could have on improvements to quality of life for the individual and also their family and do this through illustrative case examples from lived experience. We build on a small, emerging evidence base which acknowledges that gastrostomy feeding for individuals with eating disorders does not necessitate a permanent solution (Findlay *et al*., 2011). Although this study represents a very small sample size, it demonstrated that 5 of 5 patients with an eating disorder or psychiatric disorder (which may now be consistent with ARFID diagnostic criteria) restored weight with a gastrostomy feed and could continue with community treatment. Whilst the duration that the gastrostomy was longer for those with a non-weight focused restriction, 4 of 5 children made significant improvements with independent eating and had their gastrostomy removed. The study also highlighted that no further hospital admissions were necessary, and no serious relapses occurred. We therefore also suggest that gastrostomy feeding may support oral nutrition in those with ARFID (NICE, 2006). We recognise that nutritional change in people with ARFID can be very slow and that it can take years to see sustained oral improvements for some individuals (Lucarelli *et al*., 2018). This can be especially compounded by instances of co-occurring neurodevelopmental conditions, such as autism and/or intellectual disability. Gastrostomy feeding may therefore be positively indicated in a small number of cases to support nutritional adequacy, maintain community treatment, and prevent nutritional and psychological harm. We propose that gastrostomy feeding may be a tool to support the maximisation of ongoing oral nutritional change.

Multidisciplinary Decision Making

Enteral feeding has a major psychosocial impact on the individual and their family (Remijn *et al*., 2022). Therefore, the decision to place a gastrostomy should never be made by a single healthcare discipline alone and multiprofessional decision making is mandated by ESPGHAN (Homan *et al*., 2021). The decision to insert a gastrostomy should be taken by an MDT, who should consider nutritional, medical, ethical, psychological, and quality-of-life issues (Heuschkel *et al*. 2015). Healthcare professionals should ensure that all people who need nutrition support receive coordinated care from an MDT (NICE, 2017).

At present, in the United Kingdom (UK), ARFID provision is limited and regionally inconsistent (NHS England, n.d). Multiprofessional makeup can also vary significantly, and there can be cross-partnership challenges where services for physical health and mental health operate through different healthcare trusts, governing structures and funding arrangements. Dietitians should escalate any such arising concerns through their organisational structure if this is affecting quality of care and/or compromising dietetic service provision.

When a gastrostomy feeding is being considered, best practice would suggest multiprofessional cohesion and co-working. In many care settings, this is likely to necessitate partnership working across organisational structures. In this way, achieving the ideal, holistic and needs-led multidiscipline demographic. This would include:

- Psychiatry - to ensure all alternative therapeutic options that may support an improvement in oral intake have been explored and exhausted

- Occupational Therapy - to ensure that sensory adaptations are in place which would maximise oral intake
- Medical (gastroenterologist/paediatrician) - to undertake a comprehensive physical examination, review and assess growth/development/health trajectory, consider medical risk implications from surgery and to rule out the potential for oral improvement from pharmaceutical interventions (such as Cyproheptadine (GOSH, 2024))
- Dietitian - to comprehensively assess nutritional inadequacies, limitations to oral intake and long term associated health risks

Within any decision-making / care planning meeting, the MDT must comprehensively consider the risks and benefits of the gastrostomy placement and the most appropriate placement method. The MDT must also determine the most suitable feeding tube and assess for any training / ongoing care needs to achieve a positive quality of life outcome. This includes ensuring that enteral feeding can be delivered within the home and across a range of environments used by the individual, such as education or work settings and community centres.

Family-Centred Decision-Making

Beyond the clinical definition of a multiprofessional team, decisions on feeding interventions must involve and proactively centre around the thoughts and wishes of the patient and their family, including the voice of the child where appropriate (SCIE, 2022). Studies also highlight why the patient and family are an integral member of the MDT. They note that health care professionals (HCP) often base enteral feeding decisions on rational facts whereas caregivers primarily focus on the emotional issues (Remijn *et al*., 2022). A comprehensive, holistic understanding of both aspects is essential.

It is vital that the patient understands what a gastrostomy is and why it would be placed, as far as this is practically possible. This should always be communicated in a way that is developmentally appropriate, clear and understood. Wider research asserts that there can often be a disconnect between families and professionals, with care teams often making assumptions about the person's ability to eat and drink without adequate consultation with family carers (Anantapong *et al*., 2023, Clarke et al., 2015). We can extrapolate this finding to an ARFID population to stress the importance of healthcare teams listening to patients and family's own experiences of living with ARFID. They should avoid making assumptions which minimise the significant psychosocial and mental health impact of the condition.

By the stage that families are considering gastrostomy feeding, they are likely to have experienced a long journey of fighting to be heard and understood. Many families experience 'institutionalised parent carer blame' which assumes that the problems with eating and drinking are due to parental failings (CEREBRA, 2021; Bamigbade, 2024). ARFID is not widely understood by health care teams (Harrison, 2021) and families frequently report health care professionals not listening and failing to perceive the physical and psychosocial severity of the condition (Ellis *et al*., 2020). Consequently, distressed families seeking help and support can be unfairly perceived as combative or aggressive.

Healthcare professionals who do not understand a range of presentations including Persistent Demand for Autonomy (PDA - also known as Pathological Demand Avoidance, or EDA - Extreme Demand Avoidance) profiles may mislabel and misunderstand families. In extreme cases mislabelling of Fabricated Induced Illness (FII) may arise. Consequently, healthcare systems should consider the vital role that neurodevelopmental services serve in discussing a gastrostomy and shaping neurodivergent affirming care. Supporting communication and communication adjustments through a key worker or advocate who understands neurodiversity is helpful in navigating a sense of shared understanding.

Healthcare professionals should also understand that many family members may themselves be neurodivergent and require different styles of communication. Communication needs should be considered for the individual and their family to ensure that information sharing is as supportive and equitable as possible.

Aligning clinical actions with the family's insights and wishes is key. Families have an essential role in ensuring that the whole care team understands the impact of ARFID in day-to-day life. Patients and their families are the experts of their own health and lives. They are best placed to understand the potential impact of gastrostomy insertion and transition. It is essential that any concerns about the impact of ARFID on their current and future health are heard. These views must be acknowledged and considered equally in the decision-making process.

The Role of the Dietitian

Dietitians working with ARFID patients bring age-specific clinical skills and a depth of expertise that facilitates the interpretation of nutritional risk within a complex and evolving clinical picture. Dietetic core competencies position them as the professionals best equipped to assess and manage nutritional status (Cook et al., 2022), integrating medical history, clinical presentation, anthropometric and biochemical data, and a nuanced nutritional assessment. Crucially, dietitians are trained to evaluate nutritional risk longitudinally rather than as a static snapshot. This approach is essential to the nutritional complexities arising from ARFID and when considering interventions such as gastrostomy feeding.

For those with additional training in mental health or specialist expertise in ARFID, as outlined in the BDA ARFID Position Paper (BDA ARFID Special Interest Group, 2022) and draft dietetic competencies (BDA ARFID Special Interest Group, 2024), the dietetic role expands further. ARFID specialist dietitians are uniquely positioned to interpret nutritional and clinical findings alongside the broader social, psychosocial, and systemic influences that shape an individual's eating behaviour. This integrated perspective is vital when evaluating whether gastrostomy feeding may support not only physical development and nutritional safety but also social participation and emotional wellbeing.

Dietitians also play a central role in counselling individuals and families about the immediate and long-term implications of proposed treatments (Cook et al., 2022). Their interpersonal skills and grounding in patient-centred care enable them to advocate effectively for the patient's nutritional needs and preferences. In doing so, they help ensure that decisions around gastrostomy placement and subsequent feeding plans align with the patient's goals and contribute meaningfully to improved quality of life. This advocacy extends to

interdisciplinary collaboration, supporting the wider MDT in understanding practical considerations such as optimal tube placement, appropriate tube type, and the competencies required for safe tube and stoma care.

As discussions progress toward gastrostomy placement, the dietitian's role becomes even more distinct. They are the only registered healthcare professionals qualified to prescribe individualised enteral feeding regimens (BDA, 2025): determining feed type, schedule, and method of administration based on a comprehensive nutritional assessment. Ongoing monitoring of nutritional status, growth, health indicators, and tolerance allows dietitians to adjust plans responsively, balancing clinical needs with patient and carer burden. These processes are embedded within collaborative MDT practice (Armer et al., 2019). Evidence from other clinical populations further underpin the value of dietetic leadership in this area, with dietetic-led insertion pathways demonstrating both clinical benefits and cost efficiencies (Cook et al., 2023).

