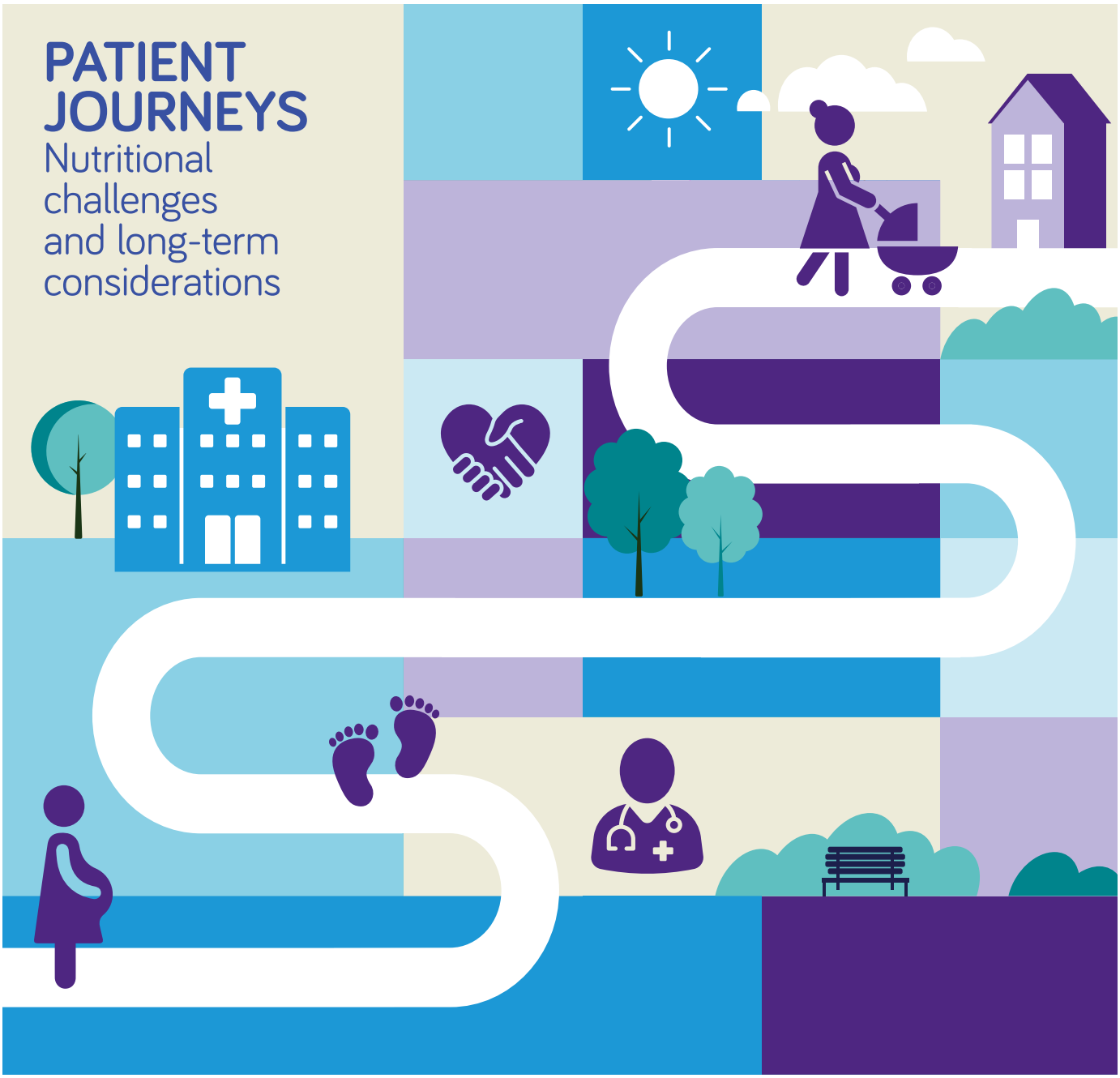
SMALLTALK

PAEDIATRIC NUTRITION MAGAZINE FOR HEALTHCARE PROFESSIONALS

PATIENT JOURNEYS

Nutritional challenges and long-term considerations



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Spring/Summer 2024

Meet the Editors

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NUTRICIA ACADEMY
Feed your mind

Welcome

to the Spring/Summer edition of Small Talk

As we move from a very mild but wet winter into, hopefully, a brighter spring, we'd like to present some of the different nutritional journeys that you may see in your day-to-day practice.

