SMALLTALK

PAEDIATRIC NUTRITION MAGAZINE FOR HEALTHCARE PROFESSIONALS

GROWTH

Putting children at the centre of every clinical decision

102

Spring 2023

Meet the Editors

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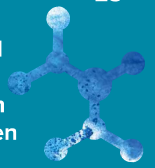

Regulars

Published by Nutricia Ltd.
White Horse Business Park,
Trowbridge, Wiltshire BA14 0XQ

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Feed your mind

Welcome

Welcome to the first Small Talk edition of 2023!

The English Poet, William Cowper first said in his poem, "The Task" that "Variety's the very spice of life, that gives it all its flavour."

By doing a range of different things within our working life, it helps us to learn, keeps us motivated and relieves any daily monotony. I have certainly never been the type of person to be happy doing the same thing, over and over, everyday. This got me thinking, of all the different roles you could have within dietetics and nutrition, is there any as naturally varied as the paediatric dietitian?

If you've never really stopped to think about it, have a browse through this edition, and you'll soon notice the breadth of paediatric dietetics!

We have an excellent article on Avoidant Restrictive Food Intake Disorder by specialist paediatric dietitian, **Rosan Meyer**, who touches on the role and responsibility of dietitians, and the dietary management principles, in the treatment and management of this condition within the paediatric population.

Catherine Kidd, Cardiac and Intensive Care Dietitian from Great Ormond Street Children's Hospital, shares the challenges of feeding preoperative cardiac infants, which include risk of malnutrition, and her fantastic top ten tips.

Finally we've summarised a fantastic article from **Chris Smith, Heather Grant and Laura Sealy** that outlines how feed intolerance can be managed by looking at what we feed, how we feed, and when we feed. What is most important in dietetic practice is that despite either the presence, or absence of clinical data and guidelines, it is always essential to put the child at the centre of every choice and decision! The case studies we have included in this edition of *SmallTalk*, show how patient choices and preferences were key to getting the best nutrition to the child at the time to bring about improved health outcomes.

If you have any feedback, any questions for next edition's, "Ask the Expert", or would like to contribute to by writing an article, we'd love to hear from you.

With best wishes,

Owen

Get in touch

If you have any feedback, any questions for our next edition, ask the expert, or would like to contribute to our next edition, we'd love to hear from you.

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DIARY DATES

13
JUNE 2023

KetoConference

WHERE: The Crown Plaza, Newcastle, NE1 3SA

MORE INFO: nutricia.co.uk/hcp/events/ketoconference-2023.html

20
JUNE 2023

Nutricia Allergy Conference 2023

WHERE: Crowne Plaza Birmingham NEC

MORE INFO: nutricia.co.uk/hcp/events

16–17
OCTOBER 2023

Nutricia Annual Congress 2023

WHERE: Royal Society of Medicine, London

MORE INFO: nutricia.co.uk/hcp/events.html

INTERNATIONAL EVENTS

17–20
MAY 2023

55th Annual Meeting of the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) 2023

WHERE: Vienna, Austria

MORE INFO: espghancongress.org/register

7–10
JUNE 2023

46th European Cystic Fibrosis Conference

WHERE: Austria Center, Bruno-Kreisky-Platz 1, 1220 Wien, Austria

MORE INFO: ecfs.eu/vienna2023

9–11
JUNE 2023

European Academy of Allergy and Clinical Immunology (EAACI) Congress 2023

WHERE: Hamburg

MORE INFO: eaaci.org/events

A DAY IN THE LIFE OF

Medical Affairs Research Manager

We both joined Nutricia during the COVID-19 pandemic in 2020 and have been Medical Affairs Research Managers for the past two and a half years. Prior to this, we had spent several years conducting clinical research in academia.

Starting the job remotely was quite challenging, however, from the very beginning we felt welcomed into the company and received plenty of support from our team. We built relationships with our colleagues, external healthcare professionals (HCPs) and NHS research and development (R&D) teams while working from home and were eager to meet everyone in person after a year of email exchanges and virtual meetings.

As Medical Affairs Research Managers we design and lead multi-centre case studies and clinical trials for new medical nutrition products used in the dietary management of a wide range of conditions, to enable their use on prescription in the UK and Irish healthcare systems. Our days vary significantly depending on which research projects we work on and the HCPs we interact with.

> **Every day is different: that's why we like our job!**

At the beginning of each project, we write study-related documents, prepare applications to be reviewed by the ethical board, interact and train HCPs on our trial processes, and liaise with NHS R&D departments to gain local approval to run studies at their sites.

During and at the end of each project, we support HCPs, monitor the trial progress, analyse trial data, work on regulatory submissions to gain approval for use on prescription, write scientific manuscripts, and present results at scientific congresses. Depending on the trial design and target population, each trial may last around 12–18 months. Working closely with HCPs to build long lasting relationships is key to ensure that our research and our products are patient-oriented and meet their clinical needs. It is rewarding to see the benefits that collaboration on research can bring.

We love being part of a company that believes in innovation and is at the forefront of clinical research that supports evidence-based practice. We all have the same goal; to improve the quality of life for patients by offering scientifically robust nutritional products.

CATHERINE KIDD
Cardiac and Intensive Care Dietitian, Great Ormond Street Children's Hospital

Challenges of feeding preoperative cardiac infants

Introduction

There are two main categories of cardiac conditions requiring dietetic input:

1. Congenital heart disease (CHD): structural abnormalities in the four main chambers of the heart and/or the great vessels. CHD makes up 1/3 of all congenital abnormalities and 0.6%–0.8% of live births. Many patients within this group require surgery within the first year of life and is the largest category of cardiac patients requiring nutrition support.[1]
2. Cardiomyopathy: a group of diseases of the heart muscle, affecting contraction and/or relaxation. Patients require nutrition support where 'normal' heart function is not achieved with medication. Some require artificial heart support (Berlin heart) or a transplant. A devastating diagnosis, though fortunately rare.

Causes of malnutrition in CHD patients

Malnutrition results from insufficient nutrient intake or utilisation for normal growth and development. Rapid breathing affects appetite and feeding skills. Poor splanchnic circulation (around abdominal gastrointestinal organs) is common. This can result in early satiety, vomiting and reflux. Furthermore, cardiac infants may have energy requirements that are greater than healthy infants. Some cardiac infants have fluid restrictions to reduce excess pressure on the already struggling heart. With all these causes of malnutrition, adequately nourishing an infant with CHD can be a real challenge.

Outcomes of malnutrition in congenital heart disease

Faltering growth can be common in this patient group. It is essential to regularly assess:

1. Weight – to gauge growth pattern and tissue acquisition. Up to a quarter of patients have marked wasting, as severe as malnutrition in developing countries.[2]

2. Length – provides a better indication of long-term nutrition. Stunting in this patient group is also common.[2]

3. Head circumference – neurological development may be adversely impacted.

Children who are better nourished presurgery can sometimes have improved postoperative outcomes. For example, reduced infection, shorter hospital stay, less time on a ventilator and lower mortality.

Continued Professional Development

- Faltering growth can be common in preoperative cardiac patients. What outcomes of malnutrition would you regularly assess?
- Consider the top ten tips, and discuss with your colleagues which of them you find most relevant.
- Which resources could you use to improve your clinical practice?

TEN TIPS FOR FEEDING THE PREOPERATIVE CARDIAC INFANT

District general or community dietitians are the unsung heroes, supporting parents through this challenging and stressful time. For the number of cardiac infants on a community dietitian caseload at any one time, these patients often take up a disproportionate amount of dietetic time. So here are my top 10 tips which may help with their management:

1 Use the DELPHI guidelines[3]. This consensus-based nutritional pathway provides advice on nutritional requirements and dietetic support depending upon: level of nutritional risk of diagnosis, growth pattern and feeding route.

2 Prioritise breastmilk wherever possible. Breastmilk is the feed of choice for all infants, particularly cardiac infants. It can help to support maturation of the digestive tract, development of a healthy microbiome and improve feeding tolerance.[4]

3 Be proactive rather than reactive to support growth. Where breastmilk is not available, or growth from breastmilk alone is inadequate, consider nutrient dense ready-to-feed formulas. If the infant becomes fluid restricted, their nutritional intake will drop, so consider a high calorie formula immediately.

4 Avoid concentrating feeds and adding modulars where possible. Where patients present with poor gastric perfusion and gastric tolerance, concentration of feeds and addition of modulars increases osmolality of feeds. This can further slow gastric emptying, thus increasing vomiting and reflux.

5 Consider hydrolysed feeds for tolerance. Hydrolysed feeds, where the protein is broken down into peptide chains, may be better tolerated than whole protein options. This does not necessarily suggest a cow's milk protein allergy, but instead is a cardiac-related feed tolerance issue. Where amino acid feeds often have a higher osmolality, they should be used with caution.

6 Always assess for heart failure symptoms. Is the patient hot, sweaty, clammy or short of breath, particularly during feeding? Are they gaining weight rapidly, which may indicate fluid retention? Any concerns about these symptoms should be immediately flagged to their cardiac specialist centre.

7 Consider medications. Although essential to avoid over-medicating and polypharmacy, many cardiac infants require laxatives (as their fluid restriction may cause constipation) and anti-reflux medications. Discuss with their prescriber, usually a GP or cardiologist.