Dietitians contribute to service improvement and clinical governance by evaluating outcomes of gastrostomy interventions through quantitative data, outcome measures, and qualitative feedback (PENG, 2021). Their educational role extends beyond patients and families to include General Practitioners (GP), Home Enteral Feeding (HEF) teams, and community nursing services, ensuring continuity of care and shared understanding across settings. Dietetic expertise is fundamental for safe, effective, and person-centred gastrostomy feeding practice for individuals with ARFID

Clinical Guidelines and Relevant Considerations in Gastrostomy Placement

There are no specific guidelines around the use of enteral feeding in ARFID. However, there is guidance based on general principles which can be used to support decision making and management of malnutrition in both paediatrics and adult patient groups (NICE, 2006; GAIN, 2015; BAPEN, 2016; Heuschkel et al., 2015).

National Institute of Clinical Excellence (NICE) Nutrition Support Clinical Guideline (2006) clearly defines a criterion to facilitate a consistent approach to enteral feeding decision making. It defines this as:

> ***1.7.1*** *Healthcare professionals should consider enteral tube feeding in people who are malnourished or at risk of malnutrition and have a) inadequate or unsafe oral intake and b) a functional, accessible gastrointestinal tract.*

The ESPGHAN Position Paper on the Management of Percutaneous Endoscopic Gastrostomy in Children and Adolescents (Heuschkel et al. 2015) goes further than this by suggesting that dietitians should advocate for gastrostomy feeding when oral intake is insufficient to promote growth / weight gain in children or weight maintenance in adults over the long term.

Both NICE (2006) and the ESPGHAN Position Paper (Heuschkel et al. 2015) specify that gastrostomy feeding should be considered for people likely to need long-term enteral feeding, with NICE (2006) stipulating this as a duration >4 weeks.

Whilst there are no specific guidelines around the use of gastrostomy feeding for those with ARFID, case series indicate gastrostomy as a treatment for severe ARFID where other interventions have been unsuccessful or exhausted (Findlay *et al*., 2011; Cucinotta *et al.*, 2023). This includes instances where:

- The person is unable to tolerate oral nutritional supplements, and a range of different types have been tried
- The person has received specialist MDT treatment for ARFID, but this has not resulted in significant change to their nutritional risk
- A trial of nasogastric (NG) feeding has been successful and well tolerated either in hospital admission or in the community

There is, however, nuance to this final case point which supports Cucinotta's (2023) stance that gastrostomy feeding for those with ARFID should be a highly individualised decision. There will be instances where individuals progress straight to gastrostomy feeding - bypassing a trial of NG tube insertion where this is not practical or is considered clinically harmful. Such examples may include:

- Individuals with active resistance to tube insertion, particularly those which may require chemical or physical restraint
- Individuals unable to tolerate sedation, particularly where there is no oral route and they find it too distressing to have a cannula
- Instances where NG feeding can only be supported on a hospital ward but where the individual is likely high risk of iatrogenic harm from an inpatient setting
- Individuals where the nutritional risk problem is considered too long term with co-occurring comorbidities or additional health complexities

Noting that a trial of NG feeding is not a suitable prerequisite for all is further supported by the 2010 ESPGHAN Review (Braegger *et al*., 2010). This noted that within adult studies NG tube feeding had a higher rate of discomfort and complications and gastrostomy provided superior nutritional efficacy, acceptability, and in turn, quality of life improvements.

The requirement for the consideration of a gastrostomy to occur following a period of skilful intervention is a protective one. Gastrostomy placement is a highly invasive medical procedure which requires hospital admission and anaesthesia and is associated with potential complications (Cucinotta *et al*., 2023). This surgical procedure is likely to be a distressing experience, particularly for any individual with co-occurring neurodevelopmental or intellectual disability (CQC, 2022). Autistic individuals or those with heightened sensory sensitivities, as is often the case for those with ARFID, are likely to find the ward environment hyper-stimulating and highly challenging. Those with hypersensitive interoception are likely to find the physical experience of health examinations, sedation, recovery and wound healing to be very difficult. Aspects for consideration extend beyond the procedure itself. The sensory and interoceptive experience of tolerating dressings, wound care, accepting and tolerating pain relief and feed administration should all be robustly considered. Gastrostomy feeding is also a relatively costly healthcare intervention (Singh *et al*., 2021). For all these reasons, oral re-feeding is the preferred route and should be the first-line approach (Cucinotta *et al*., 2023). Each of these potential concerns should be considered within the context of a comprehensive and holistic risk and needs assessment.

With that said, nutritional change for those with ARFID is likely to be very slow and requires a low-pressure exploratory approach (Thomas *et al*., 2017). Gastrostomy placement should therefore be considered more quickly where there is a profile of:

- ➢ High nutritional risk cooccurring with multiple nutritional deficits
- ➢ Sensory or interoceptive difficulties which are likely to result in clinical distress arising from hospital admission (of either NG feeding or gastrostomy)
- ➢ Evidenced probability that clinically adequate nutritional change is likely to be too slow to manage the arising risks

In these cases, moving to gastrostomy feeding may provide the essential nutrition required to manage risk. This in turn reduces systemic anxiety, consequently creating the low-pressure environment that is necessary for oral nutritional change to arise whilst also improving psychological well-being (Findlay *et al*., 2011).

Recognising the Importance of Supporting Adequate Nutrition and Hydration

The described impacts are identified throughout the literature as occurring in low weight, normal weight and overweight individuals with ARFID (James *et al*., 2024). This is an important observation in ensuring that nutritional risk is understood separately from weight status. Weight and/or growth status should not be the defining principle of risk or considered in isolation.

Hydration

Hydration is of life-sustaining importance. Most available literature explores the risk of overhydration resulting from interoceptive difficulties, particularly in autistic individuals (Mills and Wing, 2015). However clinical experience and lived experience has consistently demonstrated challenges in achieving adequate hydration for those with ARFID. This is no more evident than in the case of Joshua Allcock whose coroner's report highlights that he died from severe dehydration due to limited fluid intake exacerbated by his (undiagnosed) autism and ARFID (Judiciary 2026).

In our collective experience, individuals may struggle to maintain adequate hydration due to a combination of anxiety, difficulties interpreting interoceptive signals and sensory aversions to the taste, texture, temperature, or smell of liquids: all of which can make drinking uncomfortable or distressing. In addition, fear of choking, vomiting, or gastrointestinal discomfort can extend to liquids, especially if the individual has had negative past experiences with drinking (Thomas *et al.,* 2017). Many carers of those with ARFID find that prompting fluid intake is an ever-present feature of their caregiver role. Some individuals may also exhibit strong preferences for specific brands, containers, or routines, and may refuse fluids if these conditions are not available. These sensory-preference limitations can lead to chronically low fluid intake, increasing the risk of dehydration-related complications such as constipation, fatigue, headaches, and impaired cognitive function (Bryant-Waugh et al., 2019) all of which result in the perpetuation of poor intake.

The complication of chronic constipation can be attributed to several factors. Functional gastrointestinal symptoms also remain high in this group together with pathophysiologic changes (Gibson *et al*., 2021). Factors causing constipation can also include co-occurring gastrointestinal conditions (such as irritable bowel disease or irritable bowel syndrome), Ehlers-Danlos Syndrome, the presence of dietary allergies or dietary fibre insufficiency. Additional to this literature, our clinical experience has also identified several people with ARFID and fluid restriction resulting in chronic constipation. When combined with sensory aversion to medication, this can create a vicious circle where constipation further reduces appetite and fluid intake, in turn worsening the constipation.

At its most serious, fluid restriction can result in repeated acute admissions and resultant invasive intravenous procedures to restore hydration. As such, fluid inadequacy, or the risk of episodic high-risk fluid inadequacy (such as at times of high stress or the lack of availability of a preferred drinking container), should be identified as indicators for considering gastrostomy feeding.

Growth and Pubertal Development

Nutrition is foundational to healthy growth and development, particularly during childhood and adolescence when physiological and cognitive changes are rapid and interdependent (Sawyer *et al*., 2018). Restricted dietary intake can compromise energy, protein and micronutrient availability which are essential for linear growth, bone health, brain development, and pubertal progression (Norris *et al*., 2016). The prevalence of amenorrhoea amongst those with ARFID has been reported to be as high as 10% (James *et al*., 2024).

Puberty is a critical phase of development characterised by complex hormonal, physical, and psychological changes. Adequate macronutrient intake is essential to initiate and sustain pubertal progression, with energy deficiency playing a key role in the delayed onset or progression of puberty (Soliman *et al*., 2014).

Delayed puberty is not merely a physical concern; it carries significant implications for long-term health and wellbeing. Physiologically, it can result in short stature, reduced peak bone mass, and compromised reproductive development (Golden *et al*., 2015). Psychological impacts arising from delayed puberty can include distress, social isolation, and poor self-esteem. This is of increased likelihood when individuals perceive themselves as different from their peers (Dwyer, 2020). These psychosocial impacts can compound existing mental health vulnerabilities and affect overall quality of life.