The journey from cow's milk allergy diagnosis through to complementary feeding and milk reintroduction is one that many parents and carers struggle with, needing lots of advice and encouragement. Lucy Upton discusses how she supports families through this often complex journey, including guidance on common concerns.

We then move to the neonatal unit where Catherine Casewell takes us through the nutritional management of preterm infants post-discharge, 'The Graduates', and the many aspects that she needs to consider when they go home.

Breeana Gardiner discusses childhood cancer survivors, and why we need to focus on thriving as well as surviving in these children. Followed by Luise Marino, who explains the nutrition support principles for children with congenital heart defects. Then Jacqui Lowdon provides a very useful summary of the new European Cystic Fibrosis Society (ECFS) standards for the care in people with cystic fibrosis.

In this edition's case study, Sarah Fuller presents a case of Avoidant Restrictive Food Intake Disorder, or ARFID, and how this led to faltering growth.

Finally, Gurpreet Kaur Tatter takes us through a 'Day in the Life of a Remote Dietitian', which reflects on the pros and cons of this new way of working.

We also have all our regular features, including key diary dates and updates on topical publications to support your practice.

Best wishes,

Vicky

Vicky Furmidge-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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BY LUCY UPTON
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Navigating the journey

from complementary feeding to milk reintroduction in infants with cow's milk allergy

Introduction

Cow's Milk Allergy (CMA) is a prevalent immune-mediated allergic response to cow's milk proteins, most commonly seen in infants and young children, affecting 2-4.5% of UK children aged 1-3 years.[1] However, a 2023 position paper by the European Society of Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) identified a prevalence of less than 1% for IgE-mediated CMA, based on oral food challenge.[2] Immediate (IgE-mediated) reactions manifest within 2 hours[3], while delayed (non-IgE-mediated) reactions occur between 2-72 hours after ingestion, presenting in diverse symptoms.[2]

Immediate reactions include urticarial rash, swelling, vomiting and, rarely, anaphylaxis; while delayed reactions involve changes in bowel habits, persisting eczema, vomiting, abdominal pain, and occasionally growth issues.[2] Despite its commonality, the complexity of diagnosis is often underestimated. Clinician confidence in navigating an allergy-focused history and implementing exclusion/reintroduction protocols is crucial, especially considering that the reported suspicion of CMA by caregivers and clinicians was as high as 10%.[2,4] Additionally, awareness of non-IgE mediated presentations, like Food Protein-Induced Enterocolitis Syndrome (FPIES), Food Protein-Induced Allergic Proctocolitis (FPIAP), and Eosinophilic Esophagitis (EoE), along with access to appropriate testing, is essential for accurate diagnosis.

> Parents of infants with CMA often feel anxious about complementary feeding.

Baby A

Diagnosed with IgE-mediated CMA and established on an amino acid-based formula. Despite being 18 weeks old with good head control and hand-eye coordination, he still required seating support. Due to early severe eczema and the associated allergy risks, a decision was made, in agreement with his parents, to start foods just after 4 months. Support included ensuring a safe seating position with added trunk support, focus on preparation of puréed foods, and prioritising the introduction of key allergens, like egg and peanut, after initial acceptance of foods like vegetables.

Baby B

Diagnosed with mild non-IgE-mediated CMA and exclusively breastfed. She had no eczema and there was no family history of atopy. Her parents expressed a clear preference to follow a Baby Led Weaning (BLW) approach, whereby infants are introduced to finger foods and allowed to feed themselves based on family meals (appropriately prepared) from the outset. It was agreed to wait until she was around 6 months of age to commence solids. Once started, prioritisation of some key allergens within the first month of CF was discussed, including practical ways to support BLW.