8 Fluid restrictions are an essential part of medical management to reduce fluid load on a struggling heart. This can cause challenges from a dietetic perspective, as we must achieve adequate macro and micronutrient intake in a smaller volume. They are determined by the cardiology team and may change during the preoperative journey dependent on the child's heart function, so regular liaison with the medical team is vital.

9 Look at the wider network of support for patients. Working together effectively as a multidisciplinary team can help support parents during an immensely stressful time to avoid parents feeling 'stuck in the middle' of conflicting advice. It is essential we adopt similar strategies and all pull in the same direction. Acknowledge that the emotional and financial burden of having a cardiac baby is immense. Some parents have reported the feeding challenges being their main concern during this time, over and above their child's heart function, as feeding is such an integral part of parenting.[5] Consider what support groups might be available locally or through their cardiac centre.

10 Understand the severity of the diagnosis, and how this may impact on parents' lives, as well as the nutrition of their baby. The most severe CHD diagnosis fall into a category of having 'single ventricle' circulation (one ventricle supports the pulmonary and systemic circulation); these infants need multiple stages of surgery and are at their most vulnerable between stages 1 (which happens during the neonatal period) and stage 2 (which happens around 6 months of age). Other infants may have one major surgery during infancy, after which they are able to manage nutritionally quite well.

Useful resources

- **'For babies who need to make the most out of every mouthful' –** recipe book series produced by Southampton Children's Hospital charity with information about 'normal' weaning advice and high calorie recipe ideas
- **'Information on feeding for infants with congenital heart disease' –** leaflet produced by Southampton Children's Hospital charity which includes patient stories and general feeding advice
- **Little Heart Matters –** this charity is geared up towards the care of infants with single ventricle circulation (eg hypoplastic left heart syndrome)
- **British heart Foundation –** this charity has produced information booklets explaining different CHD diagnoses in easy-to-understand language
- **Check with the surgical centre caring for your patient** what patient information sheets they may have already given out, or would recommend.

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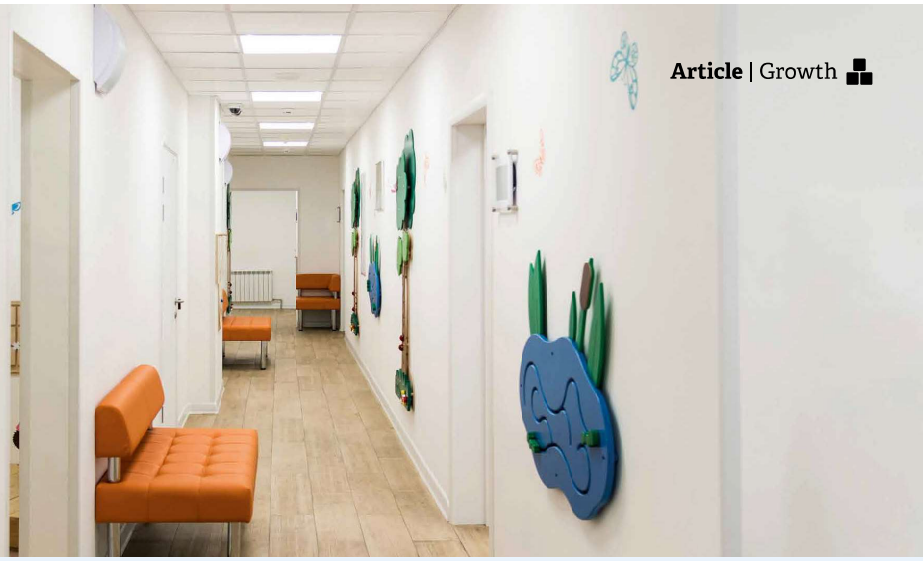
Managing feed intolerance in paediatrics – different clinical perspectives



INTRODUCTION

Dietitians are likely to be the initial point of contact for medical teams who face a patient with symptoms associated with enteral feeding. Actions that may be considered to address these revolve around three themes:

1. changing what we feed,
2. changing how we feed, and
3. when we feed.

It is widely recognised, that when enteral nutrition (EN) support is required for a child, a polymeric feed with an energy density of ≈1 kcal/ml (usually based on cow's-milk protein) is generally adequate for most patients.[1] Few conditions exist outside of allergy, where a specialised enteral feed would be used as a first line feed. Many conditions have recommendations supporting the first line use of standard feeds, despite symptoms or situations common to the condition that may predispose to poor tolerance. In 2019 The European society for paediatric gastroenterology hepatology and nutrition (ESPGHAN) published guidelines on the nutritional management of children with neuro-disability. Despite the multiple symptoms often faced by this group, including altered gastric motility and, or transit time, standard polymeric feeds are still recommended first line.[2] Another example is cystic fibrosis (CF). CF is a condition inherently associated with malabsorption and maldigestion, where theoretically it would be understandable to use specialist feeds first line. However, international guidelines support the use of a whole protein feed initially.[3-4] For other patient groups, where periods of severe gastrointestinal mucositis and malabsorption are anticipated during treatment, such as paediatric oncology and haematopoietic stem cell transplantation, consensus guidelines on choice of feed have only recently been published. These advise that feed choice is dependent on age and gastrointestinal function, or to change to hydrolysate in response to poor tolerance of feed.[5-6]

FEED CHOICE

Initiating or changing to specialised feeds requires attention to the condition, the symptoms experienced, and the context. When the decision to change a feed is made, the assessment of the impact of this is crucial, as it may alter what the child is fed for weeks, months or even years.

Some guidance exists on feed choice when facing poor tolerance. However, even when guidance does exist for a condition, the evidence that supports it is often limited, and in many cases, dietitians must look to clinical experience, and historical clinical practice to guide decisions.

> When the decision to change a feed is made, the assessment of the impact of this is crucial, as it may alter what the child is fed for weeks, months or even years

Table 1. Characteristics that might influence tolerance.

• Protein type (whey/casein predominance)	• Osmolality
• Level of hydrolysis	• pH
• Protein content	• Fibre content
• Amount and type of fat (MCT content)	• Volume
	• Energy density
	• Viscosity

When a patient has poor feeding tolerance, characteristics that might be considered clinically relevant are suggested in table 1.

Protein type is an important consideration in feed choice. The different protein types of feeds include whole protein, partially hydrolysed (PH), extensively hydrolysed (EH) or amino acid (AA)/elemental. Whole protein feeds generally contain mixes of polymeric whey and casein derived from cow's milk, or soy protein. When considering the influence of protein type, hydrolysed or amino acid feeds may be easier for the gastrointestinal system to digest and absorb, as they can be absorbed directly into the enterocyte without further hydrolysis.

When facing tolerance issues, a progressive stepwise process based on the level of protein hydrolysis can be considered. However, isolating protein type can be challenging. For example, changing from a polymeric peptide feed may create additional changes, such as osmolality, fibre content, and energy density, each of which may either positively or negatively influence tolerance. When assessing the impact of change, or when considering the evidence base of any guidelines, it is important to understand that more than one clinically relevant alteration has likely been made.

To illustrate the clinical considerations and decisions faced by practitioners, this discussion will focus on example conditions where feed choice can be challenging:

- Infants with intestinal failure (short gut)
- cancer
- cystic fibrosis

Short gut

Infants with intestinal failure, through either an anatomical or functional short gut, present a nutritional challenge. Enteral nutrition (EN) provides the cornerstone to gut adaptation with many factors contributing to expected outcome, whilst parenteral nutrition (PN) provides an initial lifesaving nutrition, but can be associated with complications.[7] The dietetic intervention aims to optimise enteral feeding to achieve enteral autonomy, minimising the need for PN.[8] There is currently no consensus on the optimal feed to use. Valuable experience within tertiary centres can help to guide management and it is common that a combination of continuous pump feeding, to promote adaptation and tolerance, and bolus feeding, where physiological benefits of fasting between feeds, is adopted.

Excluding infants at risk of cow's milk protein allergy (CMPA), and secondary protein intolerance following mucosal injury, whole protein digestion and absorption is not generally a challenge. In fact, the use of complex proteins may promote adaptation.[9]

Osmolality is an important consideration in feed choice. The higher the feed osmolality, the greater the influx of water into the GI tract, which can be associated with feed intolerance presenting with symptoms such as distention and cramping, nausea, and higher stool output/ diarrhoea.

Long-chain triacylglycerols (LCTs) are a source of essential fatty acids (EFAs), with a lower osmolality than medium chain triglycerides (MCTs) and are regarded as the greatest factor in stimulating adaptation, promoting residual bowel to 'do more' to adapt.[10] Feeds with a high LCT content can result in fat malabsorption which can limit the progression with feed volumes. The presence of MCT offers an efficiently absorbed fat, reducing the load on the bowel, yet has a higher osmolality, absence of EFA and with a lesser stimulus on adaption.