Children and adults may maintain normal growth and/or weight trajectories despite significant dietary limitations (James *et al*., 2024), masking underlying nutritional deficiencies or psychosocial distress. Therefore, clinicians should assess not only anthropometric data but also dietary quality, feeding behaviours, and developmental milestones/functional measures (Zickgraf & Ellis, 2018; Harrison *et al*., 2019; Jones, 2019; Judiciary 2021; Judiciary 2024;).

Brain Function

The brain continues to grow and reshape itself well into early adulthood in a process known as neuroplasticity. During adolescence and young adulthood, the brain is still developing,

which can make it more sensitive to external influences. Factors like poor nutrition and high levels of stress, often linked to eating disorder symptoms, can affect how the brain functions. These disruptions may interfere with important mental processes and emotional regulation (SLAM, 2025). Nutritional deficits which reduce cell size, cell volume, cell communication and brain complexity can result in impaired fine motor skills and lower IQ. This can lead to life-long impacts both within academic and social settings (Georgieff, 2007).

Although studies on individuals with eating disorders (particularly anorexia nervosa) may not be directly transferable to those with ARFID owing to differences in starvation chronicity, MRI studies on these populations have repeatedly shown significant shrinkage of grey matter volume. This has been found to primarily impact regions of the brain responsible for emotional regulation, attention and social interactions (Curzio *et al*,. 2020).

Overall, in starvation, patients experience higher levels of anxiety, a more rigid and rules-based thinking style, detail focused thinking style and difficulty in set shifting and global perspectives. Brain activity is affected by even modest dieting, with individuals struggling to make decisions, solve problems, regulate their emotions, or interpret social signals. If prolonged, these brain changes become permanent (Mainz, *et al.*, 2012; Zhang*, et al.,* 2024).

Due to the interoceptive difficulties that many patients with ARFID face, many individuals can go through prolonged periods without anything to eat or drink (NAS, 2020). Parents report that their child is more likely to become distressed when they have not eaten, and in turn this makes them less likely to be able to eat. Parents report that when regular enteral feeding is facilitated this can significantly improve mood stability.

Micronutrient Levels and Deficiencies

Individuals with ARFID experience significant challenges in achieving adequate micronutrient intake. A systematic review of 76 published cases by Yule *et al.* (2021) found that 69.7% of published ARFID-related cases involved scurvy (vitamin C deficiency) and 17.1% involved eye disorders secondary to vitamin A deficiency. Other frequently reported deficiencies included thiamin, vitamin B12, vitamin C and vitamin D. Furthermore, 62.9% of the cases reviewed involved individuals with a normal body mass index (BMI) or age-appropriate weight percentile, indicating that micronutrient deficiencies can occur even in the absence of underweight status. Earlier studies have also postulated that the incidence of iron deficiency anaemia is higher in autistic individuals (Sidrak *et al*., 2014; Mari-Bauset *et al*., 2015). If left untreated, micronutrient deficiencies can lead to significant long-term health consequences. This is corroborated by the findings of the systematic review and meta-analysis by James *et al* (2024). This review identified 22 individuals with ARFID as suffering from severe micro-nutritional deficiencies leading to clinical disorders. These included xeropthalmia (vitamin A deficiency), optic neuropathy (vitamin B12 and folate deficiency), Wernicke encephalopathy (vitamin B12 deficiency), severe osteoporosis (vitamin D and/or vitamin B12 deficiency), scurvy and pulmonary artery hypertension (vitamin C deficiency), rickets (vitamin D deficiency) and iron deficiency anaemia. Importantly, some of the most significant nutritional deficiencies were reported in healthy weight or overweight individuals.

Individuals with ARFID are therefore at risk of significant, life-impacting nutritional consequences. This is compounded by sensory sensitivities which inhibit the acceptability of various forms of oral micronutrient supplementation. This and many other experienced

limitations of treatment effectiveness are often mistakenly referred to as non-compliance, which incorrectly assumes behavioural controllability. Micronutrient risk therefore needs to be understood in the context of the individual's oral intake, the duration of the restriction, their sensory tolerance to take necessary supplementation and their sensory tolerance for adequate, time sensitive dietary change required for deficiency risk reversal.

Bone Health and Adolescence

Adolescence is a critical period for bone development, with up to 90% of peak bone mass typically achieved by late adolescence. If bone growth is impaired during this time - due to malnutrition, low body weight, or hormonal disruption - individuals may fail to reach optimal bone density, increasing their lifetime risk of osteoporosis and fractures.

Malnutrition and low energy availability can disrupt endocrine function, leading to reduced levels of sex hormones (oestrogen and testosterone), insulin-like growth factor 1 and leptin, alongside elevated cortisol levels. These hormonal changes impair bone formation and may accelerate bone loss (Misra & Klibanski, 2014). Once established, osteoporosis results in fragile bones that are prone to fractures from minimal trauma, and may lead to chronic pain, reduced mobility, and loss of stature.

Early intervention in eating disorders is essential to prevent irreversible bone damage. Nutritional rehabilitation, including a balanced diet rich in calcium, vitamin D and vitamin K, is fundamental to restoring bone health and supporting skeletal development (Weaver *et al.*, 2016; Golden *et al*., 2018).

Uncategorised Physical Health

One study found 44.9% (93 of 207) of children and adolescents with ARFID experienced physical complications secondary to energy insufficiency and low weight status (Katzman *et al*., 2021). These symptoms included lanugo, pale skin, dizziness, muscle wasting, headaches, hypothermia, constipation and cognitive problems.

The presence of electrolyte abnormalities has also been reported as between 23.1% and 73.7%. These have included hypokalaemia, hypophosphataemia hypochloremia and elevated bicarbonate (James *et al*., 2024).

Although the incidence of low heart rate and hypotension is not corroborated by the current literature, the risk of death from malnutrition is very real (Rice *et al*., 2000). ARFID carries a significant risk for the development of severe and profound physical health problems (James *et al*., 2024).

Holistic Needs of the Individual

Medication

Medication administration should be a factor of consideration for gastrostomy placement decisions. Our collective clinical experience recognises that due to sensory aversions, many individuals with ARFID will refuse medication. These medications may be required for comfort (such as light pain relief), or refusal may extend to critical preparations (such as

antibiotics or epilepsy medications). The former results in unfair levels of discomfort, potentially contributing to health inequalities, whilst the latter can result in emergency care admissions and/or episodes of preventable serious illness.

Likewise, not being able to medicate a child when they are ill or in pain is highly distressing for caregivers and they often must weigh up the benefits of accessing emergency care for intravenous cannulation against the distress this has on a high sensory-needs child. A gastrostomy tube may therefore be the most helpful mechanism to deliver regular nutrition, hydration and medication needs.

Psychosocial and Educational Impact: for the individual and the family

The all-consuming nature of ARFID can impact individuals and their families materially, relationally and affectively (LaMarre *et al*., 2023). It also has a significant educational impact for children and young people. Individuals often withdraw from social situations involving food or drink - finding themselves caught in an impossible trade-off between safety and freedom (Ruiz Fischer and Starr, 2024). This dichotomy can lead to isolation from family gatherings, travel, peer interactions, and cultural or celebratory events. It can also extend to broader socio-cultural participation, including in school and workplace environments where the consequences of the eating disorder can limit academic and career progression (Safi *et al*., 2022).

Daily activities such as grocery shopping may become highly restricted, often requiring specific brands, packaging, or preparation methods, which can result in financial strain and logistical challenges (Maunder and McNicolas, 2021). In severe cases, individuals may become entirely reliant on the safety and predictability of their home environment, leading to a complete withdrawal from external activities and environments (Weeks *et al.*, 2023).

Managing extremely avoidant and restrictive eating is not limited in impact to the individual only. The psycho-social impact on caregivers cannot be underestimated (Krom *et al*., 2021). Food disinterest and high interoceptive awareness can reduce appetite and increase fullness resulting in very long meal-time durations. Caregivers can find themselves spending several hours a day attempting to support, prompt and gently encourage an adequate safe intake which has a significant secondary psychosocial impact.