Management involves milk protein elimination, with suitable replacement hypoallergenic formulas, or maternal milk exclusion when breastfeeding. Parental education on label reading, food preparation and nutritional adequacy is vital, as CMA children face a higher risk of nutrient deficiencies.[5] The prognosis for many children with CMA is positive, with mild non-IgE forms typically resolving by one year of age and up to 80% gaining tolerance by 3 years.[6,7] However, persistence beyond 3 years is observed in more severe forms.[8]

CMA patient journey – complementary feeding (aka 'weaning')

Parents of infants with CMA often feel anxious about complementary feeding (CF). Online advice and conflicting opinions on when to start solids and which foods to offer can perpetuate uncertainty. This section aims to address common CMA CF conversations, considering parental concerns frequently raised in practice.

Age of introduction

The age to commence CF is a frequently debated topic. Recent clinical data supports introducing common allergens, like egg and peanut, between 4-6 months for allergy prevention. Generally, CF advice for the 'general population' recommends starting solids at around 6 months.[9,10] In clinical practice, deciding when to introduce CF (within the 4-6-month window) is a key topic in my conversations with parents. We consider factors like the risk of developing a food allergy, the child's developmental readiness, and parental confidence. While children with CMA are generally at a higher risk of developing other food allergies, the decision to introduce solids should be child and family-centred. Sometimes, a collaborative approach with the child's allergist is helpful. Simply put, there's no one-size-fits-all approach. This is illustrated with two clinical examples above.

Introduction of other food allergens

When discussing CF in a CMA infant, prioritising the introduction of other food allergens is now common practice. I find parents often seek practical guidance, desiring hands-on examples for introducing each allergen. While resources like the joint British Society for Allergy and Clinical Immunology & BDA Food Allergy Specialist Group[11] CF information are invaluable, parents also benefit from advice on the following:

1. **Speed of allergen exposure –** for example, rapidly increasing amounts of peanuts, tree nuts, or sesame is often acceptable, while slower increases may be preferred for egg or soya, particularly for children with non-IgE-mediated allergy backgrounds.
2. **Order of allergen introduction –** in practice, a checklist or table is often appreciated by parents, especially if multiple caregivers are involved in feeding.
3. **Tolerance and maintenance –** clarifying how much of an allergen needs to be consumed without a reaction for it to be considered 'tolerated'. Providing appropriate infant food portions and ways to maintain allergen intake, e.g. recipes, suitable foods and amounts.
4. **Family considerations –** when a family member has an existing allergy, guidance on introducing the allergen to the infant needs careful consideration, practical tips and reassurance.

Having resources to share, like videos or factsheets available from organisations such as Allergy UK, is crucial in busy clinical scenarios where dietitians have multiple topics to cover.

Avoiding 'over medicalisation' of CF

In the past 5 years, I've noticed a growing number of parents expressing increased stress and diminished enjoyment during CF. This often stems from heightened focus on allergen inclusion, selecting appropriate milk alternatives, and awareness of potential allergies. I now allocate more time in consultations to address these concerns or include video resources. I aim to reassure parents by emphasising the principles that align with those for infants without allergies, aiming to 'de-medicalise' the process. Common worries/scenarios frequently encountered in clinic include:

1. **The 'one new food every three days' approach –** this message continues to circulate on various parent forums and platforms. I have found that parents respond well to a 'can-eat' approach, emphasising dietary diversity to expand an infant's diet and the evidence that this might help prevent allergies.[12] I also highlight how the approach can differ, such as ~10 foods/month with a new food every 3 days versus 30+/month, with daily introductions. To guide parents, I often discuss adapting family meals wherever possible. I find parents respond well to this as it fits well with 'trendy' topics such as gut health.
2. **Allergen maintenance doses –** lately, parents have approached me feeling overwhelmed, especially when it comes to incorporating specific amounts of nuts into their young infant's diet, as prescribed by allergists. They are worried about days when their child refuses to eat anything. I find that parents appreciate practical tips, like creating a milled nut mix for easy incorporation into foods, and recipes for allergens such as egg.
3. **Parental anxiety –** it is well known in practice and in the literature that parents of children with food allergy experience increasing anxiety, depression and post-traumatic stress disorder (PTSD).[13] Taking time to ask parents how they are managing and recognising potential barriers to your advice is important to help reduce anxiety. For example, parents sometimes avoid the introduction of certain food allergens, e.g. peanut, due to high levels of anxiety. In such cases, I may refer the family to psychology services for assessment or ongoing support. Other factors that may help include requesting a prescription for an antihistamine for the child at home.
4. **Is it a reaction? –** parents of children with food allergies are often, understandably, more hypervigilant about possible reactions to foods during CF, which can mean that diets become over-restricted during CF and beyond. I have found it beneficial to discuss how to identify a reaction and what is normal vs a concern in relation to:
   a. Skin changes, e.g. contact/irritant reactions vs allergy
   b. Stool changes, e.g. constipation, undigested food or mucus in stools vs allergy
   c. Exacerbations of symptoms such as reflux vs allergy