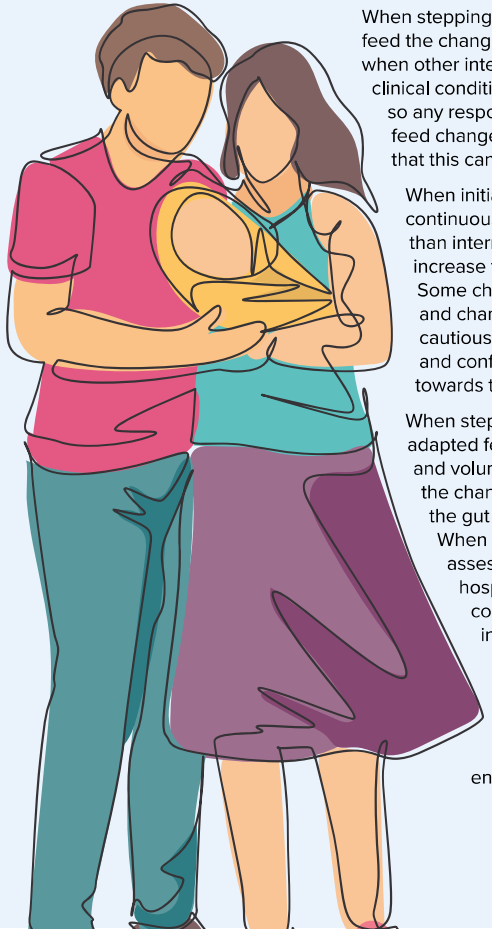
Oncology

Children undergoing cancer treatment can suffer gastrointestinal (GI) dysfunction from chemotherapy induced mucositis, which often results in pain, anorexia, taste changes, nausea, vomiting and diarrhoea. Depending on the type and doses of chemotherapy given, we can anticipate which treatments are likely to provoke severe GI disruption. For example, haematopoietic stem cell transplantation (HSCT) patients are unlikely to tolerate polymeric protein feeds during the peak of their mucositis pre-engraftment phase[11] and some centres will start an amino acid feed first line for these patients. For others, clinical experience and individual context may play a larger part. Due to the lack of evidence and guidance on feed choice for paediatric cancer patients, practice between centres varies. Micronutrient adequacy is a further consideration for these patients, due to their often-limited dietary variety and malabsorption. When using adapted feeds for prolonged periods, close attention must be paid to monitoring for adequacy.

> Patient and family quality of life is also very important when agreeing on a dietetic intervention

Cystic fibrosis

The question of what the ideal enteral feeding regimen for people with CF (pwCF) is was investigated as a PICO (population, intervention, control, and outcomes) for the Australia CF nutrition guidelines in 2017.[4] Due to a lack of evidence, no conclusion to this question was possible. Therefore, the recommendation was to select enteral feeds and devise enteral feeding regimens on an individual basis. This recognises that many pwCF will tolerate polymeric feeds well, and more specialised feeds are not usually required. Despite these recommendations, clinical practice may vary, and this was highlighted in a recent US wide published survey which showed large variation in enteral feed choice.[12] One specific group of pwCF that may be considered to theoretically benefit initially from a specialised feed is those with meconium ileus following acute surgical management if breast milk is not available. In these cases, peptide-based feeds may optimise absorption along with good MCT content in view of pancreatic insufficiency. Further research in this area is needed.



CHANGING FEEDS AND THE MANAGEMENT OF THE STEP UP OR STEP DOWN PROCESS BETWEEN FEEDS

Once the decision has been made to change the feed, and what to change it to, a plan to manage the process, and how to assess the impact of the change should be implemented.

When stepping up to a peptide or amino acid feed the change should be implemented only when other interventions e.g., medications, clinical condition, feeding regimen are stable so any response can be attributed to the feed change. In practice it is recognised that this can be hard to achieve.

When initiating feeds in oncology patients, continuous feeding may be better tolerated than intermittent boluses, which may increase the risk of gastric retention.[13-14] Some children require slower starts and changes, and starting feeds cautiously and establishing tolerance and confidence before increasing towards targets, can be beneficial.

When stepping back down to a less adapted feed, initially reduce the rate and volume of feed given, to optimise the chance of tolerating change if the gut is still sensitive or fragile. When considering feed changes or assessing tolerance the setting i.e., hospital or home is an important consideration. The benefit of an in-patient admission allows an objective, standardised MDT approach to observation and changes where potential risk of an adverse event can be managed. The home environment provides a more relaxed setting that may avoid unnecessary admissions and prioritises the parental perception of tolerance to changes. Changes at home must be very well planned and may take longer, which can increase the risk of other factors affecting symptoms that can be attributed to the feeds.

It is important to recognise that whilst feed options to address poor tolerance are often considered linear or progressive e.g., whole protein to peptide to amino acid, amino acid may not always be the most likely to be tolerated. In some cases, step ups to amino acid feeds from peptide may be associated with worse tolerance.

KEY FACTORS TO CONSIDER WHEN ASSESSING A RESPONSE TO A CHANGE IN FEED

There are several markers for intolerance commonly used in clinical practice that may suggest a feed change is required. These include stool pattern, vomiting, abdominal distension, and discomfort, and monitoring each of these is essential. However, stressors such as time, memory, communication with non-verbal patients and language barriers, all present challenges. Assessing baseline symptoms is key to interpreting clinical changes that may be associated with feed changes.

Patient and family quality of life is also very important when agreeing on a dietetic intervention. The partnership between family and practitioner should be based on shared, realistic goals and expectations. In many conditions, symptoms such as pain, behaviour, abdominal distension, vomiting, and stooling exist with a limited evidence base for effective therapies. Disease progression can mean a natural worsening of symptoms associated with their condition and feeding may exacerbate or alleviate these symptoms, whilst also meeting nutritional needs. This compromise can only be reached through open and honest discussions with family in the management of the feeding journey.

OTHER CONSIDERATIONS AND PRACTICAL SUGGESTIONS

1. Considerations of robust paperwork and use of sick day plan

Where goals differ, robust documentation on the symptoms provides a tool to guide discussion between the family and MDT. An example of some important information to collect and document for assessment is as follows in Table 2.

Patients who are on established home plans but have worsening feed tolerance through intercurrent illness may benefit from having a 'sick day plan'. These plans usually involve maintaining nutrition on a different plan for a short time. Care needs to be taken to give clear instruction on when these regimens are appropriate to use.

2. Considerations with parents and caregivers

Patients are given adapted feeds such as peptide or amino acid feeds for a specific indication. Once that indication no longer exists, there is a strong argument for returning to a polymeric feed, if nutrition support is still required. However, in practice this might be hard to achieve. The negative experiences of a patient around polymeric feed intolerance, whilst being acutely unwell, can influence a patient and/or their caregiver's desire to change an otherwise stable situation. Explaining the rationale for starting the feed and returning to a more physiologically 'natural' nutrient profile with the patient and/or caregiver may help.

3. Considerations in perplexing cases

Situations may arise where poor tolerance appears to be unexplained or in the absence of any clear physiological aetiology. In such cases blinded feed challenges have been used to assess true symptoms associated by feeding/feed, and symptoms that co-exist irrespective or independently of feeding. Such challenges require a MDT approach, with patient and family buy-in and psychological support.

ROUTES OF FEEDING IN FEED INTOLERANCE

Whilst much focus is given to what we feed, care and attention must also be given to where we feed when we are faced with poor tolerance. Jejunal feeding has clear indications for consideration in the context of poor enteral tolerance e.g., in mild acute pancreatitis, and marks an alternative route before considering the more invasive and higher risk option of parenteral nutrition.[15] Broad aspects of jejunal feeding have been addressed by ESPGHAN's position paper in 2019 which provide a comprehensive review.[16] More recently Paine et al., published a review of when jejunal feeding should be considered,[17] Jazayeri et al, in 2022 have published a review of the practical aspects surrounding this route.[18] However, addressing the choice of feed for this route was not included in either of these reviews and this issue remains limited in evidence base.

> Whilst much focus is given to what we feed, care and attention must also be given to where we feed

Table 2. Important information to document in assessment

- Patient information (including underlying acute condition, past medical history, medications), feed type, administration rate, additional water volume and administration method
- Potential problems and any preventative action for this?
- Weight and height/ length with any other relevant anthropometry including mid-upper arm circumference
- Feed volume prescribed vs feed volume delivered
- Perceived need from caregivers to change from prescribed feed plan should be discussed and documented with the doctor and/or dietitian
- Fluid balance charts including how often passing urine, stooling frequency and type including volume if appropriate, vomiting episodes and volume if appropriate
- Parental feedback
- Perceived signs of feed intolerance
- A clinical assessment includes looking at the child's physique, assessing bowel motions and other gastrointestinal symptoms and performing a feeding observation.

CONCLUSION

There is a paucity of evidence and a variance in clinical practice when faced with tolerance issues of enteral feeds in paediatrics. Dietitians have a responsibility to investigate and attempt to identify possible nutritional strategies that may alleviate or resolve the symptoms that a child has.

When working in situations of poor tolerance, working closely with key members of the MDT is good practice. It is essential to put the child at the centre of the situation and explore their and their family's situation and priorities. With close team working, clear documentation and good knowledge of the wide range of available feeds, identification of an optimal feed and feeding regime can be achieved.

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Continued Professional Development

- What resources are you aware of that might support your decision on feed choice?
- What strategies might you be able to introduce in deciding what to feed, how to feed or when to feed your patients?
- Are there other examples where feed choice can be challenging? Why not discuss these with your colleagues.