Societal expectations to feed children who are significantly and involuntarily resistant to varied and safe nutrition can also lead to a parental journey which is highly distressing. Caregivers often find their lives dictated by fixed food routines which can include travelling long distances to specific supermarkets for certain products or making multiple trips. They can find that they themselves are unable to join social engagements of their own, unable to enjoy holidays, and are placed under financial pressure from the need to purchase specific branded items. Caregiver attempts to encourage, support and accommodate those with ARFID can feel like a constant emotional entanglement which is highly anxiety provoking and full of worry and concern. This is particularly true where the individual may have low motivation to change (secondary to high anxiety over change) co-concurrently with high nutritional risk. The stress of managing a chronic health condition can cause significant changes in family functioning (Treasure *et al*., 2024). This can lead caregivers to lovingly, but inadvertently, apply accommodations to the anxiety-avoidant eating behaviour which can maintain the presentation (Wagner *et al*., 2020; Kumar *et al*., 2024). Similarly, secondary to

high parental concern and a desperate desire for nutritional safety, parents may unintentionally apply a high pressure to change. Despite their very best efforts and intentions, this is more likely to inhibit nutritional change and progress. This is a key feature of the early positive outcomes seen for the patients with non-weight-focused eating restrictions and gastrostomy placement in the Findlay *et al* (2011) paper. This cited a resolution in the power-struggle as a central determinant of the intervention's success.

Proving regular nutrition and hydration via gastrostomy tube is therefore likely to better and medication needs. Doing so may support improved energy, mood and engagement. It may enable caregiver anxiety to be reduced through allowing them to recognise that physical and nutritional needs are being met. In turn, this facilitates the low-pressure environment required to support oral food change over time. Regular nutrition may improve emotional regulation and support towards developing environmental tolerance of the other factors involved in socio-cultural engagements. For example, a person may tolerate a family gathering if there is no expectation to consume food. This is possible if their nutrition is managed discreetly (via gastrostomy) and if there is a safe space for them to retreat to during social 'food times'. Environmental adjustments in this way may then also mean that travel could be possible. Removing the negative impacts of food purchasing, variation and expectations could ultimately widen the 'safe world' of the sufferer.

For children and young people within school, the significantly restrictive intake can lead to an avoidance of food and eating spaces. Many will report a total inability to consume fluid and nutrition within school. Consequently, a young person will struggle to maintain energy levels and concentration across the day which will impact their learning capability. This is particularly relevant given evidence which notes that more challenging academic work has a higher glucose/calorie demand (Scholey *et al*., 2001). They are more likely to miss social engagement opportunities (such as break times) and be unable to participate in physical exertion - such as physical education lessons or breaktime play. Sustained periods of low intake will lead to low glucose levels which can impact cognitive function, attention and mood changes (Harvard Medical School, 2016). Consequently, children with ARFID are more likely to experience emotional dysregulation which can lead to withdrawn/shut-down responses. Such responses to manage these arising stressors can manifest as so-called 'challenging behaviour'. This may be observed within the education setting itself or noted when the young person returns to their 'safe space' (home). Not seeking to find an appropriate nutritional resolution to these challenges may contribute to an unfair and disproportionate use of disciplinary action. At its most severe, children and young people may entirely withdraw from education settings secondary to the impacts of their restrictive and avoidant intake.

Gastrostomy feeding may support discrete and low-pressure regular nutrition and hydration within an education setting. Doing so may support a return to education settings. For those already in school, enteral feeding may support improved energy, concentration and learning capacity, as well as supporting mood regulation and improving the potential for social engagement (if/as desired). Consequently, enhancing long-term academic, social-educative and health-economic outcomes.

Risk Considerations

All cases should be assessed for short-, medium-, and long-term risks of malnutrition, even when immediate growth markers appear within normal ranges. Poor nutrition can lead to reduced life expectancy and secondary health issues (Wickramasinghe, 2020). Risk assessment must be conducted across the four domains:

- Weight, growth and puberty
- Nutritional deficiencies
- Psychosocial impact
- Family functioning

The goal is to proactively identify and address risks that may lead to preventable conditions such as developmental delays, vision impairment, or other nutrition-related health issues. Reducing psycho-social harm should be equally well considered. Clinicians should also factor recurrent reliance on emergency care within their considerations.

Further risk considerations include the probability that the individual may pull out their gastrostomy causing injury and an increased risk of severe infection. There are no studies exploring this for patients with ARFID and few studies exploring self-withdrawal of NG feeding tubes in anorexia nervosa (Neiderman *et al*., 2001). Current clinical consensus acknowledges that intentional dislodgement is a common concern of families and professionals and that resultant associated risks can be very high, but the frequency of gastrostomy intentional dislodgement is very low. Although this may not be universally representative, to date, none of our consulted clinicians have encountered gastrostomy self-withdrawal within an ARFID population. With that said, to minimise such risks, consider careful counselling and prior planning using communication tailored to the individual to maximise pre-procedure understanding. Following meta-analysis of 13 non-ARFID adult studies, the proportion of accidental gastrostomy displacement was estimated as 10.8% (n=1644 tubes) (Farrugia *et al*., 2023). Consequently, the MDT may wish to consider the appropriateness of devices or clothing to mitigate against these risks. These considerations should be risk assessed and fully account for an individuals' sensory needs and sensory experiences. A post-operative care plan which includes details about what to do if intentional or accidental withdrawal occurs is also important.

ARFID Care and Treatment: Legal Frameworks

This section aims to give a perspective on the 'macro' level legal frameworks that clinicians need to be aware of when ensuring that those with ARFID are provided with the necessary nutrition and hydration in a way that appropriately respects their rights. It does not provide detail about the 'granular' aspects of legally defensible decision-making such as the assessment of the competence or capacity of a child or the role of those with parental responsibility. Such can be found elsewhere (ref: could be e.g. Children and young people under 16 and treating-16-and-17-year-olds-in-england-wales-ni-toolkit.pdf).

- **The Human Rights Act 1998 and the balancing act**

By operation of the Human Rights Act 1998 (UN General Assembly 1989), clinical teams must act in accordance with the obligations imposed by the European Convention on Human Rights (ECHR). Two key points arise in consequence.

The first point is that the obligations imposed by the ECHR are both 'negative' and 'positive':

1. Negative obligations are obligations not to do things, for instance depriving a patient of their liberty without following a procedure prescribed by law (which would give rise to a breach of Article 5 of the ECHR);
2. Positive obligations are obligations to do things, for instance the positive obligation under Article 2 ECHR to take appropriate steps to secure the life of a person at risk of death.

Clinical practice in relation to those covered by this guidance can usually – from a legal perspective – be seen as balancing these two sets of obligations.

1. The positive obligations explain why the clinicians are taking the steps they are taking (for instance to secure the person's life, as well as to ensure that they are taking them in a non-discriminatory fashion, for instance by appropriately recognising the impact of ARFID).
2. The negative obligations exist to ensure that they properly think through those steps, and also to ensure that there are appropriate checks and balances.

The second point is that, very often, the key question to be asked is whether the actions being proposed are necessary and proportionate.

1. If they are not necessary – i.e. for instance, there is no real risk to the person's life – then it would be very difficult to justify them by reference either to Article 5 (relating to liberty) or Article 8 (the right to respect for private and family life, incorporating the right to respect for autonomy);
2. Even if they might be said to be necessary, it is still vital to ask whether they are in fact proportionate to the gravity of the risk.

Asking the questions of necessity and proportionality is not only important legally, but it also enables the teasing out of whether the steps being proposed are clinically – and ethically – justified.

- **Ensuring equitable access to treatment**

Children and young people with mental health or neurodevelopmental conditions, including ARFID, often face disparities in access to treatment. Recognising ARFID within a rights-based framework ensures that individuals with ARFID are treated with dignity and respect, and that their unique needs are addressed in a way that promotes equity and inclusion.

In making arguments to ensure that children and young people with ARFID are treated equitably. From the perspective of domestic law, including such legislation as the Equality Act 2010, NHS commissioners and providers can find a highly relevant reference document for health inequalities and legal duties from: www.england.nhs.uk.

From a wider international human rights perspective, both the United Nations Convention on the Rights of the Child (UNCRC) and the UN Convention on the Rights of Persons with Disabilities support the need for equitable access to treatment, both as an aspect of the right to health, and to ensure that children are enabled to flourish more broadly. They operate differently to the European Convention on Human Rights as (with the exception of Scotland in relation to the UNCRC) they are not directly binding on clinicians. However, the UK Government, by ratifying the two conventions, has committed itself to bringing its laws and policies into compliance with them. They therefore provide a further set of tools to help frame the right course of action to ensure that those with ARFID access the care and treatment that they need.

The use of Education, Health and Care Plans (EHCPs)

An Education, Health and Care Plan (EHCP) is a statutory document in England for children and young people aged 0–25 years with special educational needs and/or disabilities whose requirements cannot be met through standard educational provision. The plan is legally binding and sets out educational, health, and social care needs within a single coordinated framework. This framework is relevant for many children and young people with ARFID where there may be co-occurring neurodevelopmental conditions and can be used to capture significant nutritional risk and associated mitigation strategies. This includes instances where an individual requires partial or complete nutritional support via an enteral route.