Use of milk alternatives

An essential discussion with parents when starting solids is the appropriate use of fortified milk alternatives. Parents often report feeling overwhelmed with choice and seek clarity on the 'best' alternative options and how to use them. Increasingly, parents report that decision-making feels clouded by nutritional noise around components often found in milk alternatives, such as seed oils or emulsifiers. Acknowledging that there is no 'perfect' alternative for infants and young children is important, while discussing some key considerations such as those shown in Table 1 below.

Table 1: Considerations for milk alternatives

Energy/protein content	Choose options that are as close to whole cow's milk as possible and provide additional energy sources when deficient
Micronutrient fortification	Check key nutrients when choosing milk alternatives (e.g. calcium, iodine, vitamins B_{12} and B_2)
'No goes'	Unfortified organic options, rice milk alternatives, low-energy alternatives, when used as a drink < 1 year
Cost	Families are increasingly challenged with the cost of milk alternatives, so practical support with appropriate choices, e.g. supermarket own brands
Sweetened	If sweetened options are provided, e.g. to support energy content, then overall diet and dental care should be considered

CMA patient journey – milk reintroduction

Reintroduction of cow's milk protein is a key milestone in a child's milk allergy journey. The process of reintroduction can depend on the nature of the reaction history, so parents benefit from individualised guidance and support.

Non-IgE-mediated CMA

Infants with non-IgE-mediated CMA typically begin milk reintroduction at around 1 year of age, with avoidance of milk for at least 6 months. However, baked forms of milk are often tolerated earlier and the milk ladder is increasingly initiated around 9-10 months of age.

For many parents, it is common to experience hurdles along the way and common causes for concern as shown in Table 2 on page 10.

IgE-mediated CMA

Reintroducing milk in children with IgE-mediated CMA involves monitoring skin prick test weal size or specific IgE levels every 6-12 months. A decrease in weal indicates a higher likelihood of tolerance.[15] For those reacting to baked milk or experiencing respiratory issues, an Oral Food Challenge (OFC) is recommended, especially for children over 3 years old.[2] Recent evidence supports introducing baked milk to promote tolerance. In an Irish cohort, 64% of infants introduced to cow's milk using the Milk Allergy in Primary Care (MAP) guideline ladder were tolerant by 1 year, compared to 37% who continued avoidance.[16] A Leicester study successfully induced cow's milk tolerance in IgE-mediated allergic children under 3 years using a low-dose home reintroduction plan.[17]

In practice, the approach to milk reintroduction depends on clinician and parent preference, resource availability, and adherence to guidelines. Considering parental confidence and ability to follow advice is crucial for minimising risk.

> For many parents, it is common to experience hurdles along the way.