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NUTRICIA ACADEMY
Feed your mind

BY ROSAN MEYER, RD, PHD
Specialist Paediatric Dietitian
Honorary Senior Lecturer Imperial College, UK Visiting Professor
University of Winchester, UK and KU Leuven, Belgium

The practical dietetic management of Avoidant Restrictive Food Intake Disorder in children

Introduction

The criteria for Avoidant Restrictive Food Intake Disorder (ARFID) was first published in the Diagnostic and Statistics Manual 5 (DSM-V) in 2013.[1] The full criteria is described in Table 1, but in short, ARFID is characterised by persistent avoidance or restriction of food intake, without weight and/or body image concerns that are characteristic of anorexia nervosa or bulimia nervosa. ARFID results in at least one of the following: substantial weight loss, including failure to gain weight as expected or faltering growth; significant nutritional deficiency; dependence on oral nutritional supplementation or enteral feeding; or marked interference with psychosocial functioning.[2]

The prevalence of ARFID in children aged 8-13 years, has been estimated at around 3.2% in a Swiss study, and more recently in the same age group, the Canadian Paediatric Surveillance Program estimated an incidence of 2.02 per 100,000 patients was found.[4-5] In medical and psychiatric settings, the prevalence has been found to be significantly higher ranging from 5-22%, with ARIFD co-existing in children with autistic spectrum disorder, attention deficit hyperactivity disorder and gastrointestinal diagnoses including food allergic conditions.[6,7,8,9,10,11] Diagnostic criteria D, requires the ruling out of other concurrent medical conditions or other mental disorders, which often poses a significant challenge. Studies have highlighted the challenges in the diagnosis of ARFID in patients with gastrointestinal disorders due to the fear of gastrointestinal symptoms,[12] gastrointestinal-related Somatic Symptom Disorders,[13] the fear of vomiting,[14] and other eating disorders.[15] The diagnosis of ARFID should ideally be made by a healthcare professional with mental health training, due to the possible overlap with other diagnoses, and should also involve members of the multidisciplinary team (MDT) to rule out underlying medical diagnoses.

20-30%

of children with ARFID only met their recommended dietary intake for vitamins and minerals

Nutritional Risk of ARFID

Children with ARFID have food preferences that are primarily sensory driven and may present itself as a combination of colour, texture, taste, smell, and temperature specificity. It is common for children with ARFIDs to consume only a small number of accepted foods, which may include brand specificity, and therefore, increases the risk for both macro and micronutrient deficiencies. Schmidt et al., assessed the dietary intake of children with ARFID and found that overall, they consumed significantly less energy and protein.[16] The macronutrient contribution heavily leans towards higher carbohydrates, refined sugars and they often consume highly processed foods.[16-17] Overall, children with ARFID had a low consumption of vegetables and fruit. The analysis of food diaries found that only 20-30% of children with ARFID met their recommended dietary intake for vitamins and minerals.[16-17] Whilst there is a risk for reduced growth in children with ARFID due to poor dietary intake,[18] many studies have also indicated similar growth parameters to healthy controls.[17] It is therefore important not to rule out a diagnosis of ARFID in the presence of normal growth.

Table 1. DSM-V – Diagnostic Criteria for ARFID[3]

A	An eating or feeding disturbance (e.g., apparent lack of interest in eating or food; avoidance based on the sensory characteristics of food; concern about aversive consequences of eating) as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following: a) Significant weight loss (or failure to achieve expected weight gain or faltering growth in children) b) Significant nutritional deficiency c) Dependence on enteral feeding or oral nutritional supplements d) Marked interference with psychosocial functioning
B	The disturbance is not better explained by lack of available food or by an associated culturally sanctioned practice.
C	The eating disturbance does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way in which one's body weight or shape is experienced.
D	The eating disturbance is not attributable to a concurrent medical condition or not better explained by another mental disorder. When the eating disturbance occurs in the context of another condition or disorder, the severity of the eating disturbance exceeds that routinely associated with the condition or disorder and warrants additional clinical attention.

There is more data pointing to micronutrient deficiencies, with cases of severe deficiencies reported, leading to scurvy, blindness, severe iron deficiency anaemia and reduced bone mineral density.[19,20,21,22] This highlights the importance for the dietitian to consider both macro and micronutrients with their functional contribution as type I and type II nutrients for optimal growth and development, when assessing dietary intake.[23] The latter will also guide the requirement for nutritional blood markers.

Role and Responsibility of the Dietitian

In 2021 Bryant-Waugh et al., published an evidence-based outpatient pathway for ARFID, highlighting the importance of dietitians from diagnosis to the dietary management and monitoring of ARFID.[24] Dietitians are a critical member of any feeding team and are involved in the whole spectrum of aversive feeding and eating disorders. They are often the first point of contact for parents with children along the spectrum of eating and feeding disorders and are frequently the first to recognise the symptoms of ARFID, and escalate this towards a diagnosis. The challenge for many dietitians is when does a feeding disorder become ARFID? In 2019 Goday et al., published the consensus definition and conceptual framework for feeding disorders, including the proposed diagnostic criteria.[25] This primarily relies on a disturbance of oral intake related to medical, nutritional, oral feeding skill and psychological dysfunction and the absence of cognitive processes consistent with eating disorders. There are often overlaps in symptoms between feeding disorders and ARFID, as ARFID resembles a feeding disorder in demographic features, comorbidities and presentation, but resembles more anorexia nervosa in terms of management and treatment.[26] With specialist nutritional knowledge, dietitians contribute towards clarifying the diagnosis, together with speech and language therapists (for assessment of oral motor skills), physicians (to assess other medical diagnoses), occupational therapists (to assess sensory hypersensitivity) and psychologists and, or psychiatrists (to assess eating and other mental health disorders). Dietitians also lead the dietary management of children with ARFID, which is reliant on the feeding history and the anthropometric, biochemical, clinical, and dietary (ABCD) of nutritional assessment described in Table 2.

Dietary Management Principles

There are three core dietary management principles:

1. Meeting nutritional requirements in a way that is acceptable for the child
2. Correcting for potential and, or existing deficiencies
3. Providing guidance to expand the diet

Meeting dietary requirements in children with ARFID usually does not occur in the traditional way of "healthy eating", including five portions of fruit and vegetables, whole grains and a mixture of haem and non-haem protein. It is important that dietitians establish different, more innovative ways to achieve requirements within the child's sensory specificities whilst taking anxieties around food into account. Dietitians may consider:

- Food fortification with protein, nutritious fats, vitamins, and minerals without changing the sensory characteristics of the food. Any change to the sensory characteristics may lead to loss of an accepted food. Examples include:
  - Replacing half of the flour used in recipes with a nut or gram flour
  - Adding olive or canola oil in baking, frying or roasting. For example, i.e. making oven chips with an additional drizzle of canola oil
  - Adding walnut oil to accepted nut butters
  - Baking biscuits and cakes with added calcium.
- Recommending foods that are fortified and within the sensory accepted range. Examples include:
  - Fortified bread, i.e., with calcium or fibre
  - Higher protein cereal
  - Fortified cereal
  - Fortified biscuits, although the variety of fortified biscuits is low.

- Oral nutritional supplements (ONS) that are acceptable from a sensory perspective to the child. Considerations included:
  - Flavour of the ONS
  - Milkshake-type, fruit juice-type, smoothie-type, yoghurt-type and powder
  - Viscosity of the ONS
  - How the ONS is presented. For example, the container, with or without a straw, the colour and label
  - When the ONS is given, as this can impact on the child's appetite during the day. For example, is it a meal replacement, a snack, or given before going to bed?
  - How much is required per day, and how and when would you stop the ONS
  - Type of ONS: whole protein, partially or extensively hydrolysed, amino acid based, and the energy density (i.e. 1 kcal/ml, 1.5 kcal/ml, 2.4 kcal/ml).

Table 2. Components of nutritional assessment

Components	Relevance
Feeding/History	Assessment of the journey of development of oral motor skills. Information on progression and acceptance of tastes and textures. Information on when feeding was disrupted to allow for a more tailored management plan.
Growth Assessment	Both weight and length/height measurements are required to establish both acute or chronic undernutrition or overnutrition. NICE guidelines for faltering growth should be used and World Health Organisation cut-off for malnutrition.[27-28]
Biochemical Assessment	Nutritional biomarkers are really important for establishing micronutrient deficiencies. These need to be targeted around the current dietary intake and there should be an understanding of sensitivity and specificity of these measures. The European Society of Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN) has published guidelines to support appropriate biomarkers.[29]
Clinical Assessment	A clinical assessment includes looking at the child's physique, assessing bowel motions and other gastrointestinal symptoms and performing a feeding observation.
Dietary Intake	It is ideal to obtain a 3-day food diary to assess macro and micronutrient intake, to advise on supplementation as well as assess the food preferences, which may include a specificity around texture, colour, taste, temperature and smell.