Equivalent processes exist more broadly across the UK. In Northern Ireland, needs are captured through a Statement of Educational Needs; in Wales, Individual Development Plans (IDPs) cover a broad range of additional learning needs; while in Scotland a Co-ordinated Support Plan (CSP) may be used for children with complex, multi-agency requirements. Regardless of jurisdiction, such plans are drafted in partnership with the child or young person and their family and are reviewed at least annually to ensure that provision remains appropriate.

Although gastrostomy feeding may be central to nutritional safety, many children with ARFID remain engaged in therapeutic work to promote oral intake. EHCPs should therefore reflect both immediate needs and longer-term goals.

For families, these documents provide security and clarity. They set out, in legally binding terms, what support a school or college must deliver, reducing the burden on parents to continually negotiate or advocate for basic provision. For children with ARFID who are fed via gastrostomy, this can mean reassurance that trained staff will always be available to administer feeds safely, that appropriate spaces and equipment will be provided, and that strategies which reduce anxiety around food will be respected. The plans act as a clear reference point for schools and education providers, ensuring expectations are explicit and consistent across all staff. It can also reduce variation in practice and avoid reliance on ad hoc arrangements, protecting children and young people from unsafe or unhelpful practices.

HCPs can contribute by providing written reports and attending review meetings, where appropriate. Effective contributions go beyond diagnosis; they describe the functional impact of health needs on education and participation. For a child with ARFID and gastrostomy, this

may include explaining that enteral nutrition is essential to sustain concentration and growth, outlining the risks associated with device care or dislodgement, and noting the effects of any food-related anxiety on classroom engagement and peer interaction.

It is important that contributions specify strategies which are effective and those which are not. For example, a child may benefit from gradual, non-pressured exposure to food in a quiet setting, but attempts to insist on oral intake are likely to heighten distress and resistance. Similarly, a minimum number of trained staff for gastrostomy management may be required to ensure safety during the school day.

Clinical Considerations in Emergency Placement

It is preferable that emergency gastrostomy placements for people with ARFID are avoided. Early education regarding the possibility of enteral tube feeding supplementation alongside thoughtful implementation is preferable (Bern *et al.,* 2024) as insufficient time is acknowledged as a factor that negatively affects decision making (Bucher *et al*., 2018). However, we acknowledge that there is large variation in commissioned services to diagnose and support people with ARFID, and large variation in the process for requesting gastrostomy placement. This variation, coupled with extended waiting times, can result in medical emergencies where the only treatment route available to restore nutrition and/or hydration is enteral feeding.

There is a continued need for gastrostomy insertion to be an MDT decision despite any emergency presentations (NICE, 2006). Therefore, it is essential to arrange urgent MDT discussion including community care teams where possible. The family and patient's wishes must remain a vital part of any emergency gastrostomy placement decision.

Familiarising the individual with their feeding tube options, and explaining what to expect before, during and after the procedure is essential regardless of the speed that a decision is required. This is to allow for safe and tolerated feeding following what could be an extremely traumatic situation for the individual and family.

Many individuals with ARFID have wider sensory sensitivities that need to be supported. From our experience, exposure to the feeding tube (holding/touching/familiarisation) and potentially a trial of a feeding tube belt, may improve acceptance and allow for a successful treatment outcome.

Considerations for Safe Discharge

Safe discharge and the provision of ongoing care is paramount following a surgical procedure for enteral feeding. Consideration must be given to complications and support for wound healing; HEF equipment access; individualised dietetic feeding plan adjustments; anthropometric and physical health monitoring and access to feed prescriptions. Furthermore, for those with ARFID, there should be robust consideration of the individuals:

- Need for psychological and emotional support
- Systemic support of the whole family

- Support and training for alternative care or environment settings (such as education settings, workplaces and community settings).

Lastly, gastrostomy feeding should not be pre-determined as life-long and final (Findlay *et al*., 2011). Depending on the individual's stage of recovery, tolerance levels and motivation to engage in pace-appropriate oral change - ongoing tailored behavioural, nutritional and psychological support to improve oral intake should remain available. This should come from the service with the therapeutic skills best able to support this need. In many cases, this is likely to mean that experts in enteral feeding and experts in ARFID-related behavioural change co-work in an agreement of shared care. Oral nutritional change remains possible following gastrostomy feeding and individuals should continue to be supported in their aims of recovery.

Nice CG32 (2017) is clear regarding the expectations for continued community care, citing:

1.9.2: *All people in the community having enteral tube feeding should be supported by a coordinated multidisciplinary team, which includes dietitians, district, care home or homecare company nurses, GPs, community pharmacists and other allied healthcare professionals (for example, speech and language therapists) as appropriate. Close liaison between the multidisciplinary team and patients and carers regarding diagnoses, prescription, arrangements and potential problems is essential.*
1.9.3: *Patients in the community having enteral tube feeding and their carers should receive an individualised care plan which includes overall aims and a monitoring plan.*
1.9.4: *Patients in the community having enteral tube feeding and their carers, should receive training and information from members of the multidisciplinary team on:*

- *the management of the tubes, delivery systems and the regimen, outlining all procedures related to setting up feeds, using feed pumps, the likely risks and methods for troubleshooting common problems and be provided with an instruction manual (and visual aids if appropriate)*
- *both routine and emergency telephone numbers to contact a healthcare professional who understands the needs and potential problems of people on home enteral tube feeding*
- *the delivery of equipment, ancillaries and feed with appropriate contact details for any homecare company involved.*

In view of the NICE guidance, dietitians should not offer continued care in isolation with any arising clinical incidents escalated appropriately through supervision and trust incident/governance structures.

Scope and Future Direction

Unfortunately, this work piece is limited to exploring the clinical considerations for gastrostomy tube placement for Individuals with ARFID. Future direction should additionally cover:

- ARFID specific feed-pace decisions, tolerance challenges and feed types
- ARFID specific wound care and post placement reasonable adjustments
- Clinically informed recommendations to support the practicalities of living with a gastrostomy tube for individuals with ARFID
- Clinically informed recommendations to support tube weaning / feed reductions, with ARFID specific tube removal considerations
- Paediatric to adult ARFID transitions with gastrostomy feeding/placement

- Strategic approaches to MDT and Allied Health Professional (AHP) partnerships and/or co-commissioning agreements
- The development of accessible information for patients and their families

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Professional Case Examples

The following dietetic case outlines are demonstrative of real clinical case examples which constitute consideration of gastrostomy feeding. They are examples for dietitians to reflect on and to apply learning from. The emphasis from these case outlines focuses on understanding the clinical rationale.

Case Example One

Brief clinical outline: 4-year-old autistic individual with a learning disability and kidney disease. The child is highly likely to require a low phosphate diet in the near future to manage their kidney disease, with a kidney transplant likely in the medium- to long- term. Their current nutritional intake is predominantly maintained by high phosphate formula milk alongside crisps, raspberries and blueberries, and chocolate. Due to their high milk intake, they are not energy deficient and are growing. There is a significant psychosocial impact from the avoidant and restrictive intake on the family. The child engages in some food exploration activities, mostly by touching foods, but these activities do not lead to increases in accepted oral intake. They are highly sensory-sensitive with a decreasing, rather than increasing, range of foods despite a comprehensive, multi-agency and MDT approach.

Rationale for gastrostomy:

1) Intake (energy and micronutrition through fortified milk) represents a very limited repertoire which cannot be maintained medium-to long-term
2) High risk of sudden loss of limited safe foods due to stress related to physical health, or imposed by the need for a low phosphate diet
3) Unable to accept nutritional supplements
4) MDT and multi-agency intervention has not improved intake or nutritional safety
5) Due to their autism and learning disability, their needs would likely benefit from a planned intervention. Gastrostomy feeding with a calm planned placement would likely produce a more positive experience and outcome compared with a medical emergency and NG placement. The latter of which would likely still lead to a long-term gastrostomy intervention

Case Example Two

Brief clinical outline: 9-year-old autistic individual with attention deficit hyperactivity disorder (ADHD) and Sensory Processing Disorder. They have lost a significant amount of weight, are underweight, tired, cold and with low blood pressure. Their diet is limited to 3 foods, and their estimated calorie intake is around 300 calories a day. They are highly triggered by smell, taste and texture of foods which causes gagging and retching and sometimes vomiting. They are unable to take prescribed oral supplements or vitamin tablets despite input from the local eating disorders team to support the integration of these

preparations, and this support has only minimally increased their total oral intake of energy. Height is recorded as 2nd centile but there has been no growth in 8 months. Fluid intake is very poor, and the individual cannot take medications. They enjoy horse riding and dog walking but have been clinically advised against continuing these due to the impact of these activities on energy demand.