Table 2: Common concerns and clinical considerations

Concern	Clinician considerations
"My child won't eat the food"	Provide examples of alternative foods or formats, blitzing biscuits or muffins to a crumb, or soaking them in a milk alternative until they are very soft and adding to commonly accepted foods, like cereal, can be effective.
"Is this symptom a reaction or not"	Illness, sleep and stool changes are common in this age group, often unrelated to milk reintroduction, but parents may question if symptoms are allergy-related. Questions to ask: • Was the child unwell/became unwell within 48 hours of starting the new food? • Are the symptoms consistent with an allergic reaction (e.g. temperature, stool changes)? • Could other factors contribute to the concern (e.g. eczema, weather changes, environment)? • Does the symptom persist and/or is it replicable? These questions can guide whether a re-trial is needed for an earlier food/step or if a delay is appropriate.
"Which milk ladder? I've seen different versions?"	Parents often feel confused when they realise multiple versions of milk ladders exist. It is important to discuss the similarity and scientific basis behind these ladders to reassure parents, while acknowledging why they differ. I often highlight how the 6-step iMAP milk ladder reduces the burden of steps and time.[14]
"How long do I spend on each step?"	Education around milk ladder progression can help reassure parents. It can differ from child to child, so I reinforce that if a food or dose of that food has been tolerated on multiple occasions, e.g. 2-3 times without reaction, they can move on. For children with more severe symptoms, I consider moving more slowly, sticking on a step for several weeks before moving on.
"We don't eat these foods"	Adapting milk ladders to local dietary habits is an important consideration given the cultural diversity in the UK. Sharing ladders across local trusts and between allergy professionals that have been adapted to include cultural foodstuffs can support compliance and progression.

CMA patient journey – the atypical journey

Whilst the milk allergy journey can feel like a familiar story to dietitians, starting in infancy through to toddlerhood for the majority of children, it is helpful to acknowledge that some children follow a different path to diagnosis. Some 'atypical' journeys I have experienced in the last 10 years include:

1. Children diagnosed later – whilst CMA is typically identified in infancy, I have experienced a number of children diagnosed in their toddler years or later, due to ambiguity with non-IgE symptoms. This included children with persisting reflux, constipation and/or growth faltering, being managed medically, but not achieving symptom resolution.
2. Children with complex medical diagnoses requiring regular medications, such as antibiotics, can have side effects like stool changes or reflux which can mask symptoms of CMA.

With these groups of children, individualised care is required. For example, navigating a more condensed timeframe, such as reducing the typical 6-month milk elimination to 12-16 weeks before attempting a baked milk challenge. Transitioning symptomatic older children, familiar with dairy in their diet, onto milk alternatives can be a challenge due to taste preferences. Discussing the diagnosis with the child, addressing unmanaged symptoms like reflux, while guiding parents on milk ladder progression in children over 3 years, and providing reassurance that they can still gain tolerance, all help empower families and enhance their quality of life.

Conclusion

CMA is a common problem in UK children, necessitating careful diagnosis and management. The difference between immediate and delayed reactions underscores the importance of tailored management approaches, including CF and beyond. CF in infants with CMA can be challenging for both child and parents, often requiring significant input from paediatric dietitians to support them in their journey. Some of the considerations include parental reassurance on allergen introduction, advice on milk replacements and the nutrient adequacy of the diet, as well as addressing common misunderstandings and fears. In older children with CMA, different issues may arise that need to be addressed, such as delayed diagnosis and longer milk reintroduction periods. Empowering families in this journey is crucial and requires an individualised approach to enhance the quality of life of those affected.

> Empowering families is crucial and requires an individualised approach to enhance the quality of life of those affected.

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NUTRICIA ACADEMY Feed your mind

BY CATHERINE CASEWELL
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Nutritional management of preterm infants post-discharge – 'The Graduates'

The survival of preterm infants has significantly improved during the last 10-20 years. As a result, preterm infants tend to be discharged from hospital earlier with body weights below typical birth weights of healthy term infants.[1] The nutritional management of preterm infants born <37 weeks needs to be carefully considered with both the infant and local guidelines in mind. Evidence also suggests that low birth weight (LBW) infants (<2.5kgs) or the late preterm infant (LPT) (34-36 weeks) may have higher nutritional requirements compared with term infants after hospital discharge. Therefore, the nutritional management of LBW or LPT infants is considered similar to that of preterm infants.[2]

Most babies born preterm have higher fat and lower fat free mass compared with term infants.[3] Protein is required for building the fat free mass, as well as brain and bone growth, and supporting weight gain. The Protein:Energy Ratio (PER) of the feed is therefore of crucial importance for preterm infants. Studies have shown that using feeds with a higher PER following discharge results in improved recovery of growth and body composition.[3]

Preterm infants weighing between 1800-2200g require approximately 2.7g protein per 100 kcal.[3] This is reflected in the nutritional content of mother's own milk supplemented with full-strength breast milk fortifier (BMF), or in post-discharge formulas (PDF). Breast milk combined with full-strength fortifier or PDF provide between 75-82kcals/100ml and 2.1-2.7g protein/100ml, depending on the nutritional content of mother's own milk and the PDFs available on the market. Standard term formula or specialist prescribable term formula will not meet the recommended nutrient intake for calories or protein for a preterm or LBW infant receiving 150ml/kg/day.