Table 3. Guidance for vitamin and mineral supplementations in children with ARFID

Vitamin and Mineral Supplement	Advantage	Disadvantage	Suggestions
Vitamin and mineral drops	• Small volume • No excipients that could cause an allergy/intolerance reaction	• Dosage of vitamins are often not age appropriate • Not tasteless • Strong smell	• Adjust the dose to account for age • Mix with fruit puree, fruit juice, or smoothies
Vitamin and mineral syrup	• Tastes better • May be a smell that is acceptable for the child	• Bigger volume • May contain excipients that may cause allergic or reactions or intolerances • Higher viscosity • May have a flavour disliked by the child	• Mix with fruit puree, fruit juice, or smoothies, and can be added to jams
Oral Spray	• Multivitamin and mineral supplements available • Iron, zinc and vitamin D supplement at different dosages available • Small dose • Flavoured (i.e. mint)	• Iron is not usually part of the multivitamin and mineral spray • Not tasteless and can change mouth feel • Often needs multiple pumps to achieve dosage	• Discuss with the child the suitability, as self-administration is often more successful
Chewable vitamins and minerals (chalky-type)	• Contains vitamins and minerals • Different flavours, colours and shapes available that may be preferred by the child	• Chalky texture that may be difficult to tolerate • Variations in levels of vitamins and minerals between brands • Suitability depends on oral motor skills	• Suggest sucking instead of chewing the supplement • Grinding into a powder and mixing in fruit puree
Chewable vitamins and minerals (jelly-type)	• Often preferred by children as they taste like sweets • Different flavours and shapes available	• Most jelly type vitamin supplements do not contain minerals, i.e., iron, zinc, or selenium • Suitability depends on oral motor skills • Dental hygiene is important due to the jelly sticking on teeth	• Need to combine with a mineral supplement • Cut up into smaller pieces for young children that like the taste but cannot manage the whole supplement • Ensure that the child has the necessary oral motor skills to manage this without choking
Vitamin and mineral powders	• Can be mixed into food • Encapsulated vitamin and mineral powders available with minimal taste • Dosage can be adjusted	• Need foods to be mixed with • Content of vitamins and minerals vary	• Different powder brands have different tastes
Vitamin patches	• Suitable for children that refuse all oral supplements • Patches are placed overnight, and do not impact day-to-day life	• Not all vitamins and minerals have proven skin absorption data • Absorption may vary between children • Absorption may be hindered by body creams, i.e., in children with eczema	• Use when all other vitamin and mineral supplements are refused • Ideally have targeted nutritional bloods, i.e., vitamin D, or ferritin, performed before and after 2-3 months on the patches to ensure that vitamin levels are maintained or are increasing
IV/IM vitamins and minerals	• Mega dosages available, reducing the need for frequent IM/IV • Ability to correct vitamin and mineral deficiencies fast • No need for oral intake	• Not all vitamins and minerals are available in this form • Administration can be traumatic for children and is not without risk	

Whilst the use of enteral nutritional support has been documented in children with ARFID, primarily in feeding units where children are admitted for therapy, this should be carefully considered.[30] ESPGHAN provides general guidelines for indications for tube feeding in paediatrics, which are applicable to ARFID.[31] This should be a MDT decision, and therapy to improve oral intake should go alongside the placement of any enteral feeding tube. Dovey et al., highlighted concern about enteral feed dependency in children with ARFID, which should be considered when either enteral feed and, or ONS are considered.[32]

The correction of vitamin and mineral deficiencies can be particularly challenging for the dietitian due to sensory specificities, limiting suitable and accepted supplements. Drops, liquids, chewable tablets, oral sprays, capsules, tablets, vitamin patches, and intravenous (IV), and intramuscular (IM) options need to be considered carefully in children with ARFID. This is shown in Table 3.

> ARFID is an evolving service and there is an opportunity for dietitians working in this field to develop the evidence base

Regarding the third dietary principle of food expansion, several techniques have been published to aid the introduction of new foods, but none are specific to ARFID. These include the Sensory Oral Sensory Approach (SOS), Food Chaining Approach and the Division of Responsibility Approach.[33,34,35] All of these techniques are based on finding new foods that resemble the sensory accepted foods, and offering them in a way where the child decides whether they want to trial the food or not. This should occur with the background knowledge that a child with ARFID will not just eat new food, even if they are very hungry, and that eating can be a great cause of anxiety. Initially, it may be necessary to keep eating distractions, like TV and tablet reading, to reduce anxiety around mealtimes, and slowly work towards reducing this at a rate that is acceptable for the child to maintain nutritional status.[36] Children with ARFID can also benefit from having psychology and, or psychiatry involvement alongside dietetic input to reduce the anxiety around meals and new food introductions. This may include cognitive behavioural therapy where age appropriate.

Conclusion

AFRID is an eating disorder that significantly affects the nutritional intake of children and impacts on the quality of life of families.[37] Dietitians play an important role, as part of the MDT, in the journey of the child with ARFID from diagnosis to management and review. The principles of dietary management rely on meeting macro and micronutrients in an innovative way, and providing guidance on how to expand foods using techniques that are acceptable to the child with ARFID.

Useful resources for dietitians working in this area include:

The position statement recently published by the British Dietetic Association www.bda.uk.com/specialist-groups-and-branches/mental-health-specialist-group/child-adolescent-mental-health-services-sub-group/arfid-position-statement.

The ARFID Awareness Charity www.arfidawarenessuk.org

For further education:

Search online for Winchester University and ARFID Awareness

Continued Professional Development

- What innovative ideas could you introduce to encourage children with ARFID to help them achieve their nutritional requirements?
- How can you ensure cross functional working for a holistic MDT approach for children with ARFID?
- What techniques could you use to encourage food expansion in children with ARFID?

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The successful use of **Fortini Compact Multi Fibre** in a teenager with Anorexia Nervosa

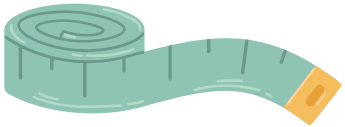
BACKGROUND

S is a 15-year-old girl who was assessed by her local child and adolescent mental health (CAMH) eating disorders service. She presented with a 4-month history of escalating dietary restrictions, daily exercise, and weight loss. S reported that initially she wanted to eat healthier, so she reduced the number of puddings and snacks that she ate. She then became vegetarian and tried to set herself a strict calorie limit of 400 kcal/day and would drink one diet fizzy drink a day. S has lost 10kg of weight in the past 6 weeks and not had a period for 2 months. S's family had become worried and sought a referral from their GP. On admission her anthropometrics were: weight 40.3kg (>0.4th centile) and height 168cm (>75th centile) which equated to 70.5% median BMI. Although S acknowledged that she had lost weight, she still thought she needed to lose more and became very distressed when the team spoke about needing to eat more to restore her physical health and gain weight. S was diagnosed with Anorexia Nervosa.

The clinicians who assessed her noted that she struggled to walk up the stairs and requested a full physical health screen from her local paediatric ward. On the paediatric assessment unit, the paediatric team used the Medical Emergencies in Eating Disorders (MEED) guidelines[1] and several 'red flag' symptoms were identified: losing more than 1kg a week, restricting oral intake to <500 kcal, her resting pulse was 35 bpm on her electrocardiogram (ECG) and her temperature was 34.5°C. It was decided that S should be admitted for medical stabilisation under the refeeding pathway.

DIETETIC MANAGEMENT

In line with the MEED guidelines[1], the paediatric dietitians started S on a 1,400kcal/day meal plan while the team monitored her risk of refeeding syndrome. On dietetic review, S was clearly distressed at the amount of food that she needed to eat to become medically stable. However, she was encouraged to eat what she could manage, and the rest could be made up with Fortini Compact Multi Fibre, a nutritionally complete 2.4 kcal/ml ready to drink compact paediatric oral nutritional supplement (ONS), which would be offered as a drink. Over the next week, S managed to achieve the total calories required (1,400 kcal on day 1 of the refeeding plan, going up by 200 kcal/day every day until she achieved 2,200 kcal/day) with a combination of food and Fortini Compact Multi Fibre. A sample meal plan is shown on the right. S experienced a particularly challenging meal which consisted of a 600-kcal portion of fish, chips and baked beans that she was not able to eat. The ward staff offered the whole meal as a replacement drink of 2 x 125ml bottles of Fortini Compact Multi Fibre with equivalent 600 kcal and 14g of protein which allowed S to still achieve her required nutrition for the day.



SAMPLE 1,400 KCAL REFEEDING MEAL PLAN

If meal not completed within 30 mins to offer the equivalent of Fortini Compact Multi Fibre for the outstanding calories.

Breakfast 300 kcal
= 125ml Fortini Compact Multi Fibre (1 bottle)
= 2 x Weetabix with 150ml semi-skimmed milk and 150ml fruit juice

AM snack 100 kcal
= 42ml Fortini Compact Multi Fibre
= Large banana or 1 x slice toast with spread

Lunch 400 kcal
= 167ml Fortini Compact Multi Fibre
= Half portion of ward meal (300 kcal) and 125g yoghurt pot (100kcal)

PM snack 100 kcal
= 42ml Fortini Compact Multi Fibre
= 2 x crackers with ½ portion cheese or 2 x biscuits

Evening meal 400 kcal
= 167ml Fortini Compact Multi Fibre
= Half portion of ward meal (300 kcal) and 125g yoghurt pot (100kcal)

Night snack 100 kcal
= 42ml Fortini Compact Multi Fibre
= 200ml semi-skimmed milk

After a 10-day admission, S's heart rate was stable, and all her physical observations were within normal range. The paediatric team agreed that she could have a 3-day phased discharge home, gradually eating more meals and snacks at home and less on the ward. On discharge the paediatric dietitian ensured that S's family had a prescription for Fortini Compact Multi Fibre for home use, so when needed, could offer it as a meal or snack alternative. By this stage S was established on a 2,500kcal meal plan and her parents were taught how to calculate the required volumes of Fortini Compact Multi Fibre.