Rationale for gastrostomy:

1) Highly limited, inadequate and unsafe nutritional intake with current, medium and long-term risks
2) Unable to treat ADHD with medication - no oral route, and unable to use pharmaceutical support for any other health or mental health needs.
3) Unable to accept nutritional supplements or micronutrient supplementation
4) MDT intervention has not improved intake or nutritional safety
5) Worsened physical health would lead to withdrawal from protective and quality-of-life factors (horse riding and dog walking)
6) NG placement would likely still lead to a long-term gastrostomy intervention and is likely to be distressing

A gastrostomy was placed and nutritional status significantly improved. The patient was discharged with weight at 40th centile and evidence of height growth. The parent reported: “we have our child back”.

Case Example Three

Brief clinical outline: 4-year-old child admitted with hypoglycaemia and dehydration to a paediatric ward following 20 days of no solid intake (only drinking milk and water) which escalated to a refusal of fluids immediately prior to admission. Avoidant presentation consistent with a fear of aversive consequences following a choking episode 2 months prior. Although the child resumed eating after this, they experienced an episode of illness 2 weeks later requiring antibiotics and began to reduce their intake and refuse medication following this. Prior to this, there was no history of feeding difficulties. The child had chronic constipation, and their bowels had not opened for 2 weeks causing pain and distress. During the 3-week paediatric admission, an NG tube was cited 3 times under anaesthetic, but intentional withdrawal occurred each time causing distress and trauma, and anaesthetic risk. The child was therefore only being treated with intravenous rehydration and dextrose. Physical causes were ruled out. ARFID expertise was consulted, and a gastrostomy placement was recommended.

Rationale for gastrostomy:

1) Inadequate and unsafe oral intake of both hydration and nutrition
2) Evidence of NG associated trauma without evidence of success from NG feeding
3) Intravenous hydration is an inadequate long-term solution and oral change highly likely to be a slow process that would not achieve nutritional safety within an adequate timeframe
4) Unable to take medications

Post gastrostomy Insertion (change within 4 weeks)

Discharge included dietetic and psychological care, including ARFID expertise. The child has regained energy, interest and strength. Parents and care-team are actively supporting a therapeutic approach to regain a full oral intake over time, using a relaxed and low-pressure play-based exposure approach. The child resumed an oral intake of fluids using this therapeutic approach and has started to lick food from fingers and ate a little ice-cream.

Case Example Four

Brief clinical outline: 8-year-old autistic individual with learning disability. He has recently had a vitamin C and D deficiency which affected his legs, and he was unable to walk, so he now requires a pushchair. He also had random nose bleeds, with frequent illnesses and infections. He does not verbally communicate. The child refuses all medications, vitamins and nutritional supplements including antibiotics and laxatives, and eats only specific brands of cheddar biscuits, nice biscuits, bread sticks and Doritos. He will often go for days without eating, particularly when ill and drinks water - up to 7 cups a day from a specific beaker. He will not accept multi-vitamins from this beaker as it changes the flavour. The child attends a special education needs school and enjoys this, but food intake is negligible. He shows no interest in eating in school but has started to tolerate children eating food next to him, and he will play with icing sugar and cocoa powder. He struggles to leave mum and will get very distressed when away from her. When he feels frustrated, he will scratch or bite himself and may also hit out towards others. He requires help in all areas of activities of daily living and is dependent on parents to keep him safe. There were no growth concerns as weight and height were both following the 25th centiles. The child is now being supported by the Child and Adolescent Mental Health Service (CAMHS), the Learning Disabilities team, Community Paediatrician and Dietitian.

Rationale for gastrostomy:

1) Highly limited and inadequate nutritional intake
2) High risk of sudden loss of safe foods
3) Unable to accept nutritional supplements or micronutrient supplementation
4) Limited communication impacts his ability to communicate his needs
5) Worsened physical health would lead to withdrawal from his protective and quality-of-life factors (school)
6) Due to his autism and learning disability, his needs would likely benefit from a planned intervention. Gastrostomy feeding with a calm planned placement would likely produce a more positive experience and outcome compared with a medical emergency and NG placement. The latter of which would likely still lead to a long-term gastrostomy intervention
7) Experiences increased distress and discomfort (as seen through his behaviour reactions) which appear to correlate to a lack of nutrition

Preparation for gastrostomy:
Parents met with Home Enteral Nutrition Support (HENS) Dietitians to discuss the different types of gastrostomy tubes and pump versus bolus feeding. Parents were concerned that the child would pull the tube out. The school spoke about allowing the child to have time to play with the feeding tube.

Post gastrostomy Insertion

CAMHS Team supported parents during the hospital admission for the gastrostomy. The child has adjusted well to having the PEG and has been helping parents to administer the feeds. Weight has increased to the 75th centile and he is tolerating the feeds well. Medical health and quality of life have improved.

Case Examples from the Voices of those with Lived Experience

Case Example One

A plea to all health care professionals to please listen to parents and young people.

Please try to understand that when we/they come to you asking for help, we/they have already exhausted all the usual "tips and tricks". We are forever hearing that early intervention is paramount. It absolutely is… but so many young children are being sent away or passed on to another service who have no understanding of ARFID. They are then passed back to the original service who don't know what to do with them. Referrals are rejected on the basis that the service "doesn't deal with faddy/fussy eaters". **Eating is different for everyone.**

For us, despite always having a very restricted diet from day one, R was generally healthy, active and happy so no HCP's were concerned. By the age of 10, things deteriorated and we sought support from our GP who completely dismissed our concerns. At this time, ARFID wasn't a recognised condition so perhaps it wasn't surprising. By age 11/12, she was barely eating at all. No breakfast, nothing all day at school and the bare minimum when she came home. Already underweight, she was losing even more weight and often felt faint and dizzy. She was misdiagnosed and subsequently mistreated with anorexia. She was taken out of school and **the trauma this caused was horrendous.**

At age 14 R desperately wanted to get better. She wanted to be well, healthy and to go back to school to be with her friends. She pleaded with her paediatrician and CAMHS for a gastrostomy. She personally asked several HCP's to please let her have one so that she can live her life again. She had already had an NG tube which had had some success; however it was removed on discharge from hospital. The response to her request was: "If you want your life back that badly, you will eat more to make it happen". **They didn't understand that it wasn't that she wouldn't eat it, it was because she couldn't eat.**

At age 20, under adult services, R was finally fitted with a gastrostomy feeding tube after a multidisciplinary meeting. This included her dietitian, gastroenterologist, psychiatrist and her care coordinator. While we were very grateful and hopeful, it sadly came too late for her. By this time, all her friends had gone to university, got jobs and moved on with their lives. She had been chronically underweight and malnourished for so long that she had developed other health conditions and some of these were irreversible. These included osteoporosis, scoliosis, irritable bowel syndrome, chronic fatigue syndrome, and nerve damage due to a long term folate deficiency. Her mental health deteriorated so she found it increasingly difficult to engage. Her emetophobia was significantly exacerbated by NG feeding, so

tolerating the gastrostomy feeds was difficult initially and is now impossible. **She is currently considering having the PEG tube removed.**

Would things have been different or better if she had been given the gastrostomy at 14? We'll never know, but I honestly believe that she would have found it easier to accept the feeds as she was in a much better place. Her mindset was so different. She was more positive, she had a peer group to return to and a chance to complete her education with her friends. Her emetophobia had been dormant for some time, so that would have made the feeds easier to accept.

Now? Her emetophobia is the worst it has ever been, she has no friends, no motivation and her self-esteem is at rock bottom. She has no quality of life. **What is more sad, is that she is not the only one.**

Over in a parent/carer group I am a part of, there are many, many older teens and young adults who were not listened to. They were passed between services, accused of not engaging, misdiagnosed, denied enteral feeding as an option to re-feed and gain weight, and become nutritionally balanced. Many were left far too long before support was offered and reached crisis point before any intervention.

Please, listen to the young people you see. Please listen to the worried parents. No one expects a miracle. We are not looking for a cure. We don't expect you to wave a magic wand and make ARFID go away. **What we want is empathy, understanding, support and honesty.**

The HCP my daughter had her very last appointment with, apologised. Her parting words were "I'm so sorry you were not listened to. I'm sorry we didn't research ARFID when you asked us to. Please don't sue me".