Other strategies considered to optimise nutrient intake, as alternatives to using human milk fortifiers or PDF, may lead to different complications:

1) *Increasing feed volumes* (>180ml/kg/day) may lead to complications such as reflux.

2) *Concentrating the feed* may lead to feed intolerance due to increased osmolality, or result in incorrect feed preparation, subsequently causing complications such as constipation.

Table 1 highlights the differences between preterm and term nutrient requirements, indicating the need for a more nutrient dense feed when born <36 weeks gestation.

Table 1. A comparison between the nutrient requirements of preterm and term infants

Requirement	Recommended Intakes Preterm (<36weeks/<1.8kgs)[1]	RNI Intakes Term (0-3 months)[4]
Fluid (ml/kg)	150-180	150
Energy (kcal/kg)	115-140	96-120
Protein (g/kg)	3.5-4.0 (up to 4.5g)	2.1
Sodium (mmol/kg)	3.0-5.0	1.9
Calcium (mmol)	3.0-5.0/kg/day	13.1/day
Phosphorus (mmol)	2.2-3.7/kg/day	13.1/day
Vitamin A (IU)	1333-3300/kg/day	1167/day
Vitamin D (IU)	400-700IU/kg/day (up to 1000/kg/day)	400-800/day
Vitamin E (mg)	2.2-11/kg/day	3.3/day
Iron (mg)	2-3/kg	1.68/day

IU, International unit; RNI, Recommended Nutrient Intake

MANAGING THE REQUIREMENTS OF A BREAST-FED INFANT

Current recommendations[5] suggest that preterm infants ***who receive preterm formula milk stage 1*** and who haven't caught-up in growth should be transitioned onto a nutrient enriched post-discharge formula (NEPDF) once they are between 1.8 and 2.5kgs, depending on gestational age and growth. However, there are no recommendations for infants receiving fortified breast milk on discharge; at present they tend to be discharged home breastfeeding without supplementation.

'The evidence' for continuing fortification once discharged

Young et al (2013) summarised the evidence from two small RCTs involving 246 infants in a Cochrane literature review.[6] They found that there was:

- no consistent evidence that feeding preterm infants with multi-nutrient fortified breast milk (BM) versus unfortified BM for 3–4 months post-discharge affected growth parameters through infancy.
- very limited data on developmental outcomes presented.
- no assessment of long-term growth or health outcomes.

However, there is emerging evidence that the use of BMF beyond discharge may help to prevent growth failure and achieve optimal growth.[7] Using BMF may also have a positive impact on the duration of breastfeeding and have the potential to further protect breastfeeding in the preterm population.[8]

Practical application of BMF at discharge

Currently, there is no standard approach on the use of BMF after discharge for preterm infants in the UK. Consequently, it is important to establish the need for BMF on an individual basis, which should be agreed by the multidisciplinary team before discharge and in accordance with local or Neonatal Network guidelines. Guidance for parents to support appropriate use in the community should also be provided.

Infants may be gradually weaned off BMF **prior to discharge** if:

- There is a parental preference to transition off breast milk. A suitable formula should be discussed with the parents, which may include a standard preterm, standard term, or high energy formula depending on the gestational age and growth of the infant.
- Infants are receiving >50% of their feeds as preterm formula. However, if there is evidence of poor growth, or the infant is taking reduced volumes of milk due to other medical issues, the use of breast milk fortifier added to the breast milk component of the infants' feeds, may be continued in combination with an appropriate formula.
- Optimal growth has been achieved. Once expected growth has been achieved over a period of weeks, BMF can be slowly discontinued.

However, **at the time of discharge**, if BMF is required to meet the ongoing nutritional requirements and growth needs of the preterm infant, it can be continued. This requires the support of a Neonatal Dietitian and/or Outreach Team or Clinician. Two types of BMF are currently available in the UK; Nutriprem Human Milk Fortifier, which is ACBS approved and can be prescribed for community use, and SMA Breast Milk Fortifier which is a hospital product and would need to be supplied by individual units.