> Compact versions of ONS are ideally suited where a low volume is key to compliance and can provide significantly better nutrient intakes

Over the next 6 months, S and her family progressed through a family-based treatment for Anorexia Nervosa in line with NICE guidelines[2] and she continued to restore her physical health, broaden the variety of meals she could eat and was able to eat independently in school and when out with friends.

DISCUSSION & SUMMARY

It is important to acknowledge that patients with Anorexia Nervosa often present with intense fear around food and weight gain. Typically, patients will restrict the number of foods they eat as the illness progresses and will often avoid foods that they perceive as 'fattening' or high in calories such as cakes, biscuits, chocolate, and crisps. Fortini Compact Multi Fibre comes in 3 flavours, Neutral, Strawberry and Chocolate-Caramel, of identical nutritional value. However, psychologically many patients with Anorexia Nervosa will fear the Chocolate-Caramel flavour more than the other options. In acknowledging this, the dietitian was able to offer the other flavours and the nursing team knew to only offer the Neutral and Strawberry flavours.

This case study illustrates how young patients with restrictive eating disorders can become medically unstable and need paediatric admission. Once on the ward the paediatric dietitians took a pragmatic food first approach but were able to acknowledge that some meals or snacks would be challenging and scary to S, and offering Fortini Compact Multi Fibre allowed this young person to comply with the treatment plan and work towards a discharge home.

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A study to monitor the effect of an amino acid formula containing synbiotics on symptom management in children with spinal muscular atrophy type 1: **The SMAAF Pilot Study**[1]

BACKGROUND

Spinal Muscular Atrophy (SMA) is characterised by degeneration of brainstem and spinal cord motor neurons that lead to progressive muscle weakness and atrophy.[2] These neurological changes result in progressive swallowing, feeding and gastrointestinal complications.[3]

Current dietetic recommendations for children with SMA are based on individual tolerance.[4-5] However, an increasing number of families of SMA children are incorporating amino acid based enteral formulas into their child's feeding regimens. Characteristics of the traditional SMA amino acid formula diet (www.aadietinfo.com) include high carbohydrates, low fats, probiotics, and oral hydration solutions. Anecdotally, families have reported improvements in their child's symptoms which are often associated with SMA including airway secretions, drooling, respiratory infections, constipation, and gastroesophageal reflux.

Due to insufficient evidenced based research, clinicians are unable to prescribe or endorse the SMA amino acid diet, particularly in relation to associated risks between a high carbohydrate diet with hypertriglyceridemia[6-7] and non-alcoholic fatty liver disease.[8-9]

Working with SMA families, we devised an adapted version of the traditional SMA amino acid diet. The aim of this study was to assess the tolerability and safety of an adapted version of the traditional SMA amino acid diet that contains an amino acid-based formula with added synbiotics (the term for pre and probiotics combined) and additional carbohydrates (SMAAF).

METHOD

PATIENTS
Children were recruited from our specialist tertiary neuromuscular SMA outpatient's clinic between June 2021 to May 2022. Table 1 outlines the demographic characteristics of all children who changed to Spinal Muscular Atrophy Amino Acid Formula (SMAAF).

PROCEDURE

Recruited children were transferred on to an amino acid formula, Neocate Syneo, which contains 33% medium chain triglycerides, 50% carbohydrate, probiotic *Bifidobacterium breve* M-16V, and prebiotic-fructo-oligosaccharide. SMAAF was followed for eight weeks; after two weeks on SMAAF, additional carbohydrates (using Super Soluble Maxijul)

Table 1. Demographic summary of recruits

Characteristic	Relevance
Sex, N (%)	
Male	5 (36)
Female	9 (64)
Age in decimal years, mean (SD)	4.1 (1.2)
Weight, mean (SD), kg	14.8 (1.9)
Weight Z score (SD)	-0.7 (0.9)
Height, mean (SD), cm	98.0 (8.6)
Height Z score (SD)	-0.6 (0.9)
Race/Ethnicity, N (%)	
White/White Other	8 (58)
Black African	1 (7)
Asian/Asian Indian/Asian other	5 (35)
Ventilation support, N (%)	
Self-ventilating in air	3 (21)
Non-Invasive Ventilation – overnight only	10 (71)
Non-Invasive Ventilation – dependent	1 (8)
Feeding route, N (%)	
Gastrostomy	12 (84)
Gastrostomy with jejunal extension	1 (8)
Naso Gastric Tube	1 (8)
Type of feed, N (%)	
Standard whole protein (1.0 kcal/ml)	7 (50)
Low energy whole protein (0.7 kcal/ml)	3 (21)
Hydrolysed Formula (1.0 kcal/ml)	1 (8)
Amino acid without Probiotics	3 (21)

Table 2. Reported change in symptoms after children with SMA Type 1 changed to an Amino Acid Formula (SMAAF)

Gastrointestinal Intolerance Symptom	Number of patients with symptom	Number of patients with improved symptoms post switch to SMAAF	P value (95% Confidence Interval)
Reflux, N (%)	5/14 (35)	4/5 (80)	
Loose stools, N (%)	1/14 (7)	1/1 (100)	
Constipation, N (%)	12/14 (85)	10/12 (83)	
Of which on,			
Stool softener medication, N (%)	10/12 (83)	8/10 (80)	
Stool consistency, Bristol Stool Chart Category, (SD)	2.2 (0.4)	3.6 (0.4)	0.001 (2.72-3.72)
Stool frequency – bowel movements per week, (SD)	3.6 (1.08)	4.9 (0.45)	0.09 (-0.65-2.0)

were planned to be supplemented to 60% total energy intake. (Figure 1).

DATA GATHERING

GASTROINTESTINAL TOLERANCE MONITORING

Feed tolerance and details of stooling patterns were recorded by families in weekly diaries. Descriptions of feed tolerance included the following variables:

Reflux – defined as parental observation of the passage of gastric contents into the oesophagus causing regurgitation, posseting or vomiting, which leads to troublesome symptoms that affect daily functioning[10]; constipation – defined as Rome IV Criteria, less than three defecations a week/painful and hard stools[11]; persistent loose stools – lasting longer than 14 days, consisting of more than one loose stool a day.[12]

Parents were requested to report symptoms as either: improved, no change or worsened.

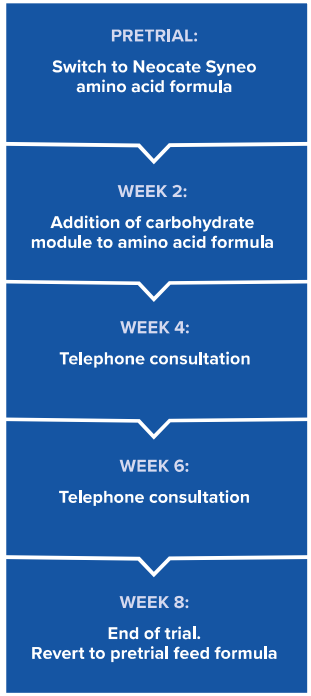
RESULTS

Fourteen children were recruited, with a mean age of 4.1 years (1.2 SD), of which 64% were female. The mean WAZ at baseline was -0.7 (0.9SD).

The most common gastrointestinal complaint reported prior to switching to SMAAF was constipation, present in 12 of 14 (85%) children, of which 10 of the 12 (83%) children required daily stool softeners and laxatives were used to help regulate bowel function. Reflux was reported in 5 of 14 (35%) children (Table 2). Within one week of switching to SMAAF families reported a significant improvement in constipation symptoms.

Eight of the 10 (80%) children who received laxatives saw an improvement in constipation symptoms, and either stopped or reduced medication. All three children who were previously on

Figure 1. Summary of protocol pathway



standard amino acid formula prior to switching to amino acid formula with added pre and probiotics reported an improvement in stool consistency and frequency.

Appropriate weight gain was observed while children were following SMAAF for the eight-week trial (baseline WAZ score: -0.7 [0.9 SD] vs 8-weeks -0.5 [0.7 SD], p=.03).

Due to improved gastrointestinal symptoms within one week of starting Neocate Syneo, only two families chose to add additional carbohydrates. Furthermore, 12 of the 14 families refused to revert to their original feed formula after the eight-week trial. The two families who did revert to their previous formula reported resumption of constipation within one week and requested to restart SMAAF.

DISCUSSION

Our pilot study suggests that children with SMA Type I who are displaying gastrointestinal symptoms, especially when constipation is a key feature of their clinical phenotype, may benefit from an amino acid formula that is fortified with synbiotics.

The cause of chronic constipation in children with SMA Type I is multifactorial, including reduced intake of fibre and fluids, gastrointestinal dysmotility related to a reduced tone and impaired strength of abdominal wall muscles.[13] Additionally, animal studies have also reported both morphological gross, and microscopic structural changes within the gastrointestinal tract, along with alterations with the enteric nervous system, resulting in inflammation and subsequent macrophage infiltration of the small intestine.[14]

CONCLUSION

Advances in SMA Type I therapy pose new challenges, particularly in relation to the management of gastrointestinal symptoms and liver disorders. Children with SMA Type I who are displaying gastrointestinal symptoms such as constipation and reflux may benefit from an amino acid formula that is fortified with probiotics. More research into fatty acid metabolism and manipulation of type of fats in children with SMA Type I is warranted.