Case Example Two

Dude (parent chosen pseudonym) was diagnosed with ARFID at around the age of 2.5 years, after input to encourage eating by community dietetics, speech and language therapists and the complex feeding team wasn’t successful. We (his parents) were the ones that initiated the discussion about a gastrostomy, roughly a year later, as he was rapidly dropping safe foods. He was so underweight that his ribs, spine and hips were clearly visible. He was lethargic, always tired and very emotional. His hair and nails were in a bad condition, he had a yellow tone to his skin, and he struggled to concentrate on anything. At first we were given a blanket refusal. This was because the dietitian said she would absolutely not consider it as she believed it would make his eating worse. Instead, she said that we needed to work on getting him to eat more instead. **We didn’t push too much after that, out of fear of being accused of FII**. We knew many ARFID parents who had been, or were going through, this.

Going back a bit - Dude was a premature baby with severe jaundice, reflux, a dairy allergy (which he has since outgrown), and spent his first two weeks in the neonatal intensive care unit. He had been NG fed for ten weeks from birth and really didn’t tolerate it well at all. We

very much believe that this contributed to his food aversions. He can't tolerate things up his nose and we knew that something that had to remain in place down the back of his throat, would be really traumatic for him. The Complex Feeding Team agreed.

He couldn't swallow any medication or vitamins, even when severely poorly. At the age of 4, this also caused him to need a 2-week infusion of intra-venous antibiotics at home for a chest infection. It became so severe because it was left unrated for 6 weeks as the GP didn't believe us when we said that he couldn't take anything orally.

The older he got, the worse it got, so we struck up the conversation again just before his 6th birthday.

He finally got his gastrostomy in August 2024 - nearly 5 years after diagnosis.

We have definitely seen an improvement since he had the gastrostomy inserted. He has much more energy, his nails and hair are recovering, and his skin is pinker. He is catching up more at school and his attention span has increased. He has also gained weight and height. We have gone from him still fitting into his aged 2-3 clothes in August, to now being in age 6-7 clothes just 7 months later. Curiously, we have found that he seems to be going through developmental/behaviour milestones that he missed such as having tantrums, pushing boundaries, and lying etc. We weren't prepared for this, but in trying to understand it - it's like his body and brain now have the energy they need and so they are playing rapid catch up.

Right from when we first mentioned our concerns, up to him actually having it fitted, there are many things we wish we could have done differently. Some examples include:

- Pushing more for the clinical reasoning and pushing for a better plan of action when tube feeding was first refused. As mentioned above, we were worried about being accused of FII. It's awful that there are families who have been put under Social Services due to them advocating for their children because a HCP has decided that it's the family's/parent's fault
- Doing some more research ourselves in the early stages
- Once the gastrostomy was fitted, we would rather the dietitian and surgeon had communicated better with us and with each other. The dietitian wanted him to complete a 'water test' before a feed (checking how much water came back after an hour) but he kept failing. The surgeon said "don't bother, give him a feed". It turned out that he was absolutely fine with the feed approach.
- A more cohesive approach from all the teams involved in his care.

Case Example Three

My little one (LO) is seven years old and has struggled with eating since she was 18 months old. I expressed concern multiple times to the Primary Health Care team but I was told it was normal despite her continuing to get worse every year.

It has been four years since my LO has eaten solid food. In 2021 she had a vomiting bug which resulted in a hospital admission. Prior to the vomiting bug we had 6 safe foods. While we were in the hospital, so much pressure was applied to get her to consume more than water. They treated me like I was negligent when I told them how little variety she has. She was put on a drip to get her hydrated, was denied discharge, and one doctor scolded me for wasting their time. It was extremely traumatic for both of us and after this she refused all solid food. Luckily, she finally accepted cows' milk and homemade smoothies. This was her diet for 2 years until the summer of 2023.

After the hospital admission I went on a deep dive into extreme fussy eating and discovered ARFID. I knew immediately that this is what she had. We started with a psychologist in Primary Care. I expressed that I suspected ARFID and autism but felt dismissed. After 8-months of treatment I received a letter stating that he thinks she may have ARFID afterall and it was beyond his scope so there would be no further support. A dietitian in primary care agreed to keep an eye on LO's physical monitoring every 4 months but admitted that she knew nothing about ARFID. LO always plotted on the growth curve and maintained 75%W4H.

We went to the GP twice during this time to see if we could get additional help. One doctor told me to stop filling her up with water and the other said "if she was normal, she would eat. She won't die" **I have never felt so let down, alone and terrified before. It's an extremely isolating disorder.**

Most professionals we met cared and wanted to help but they admitted that they had little knowledge or skills on ARFID. Everyone reassured me that we are doing everything right, but she continued to get worse.

In June 2023 she stopped having the smoothies and survived solely on super milk (cows'). Sometimes with Nutrigen multivitamins hidden in it. This was an extremely hard summer. LO was hungry a lot and would get upset/tired easily. We were restricted to where we could go as we needed to be home so LO could have her milk in front of the TV. We were terrified of losing milk and didn't want to put any pressure on her to drink it but we also needed to make sure she was getting enough so she would have energy. Hiding vitamins in her milk became a struggle. There was a constant fear of her getting ill and having a temperature that we couldn't bring down because LO would never accept medicine. **We lived in constant fear and anxiety which in turn affected both our daughters.**

In September 2023 we got an appointment with a specialist feeding team. They immediately diagnosed LO with ARFID. **It was such relief to finally be listened to and believed.** After that we had parent group sessions on ARFID. We had one OT appointment with LO and five online psychology appointments. Unfortunately, we were outside the catchment area so they couldn't offer us any more than that. It was really comforting meeting other parents, but we didn't really get much else from the meetings. They then wanted to discharge us back to the Primary Care team with the promise of them training them up on ARFID. This never happened while we were there. The local occupational therapist also put our sessions on hold as she felt she couldn't support us as we were too complex.

In October 2024 we started discussions with the feeding team to have a PEG as LO's iron was extremely low and her energy levels were being massively affected. Our dietician continued to monitor her and assured us that she was getting everything she needed from the super milk, with the exception of the Iron, but my instincts were saying otherwise. **No one could tell me how it would affect her in the future**. The paediatrician in the feeding clinic agreed and sent a recommendation for a PEG for LO.

Emergency PEG Procedure

In October 2024 LO was diagnosed autistic. In December she hit an all-time low. She had been masking autism for such a long time along with physically deteriorating and her body went into burn out - becoming extremely erratic and dysregulated and dropping her milk intake. She hid away from everyone and talked about wanting to die. She eventually stopped drinking water and milk. We took her to hospital where she was given a glucose drip.

Two options were offered to us: one was to have a NG tube inserted which could be done immediately or to have the PEG placed which depended on surgeon availability. The whole experience was traumatic and it was such a hard environment to make such a big decision.

My LO can be extremely sensitive and also aggressive so we agreed that she would not tolerate the NG tube and chose the PEG. It felt cruel to put LO through surgery when she was already really unwell but we felt we had no other option.

We attempted to explain all this to my LO but she was in no state to listen to anything. She was in a state of constant dysregulation.

After the surgery - recovery was extremely hard. We spent the next five days in the hospital where she was afraid to move. We were in a dorm room with very little space and a curtain separating us from other families. I slept on the floor beside her and had to move every time a nurse came to check in on her. She repeatedly wet the bed and wouldn't let anyone touch her. She had lost all autotomy. She couldn't understand why it was done to her. She kept repeating "I just went to sleep and then they did this to me". She was angry at me and my husband for letting it happen. It was a very traumatic time for all of us and our other 5-year-old daughter. It was right before Christmas, and I hadn't seen my other daughter for a week. I missed her first school play and she missed her sister. LO was discharged on Christmas eve and Christmas didn't really happen for us that year.

In the hospital we got into a good routine of giving her the feeds and we had to adjust this when we got home. It was trial and error to see what worked best for her.

Aftercare

When we got out of hospital, we found out that we had even less support than before.

- Because of the tube we were deemed too complex for the Primary Care team, and we were told we should be with the Children's Disability Team.
- We were on the waiting list for the CDNT but were told the waiting list was around two years and that even then, they didn't have anyone qualified to support us with ARFID.

- The hospital discharged us saying they could no longer support us as we are not in their area and that we should be under the main hospital team or Children's Disability Team.
- The main hospital discharged us saying we should be under the other hospital or CDNT.

We were left with NO ONE supporting us. Finally, the main hospital dietician agreed to support us until we found someone else. I wrote countless letters to everyone including our GP. The dietician has been really helpful. The main hospital paediatrician also agreed to look after us so we currently have appointments every 6 months. We are on the waiting list for support within the Children's Disability Team but they continue to tell us that they don't have anyone trained in ARFID. So, in summary, we are still without a team.

Trying to navigate all of this whilst looking after my very traumatised daughter and maintaining a happy household for my youngest was an extremely challenging time. **Absolutely nothing was in place when we left the hospital in regard to ongoing support.** The school had never dealt with anything like this before and were unsure of how to support us.