The quantity of BMF needed will be advised at the time of discharge by the Neonatal Unit team. It can either be added to expressed breast milk (EBM) (1g sachet/25ml) and bottle fed, or given as a BMF booster, via a syringe or teat, just before a breast feed. It should be continued until optimal growth has been achieved.

After optimal growth has been achieved, the daily quantity of BMF should be reduced gradually, following local guidelines, or on advice from a Neonatal Dietitian or Outreach Nurse. **Figure 1** provides an example from a local guideline[7] on how to gradually wean off BMF in the community.

Figure 1.

Example of how to reduce BMF as a booster after discharge once optimal growth has been achieved

Calculation of the daily BMF dosage for a 2kg infant who is exclusively breast-fed:

- Feed 150ml/kg/day = 300ml/day
- 300ml ÷ 25ml = 12 sachets per day
- 50% requirement as recommended for preterm infants on discharge = **6 sachets per day**

1) Mix one 1g sachet BMF with 3-4ml EBM to make one booster and give to infant before their feed.
2) Use six sachets per day to make **6 BMF boosters/day**.
3) Continue the 6 BMF boosters/day until weight is following the appropriate centile.
4) Reduce by 1 BMF booster/day/week or as advised by the Dietitian/NCOT until none is required.

The duration of use of BMF after discharge depends on the infants' growth trajectory. McCormick et al (2021)[8] suggest that BMF is not usually required after term plus 6-12 weeks corrected age. Infants should have developed a mature sleep/wake pattern as well as oral reflexes by this time, meaning they are more likely to successfully breast feed.

Further dietetic assessments should be sought if growth remains a concern after 6-12 weeks.[8] There may be circumstances when the Dietitian advises that BMF is continued for longer.

Practical tips for discharging infants' home on BMF

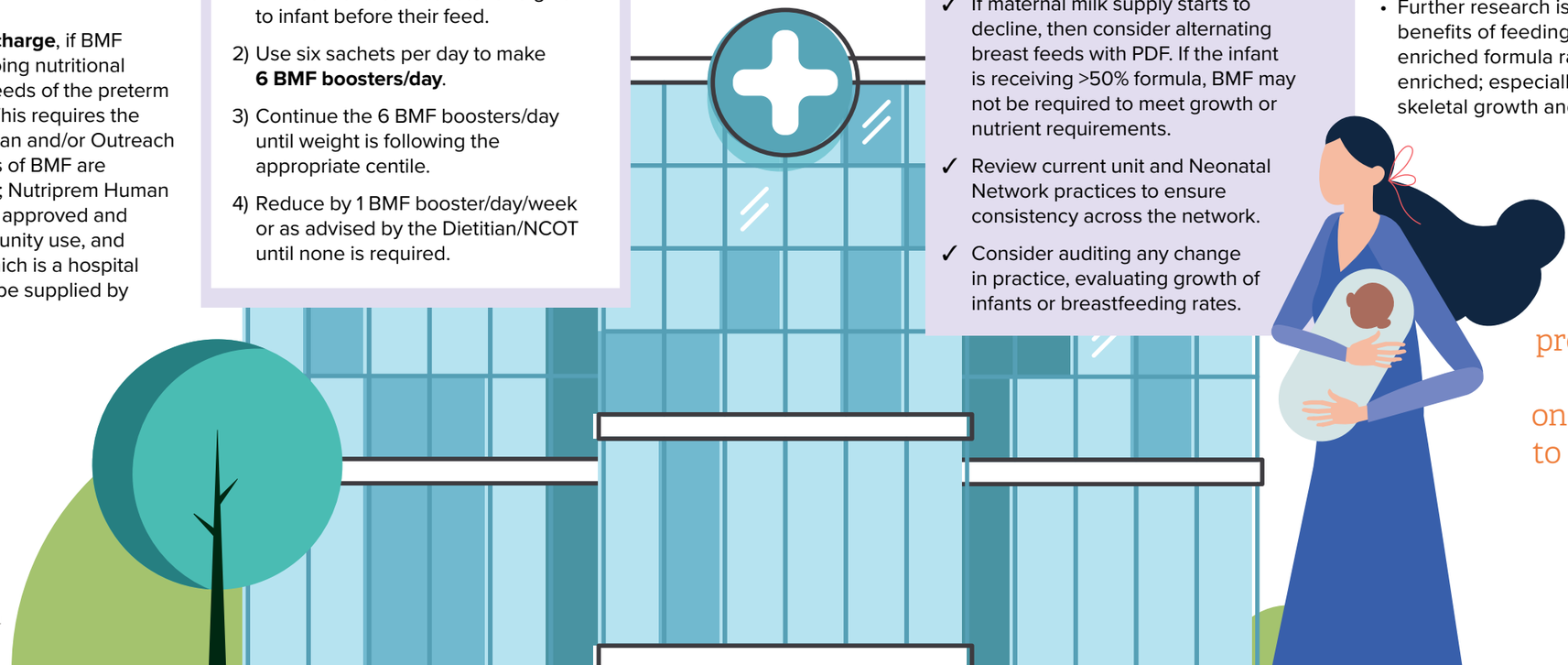
- ✓ Monitoring growth, including weight, head circumference and length, will ensure that infants are prescribed BMF appropriately. Each individual unit should consider who is going to monitor growth prior to discharge, which will depend on availability of resources.
- ✓ Education and training of all Health Care Professionals is essential to ensure BMF is prescribed appropriately with clear parental and professional guidelines on how to discontinue use.
- ✓ If maternal milk supply starts to decline, then consider alternating breast feeds with PDF. If the infant is receiving >50% formula, BMF may not be required to meet growth or nutrient requirements.
- ✓ Review current unit and Neonatal Network practices to ensure consistency across the network.
- ✓ Consider auditing any change in practice, evaluating growth of infants or breastfeeding rates.