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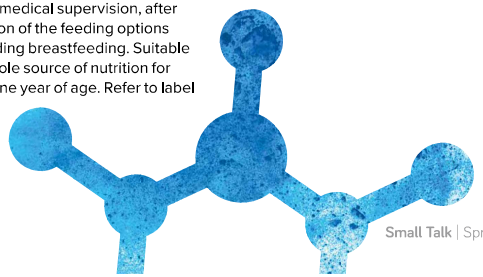


LUCY UPTON
Specialist Paediatric Dietitian

Case study
The flexible use of Fortini Smoothie Multi Fibre for a child with a complex feeding background and ARFID

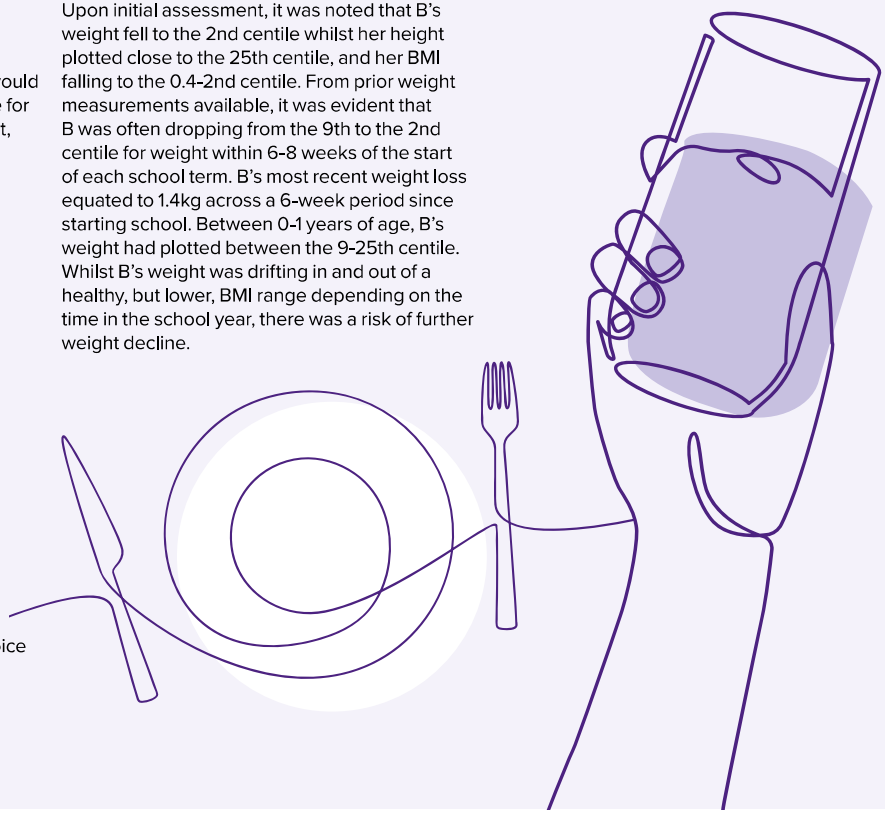
BACKGROUND

B first presented to Paediatric Dietetics at 7 years of age, with a long-standing history of food refusal, periods of poor appetite and complex feeding challenges beyond what would be considered developmentally appropriate for a child her age. During her initial assessment, a wide range of concurrent diagnoses that were directly impacting the presentation of B's feeding behaviours and dietary range were noted. These are detailed below:

- Sensory processing disorder
- Pica
- Developmental coordination disorder
- Autistic spectrum condition
- Attention-deficit hyperactivity disorder (ADHD) – medicated at school
- Reflux and rumination disorder
- Generalised anxiety disorder
- Avoidant restrictive food intake disorder (ARFID)
- Constipation – with poor tolerance for laxatives orally
- Following a gluten-free diet – through choice due to reported impact on her behaviour

ANTHROPOMETRICS

Upon initial assessment, it was noted that B's weight fell to the 2nd centile whilst her height plotted close to the 25th centile, and her BMI falling to the 0.4-2nd centile. From prior weight measurements available, it was evident that B was often dropping from the 9th to the 2nd centile for weight within 6-8 weeks of the start of each school term. B's most recent weight loss equated to 1.4kg across a 6-week period since starting school. Between 0-1 years of age, B's weight had plotted between the 9-25th centile. Whilst B's weight was drifting in and out of a healthy, but lower, BMI range depending on the time in the school year, there was a risk of further weight decline.



DIETARY ASSESSMENT

A full dietary assessment identified the restricted nature of B's diet, with an evident preference for plain and crispy carbohydrate-based foods such as dried gluten-free sweetened cereal and occasionally potato fries. At the time of initial assessment, B wasn't consuming any protein-rich foods, dairy or vegetables, with the remainder of her diet consisting of a variety of 8 different fruits, and sugared fruit-flavoured waters or cordials. B expressed clear preferences about the temperature of her food and drinks, alongside other sensory preferences. B's parents had trialled a range of multivitamin and mineral supplements but had been unsuccessful in finding a preparation she would tolerate.

In addition, B presented with a number of other factors which contributed to notable fluctuations in the volumes of foods she would accept including;

- Rigidity and the need for routine at mealtimes
- Significant anxiety associated with attendance at school or social situations
- Reduced appetite as a side effect of ADHD medications taken for school
- Exacerbation of reflux and rumination disorder

> This case study highlights how patient involvement is key to getting the best ONS to improve health outcomes

MANAGEMENT

In recognition of the complexity of B's feeding difficulties, it was agreed to trial the use of oral nutritional supplements (ONS) to:

- Introduce a reliable source of protein, and key vitamins and minerals B was at risk of deficiency of, i.e., calcium, iodine, vitamin A, iron, zinc, magnesium
- Support energy requirements during periods of poor intake, or at school where acceptance of foods could be poor
- Prevent repeated periods of weight loss and improve BMI to the 9th centile

With B's dietary preferences in mind, B was trialled with Fortini Smoothie Multi Fibre, a nutritionally complete 1.5kcal/ml ready to drink smoothie style ONS. This was initially trialled with her in the clinic, which she accepted very well. Samples were taken directly from the fridge, to support her preference for very cold food and drinks. Given her academic age and high functioning, B was involved in discussions about why ONS drinks were being trialled, what fruits were included and how these would fit in her daily routine. This allowed B to have as much autonomy with choices as possible. B chose to decant them into a bottle for school that would keep them cool and avoid others asking what she was drinking. In addition, it was agreed with her parents that the frequency of use could be flexible. For example, reducing intake to 1-2 bottles per day to fulfil 25-50% of her estimated average requirement (EAR) during school holidays, and increasing the intake to 2-3 bottles per day to fulfil 50-75% of her EAR during times of elevated anxiety and reduced appetite. B's parents were happy for dietetics to liaise with the school to ensure the use of the Fortini Smoothie Multi Fibre was supported.

OUTCOMES

B has been reviewed every 4 to 6 months over the past 2 years, with ongoing use of Fortini Smoothie Multi Fibre. During this time B has commenced feeding therapy, alongside additional psychology and occupational therapy support for her concurrent diagnoses. B has tolerated Fortini Smoothie Multi Fibre very well, with acceptance of both flavours. Over the last year, the frequency of use has reduced to a maximum of 1 bottle of Fortini Smoothie Multi Fibre per day. At 8 years and 11 months of age, B's weight was 25kg, plotting the 25th centile in line with her height. B is described as having more energy and better able to engage with demanding tasks, including schooling. B's case demonstrates the benefit of longer-term, but flexible use of ONS in a child with complex feeding difficulties.

Ask The Expert

Jacqui Lowdon

Do you have a question for our expert? Ask your question to Jacqui **resourcecentre@nutricia.com** and your question might be answered in our next edition!

With increasing interest in sustainable diets and the general public becoming more aware, I am keen to incorporate more of this into my dietetic practice, but I am not sure where to start. Are there any good resources available?

Sustainable diets are high on the agenda right now and dietitians are being encouraged to be proactive advocates for healthy, environmentally sustainable diets. Currently in the UK, we do not have the correct balance of food recommended for a healthy, sustainable diet.[1] Although the awareness is there, there are significant barriers to overcome.[2-3] As a profession, we have the expert knowledge to bring together healthy eating messages and environmentally sustainable dietary advice that is affordable. We need to use this broad base of expertise to be a catalyst for behaviour change and influence both local and national policies.

There are a lot of resources to help you. The British Dietetic Association (BDA) has a Sustainable Diets Policy and has developed One Blue Dot, the BDA's Environmentally Sustainable Diet Project. The One Blue Dot toolkit is an evidence-based source of information on environmentally sustainable diets for dietitians, which you can use with your patients or clients. It includes a reference guide for dietitians, frequently asked questions, a powerpoint presentation and ideas for meal swaps.

There is also the BDA Sustainable Diets Specialist Group, who can provide guidance and Continued Professional Development (CPD) on environmentally sustainable diets. They have helped to produce a number of resources including: a seasonal fruit and vegetable guide, sustainable hacks, a shopping basket, recipes and sustainable Fakeaways.