After returning home, it was like having a newborn again. She couldn't do anything for herself and refused to leave the house. She was traumatised, angry and resentful. We explained everything numerous times to her until she understood.

After a couple of months things started to improve and she became healthier and happy. We were able to give her iron directly through the tube which was such an incredible relief to us. She got sick a few times - the first was a urinary tract infection and we were able to give the antibiotics for the first time in years along with Calpol. All through the tube.

Today (October 2025)

It has been nine months since the procedure and it's like we have a new person. She takes care of the tube herself. She cleans and twists it at nighttime. She can fix tape herself. She owns it and is not afraid or ashamed to show it to her friends. She currently accepts three feeds a day with the pump and a bolus feed which is administered by a Special Needs Assistant during school which meets her nutritional requirements.

We don't have the constant worry of whether she is getting enough nutrition, or constantly checking the time until she needs to go home to give her milk. I have had so many sleepless nights worrying what this was all doing to her body and how it would affect her physically in the future. Coming into winter was always the hardest time for us. The constant fear of her getting sick and not being able to give her medicine was exhausting - not only for us as parents but to our whole family. We can go out for longer during the day. We can relax knowing she is getting everything she needs for now.

My LO still does not take anything orally, but she is exploring food by touch again with absolutely no pressure to try it. Our hope is that she will one day want to try it for herself.

The hardest part of it all was the trauma of the emergency situation and accepting the feeding tube after the surgery. All control was taken away from my LO which affected her massively. I wish we had more time to explain what was going to happen, do some play therapy and give her time to accept it. I feel the recovery would have been a lot easier.

Looking back, I wish we had the option of getting the tube back when LO stopped having the smoothies and she only had one safe food left. At that point I feel there should have been the option of having a tube. **It would have saved us years of anxiety and upset ultimately making it harder for LO which resulted in an extremely traumatic experience.** I believe our family could have been prepared. We could have requested a private room given that LO was autistic and wouldn't deal well with a noisy room. We would have been able to fight for ongoing support before the procedure and have had a plan in place. All this happened at the worst possible time and we are all still traumatised by the experience. **The PEG has been the best thing to happen to us in a very long time. The constant worry is gone**. We are still very concerned for LO's future and still don't have appropriate support, but we are managing so much better than before. We are slowly getting our lives back.

Case Example Four

Our daughter (G) has always had a small appetite despite eating a range of foods during weaning and into early childhood.

G's eating problems began to worsen around the age of 11-12. She developed epilepsy and after a seizure would vomit or feel nauseous. This developed into a fear of being sick. Her mouth would be sore after a tonic clonic seizure from biting her tongue which would also limit food intake. She started on a cocktail of drugs, some of which also reduced her appetite. About a year after her seizures started she had a bad COVID infection and her food intake dropped dramatically after she lost all appetite. She often felt sick which was probably due to hunger but she failed to recognise hunger signals. She lost a lot of weight and her growth stalled. She was referred to a dietician and prescribed nutritional shakes but she couldn't tolerate the taste or they made her feel sick. Her food intake was very limited and she would eat the same food for a number of weeks then sicken herself with it and lose that food. This is a worrying pattern that still happens.

G started to struggle with her energy levels. She struggled to stay in school as she couldn't tolerate the smell of the school lunch hall so I had to bring her home for lunch each day. She often didn't have the energy to complete a full school day and started napping more during the day. There was a concern G would not hit puberty if the eating problems continued.

As a result, G was referred to a CAMHS eating disorders clinic and they confirmed she didn't have anorexia or bulimia but did have restricted eating. Unfortunately they didn't have a pathway for ARFID so we were discharged under the care of her epilepsy paediatrician and her hospital dietician. She was lucky to have psychological support from the epilepsy team as her mood really started to suffer and she would admit feeling like she wanted to selfharm. The team were brilliant with her mood problems but said that low nutrition was probably contributing to how her brain was reacting however they couldn't help with the eating part.

We were very lucky that the paediatrician, psychologist and dietician all talked to each other and communicated very well. We had some joint sessions with the psychologist and dietician around the food and nutrition issues.

None of this support led to G eating more and a few months later she had a NG tube inserted. We didn't know whether this was the right decision but we were lucky that G was at an age where she could have discussions with the team and had come to the decision herself. She decided that it would be preferable to eating. **She wanted to eat but her brain kept telling her she couldn't.**

G was admitted to hospital to start her feeding plan. Initially she really struggled with the feeds and would vomit after or feel so unwell they would have to stop. Her little body was so unfamiliar with the feeling of food in her stomach that we had to slow the feed down to the lowest rate and build up very gradually over a month or two. Due to this, her weight increase was slow but we started to see improvement in her energy levels. She was able to take some food orally but again her diet was very limited.

She had the NG tube for a year. Changing of the tube was very traumatic and as there was no real improvement in her oral intake over all that time, she was listed for PEG surgery.

G was worried about the surgery and the hospital stay… She had got used to the NG and was hesitant with change but again with support of the team she agreed to go for the PEG. G loved dancing and had been performing on stage with an NG for over a year and the thought of being able to perform and put on a full face of make up without the tube was the incentive for her. **She was also glad the PEG would be hidden and people would stop staring at her at school and asking why she had the NG tube.**

Immediately after the surgery G was in a lot of pain and was having regrets about having it done. Walking was painful initially but after a few days in hospital she managed to come home and a few weeks after that she started to return to light dance training. By 6 weeks after she was pretty much back to normal. We started on night feeds as this suited G much better as her rate of feeding was so slow she could allow it to trickle through overnight. Doing this freed up her evenings where she would normally be having a NG feed too. Her stomach initially struggled with feeding overnight but we reduced the volume and over time it has settled. She also had problems with granulation tissue but the nursing team helped sort that.

We are now 6 months post PEG surgery, G is back to dance and as her energy levels have improved so much she is taking more classes. She is managing better at school and naps much less often. Her oral intake is still very limited and we lose and then find new safe foods often. She still comes home every lunch time. She still gets frustrated with her eating and often knows she wants something but doesn't know what. She still struggles with hunger and thirst cues and is awaiting an autism assessment. Her mood has improved and although she still has the teenage ups and downs she is no longer under psychology.

We have been on this ARFID journey for around 2 years now. It has been tough and long. Socially, so many celebrations revolve around food but now our family are aware that G will not sit at the table or won't eat if she is sat with us. We never pressure G to try anything and when she does try we offer a lot of praise even though 95% of the time she doesn't like it or want to eat it again. We will still rush to the shop at ten at night if she wants to try something specific and if we make something and it's another failure we don't comment on it… it's been a huge learning experience for her and us as a family. It affects the whole family and where / how we eat… however **we managed our first trip abroad as a family since this all started. This was a huge step as G would not have had the energy previously to manage such a holiday.** It was another learning experience and G struggled with the menus in a different language. We were mainly self catering which helped and she found some foods she would take orally. Her feeds came with us on a long car journey and apart from the odd day off she managed to continue with these.

The learning process continues for us every day. Talking with other ARFID parents in social media support groups has helped, and G learning there are others out there with the same problem has helped too. **We have learned to take it a day at a time and hope that one day G will no longer need the PEG but in the meantime we know that the NG tube and PEG have been life saving and as long as she is getting the nutrition she needs we don't mind how that is achieved.**

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Lived Experience

Several experts by carer experience (caring for adults and children with ARFID) have contributed to this work by sharing direct experiences, informing or reviewing this body of work. To maintain anonymity of their loved ones, their contributions are included anonymously.

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Disclaimer

This document represents a clinically robust consensus on the use of PEG care in the care and treatment of ARFID. It is not a clinical guideline, original research piece or national directive.

Glossary of terms

AHP	Allied Health Professional
ADHD	Attention Deficit Hyperactivity Disorder
ARFID	Avoidant Restrictive Food Intake Disorder
BDA	British Dietetic Association
BMI	Body Mass Index

CAMHS	Child and Adolescent Mental Health Service
CSP	Co-ordinated Support Plan
ECHR	European Convention on Human Rights
EHCP	Education Health and Care Plan
ESPGHAN	European Society for Paediatric Gastroenterology Hepatology and Nutrition
FII	Fabricated and induced illness
GP	General Practitioner
HCP	Health care professional
HEF	Home enteral feeding
HENS	Home Enteral Nutrition Support
IDP	Individual Development Plans
IGF-1	Insulin-like growth factor 1
MDT	Multidisciplinary team
NG	Nasogastric
NICE	National Institute of Clinical Excellence
PDA	Persistent Demand for Autonomy / Pathological Demand Avoidance
PEG	Percutaneous Endoscopic Gastrostomy
SPD	Sensory Processing Disorder
UK	United Kingdom
UNCRC	United Nations Convention on the Rights of the Child

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