Some other resources to consider are:

- The Food Services Specialist group of the BDA "The Nutrition and Hydration Digest"[4]
- The WWF "Eating for 2 degrees"[5] report which includes new and updated Livewell Plates
- The Greener Allied Health Professional Hub "Delivering a Net Zero NHS"[6]

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In my dietetic clinic, I often see children with poor dental health. Although this is not the reason for the referral, I would like to be more proactive. Are there any resources available that may be of help?

Making Every Contact Count (MECC) is an evidence-based approach to improving people's health and wellbeing by helping them change their behaviour. This approach enables us to engage people in conversations about improving their health, and one of the key areas is oral and dental health. MECC has a toolkit where there is a free training programme. In one of the sessions, you can learn how to start a conversation with someone about their health and well-being.
15 May–15 June 2023 is National Smile Month. The Oral Health Foundation will be raising awareness of important oral health issues with the theme "brush for better health". Each week a different topic will be highlighted, from daily routines to how technology can help you improve the health of your mouth. There are also several different resources that you can download and use to promote National Smile Month. You can visit www.smilemonth.org to sign up to support the campaign and receive free resources and materials.

Other free resources include:

- Dental Buddy[1] which provides everything you need to teach oral health education, aligning itself with adult Mouth Care Matters is a new arm of this initiative, "Mini Mouth Care Matters"[2] an e learning resource which has been funded by Health Education England

One simple measure you can easily adopt is to ask every paediatric in-patient with a hospital stay of more than 24 hours, whether they have brought their toothbrush, and if not, to provide one. This may make all the difference to how the oral health of that child is maintained whilst in a hospital setting, with a view to continue good practices at home.

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Up2Date

by **Owen Bull**

Source of human milk (mother or donor) is more important than fortifier type (human or bovine) in shaping the preterm infant microbiome

Kumbhare SV, et al.

Cell Reports Medicine 3. 2022. https://doi.org/10.1016/j.xcrm.2022.100712

Whilst breastfeeding is the best source of nutrition for all babies, the composition of breastmilk alone may not meet the unique requirements to support preterm growth and development. Human milk fortifiers (HMFs) may be used to increase the energy density and other nutrients in the mothers own milk (MOM) or donor human milk (DHM). Standard HMFs are derived from bovine milk and recently, human-derived HMF (H2MF) have been developed, but their impact on oxidative stress and inflammation is not known. In addition to the type of fortifier, the source of human milk, MOM or DHM, may also influence infant physiology and their developing microbiome.

In a randomised controlled trial, 30 very low birth weight (VLBW) premature neonates fed either MOM or DHM, were randomised to receive either H2MF or BHMF.

In this study, the type of milk fortifier used, bovine versus human, had minimal impact on the gut microbiome, whereas the source of human milk, MOM or DHM, was associated with microbiome composition in VLBW preterm infants. In univariate analyses at 33 weeks adjusted gestational age (AGA) which was the end of the fortification, MOM explained 22% of the microbiome variation (r2 = 0.22, p = 0.01), while fortifier type had no effect (r2 = 0.01, p = 0.99). Furthermore, there was no evidence of an interaction between MOM intake and fortifier type.

The findings do not provide a clear biological basis for the clinical impact of H2MF, but emphasise the importance of feeding MOM to preterm infants.

The health economic impact of cow's milk allergy in childhood: A retrospective cohort study

Cawood AL, et al.

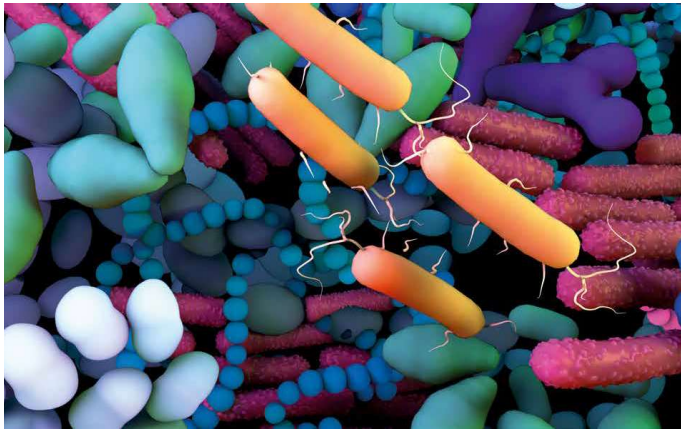
Clin Transl Allergy. 2022;e12187.

Cow's milk allergy (CMA) is a common food allergy among children. Treatment of presenting symptoms and allergic comorbidities such as gastrointestinal, skin and respiratory systems often require the use of a range of additional medications. The cost of treatment of allergic conditions have been estimated to account for 11% of the primary care prescribing budget in the United Kingdom. This study aimed to quantify the wider economic impact of CMA and its management.

This retrospective cohort study compared case records extracted from The Health Improvement Network (THIN) of children with CMA compared to children without CMA in the UK. Unit costs for each healthcare resource were extrapolated to the respective healthcare usage rates to give an indication of CMA-associated healthcare costs over 1 year, and 5 years, of early life.

Children with CMA used significantly more healthcare resources, including medication prescriptions and more healthcare contacts than children without CMA, and were associated with additional potential healthcare costs of £1381.53 per person per year.

Further research is required to investigate the clinical phenotypes and management approaches that may impact clinical and health economic outcomes.



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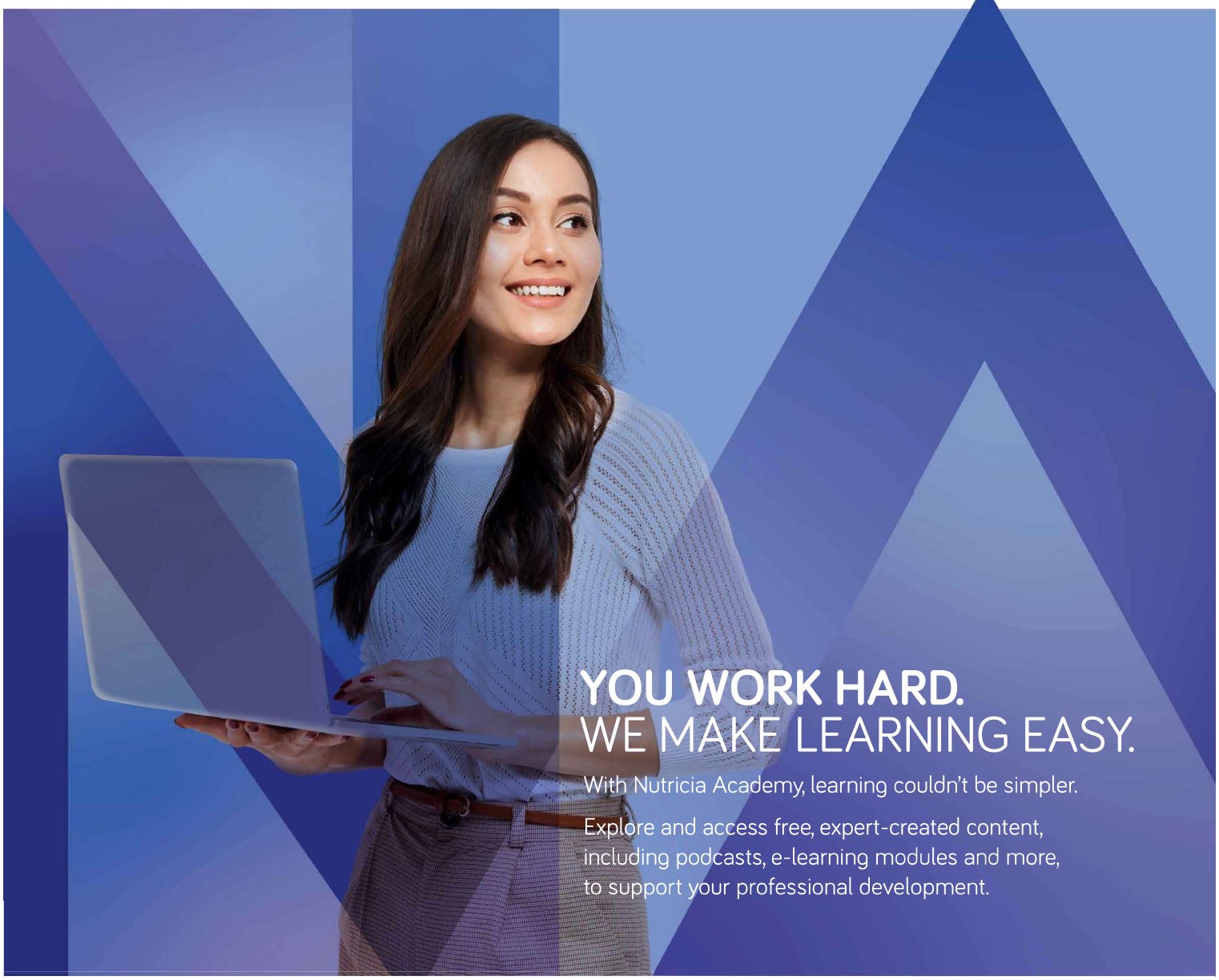

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