MANAGING THE FORMULA FED INFANT POST-DISCHARGE

'The evidence' for post-discharge formula on discharge:

When considering the evidence for continuing NEPDF, the findings are not conclusive. The most recent review was by Young et al (Cochrane review) in March 2012.[5] The review included seven trials, comprising 631 infants, with generally good methodological quality. They concluded that:

- The differences between how the trials were conducted, with differing methodologies as well as outcomes presented, limited the data assessment.
- There was insufficient data presented on neurodevelopmental outcomes.
- There was insufficient evidence to support feeding preterm infants with a nutrient enriched formula compared with standard term formula.
- The difference in growth and neurodevelopment outcomes at 12-18 months of age was considered insignificant.
- The evidence did not consistently support the benefits of feeding PDF, possibly due infants reducing their intake relative to the calorie-density of the milk.
- Further research is required looking at the benefits of feeding protein and mineral enriched formula rather than energy-enriched; especially on lean mass, and skeletal growth and development.



> The use of BMF on prescription post-discharge can be considered for ongoing nutritional support to aid growth and maintain breastfeeding.

Despite these findings, the potential benefit of PDF is being increasingly recognised. For example, improved growth and bone mineralisation have been reported in preterm infants fed nutrient-enriched formulas post hospital discharge.[9] In another study, 31 published papers mapped out the information on Participants, Intervention, Comparator and Outcomes (PICO).[3] The results and conclusions from this review noted:

- An improvement in growth parameters, particularly for boys.
- A significant improvement in all growth parameters at 12-18 months when comparing post-discharge preterm formula to standard term formula.
- When energy requirements were achieved, the increased protein content of the feed appeared to be used for growth and for lean mass accretion.
- The high PER of the feeds encouraged lean mass accretion and improved head circumference growth.

Indications for the use of PDF

Indication	Additional considerations
All preterm infants born <34 weeks and now >1.8kgs transitioning from preterm formula.	
All preterm infants born 34-37 with birth weight 1.8-2.5kgs.	
All preterm infants born 34-37 weeks with birth weight >2.5kgs plus one or more additional considerations:	• taking <150ml/kg/day of a standard term formula and, therefore, may compromise growth. • length >2 centiles from weight centile. • weight is not tracking the same centile 10-14 days after birth.

Discontinuing PDF

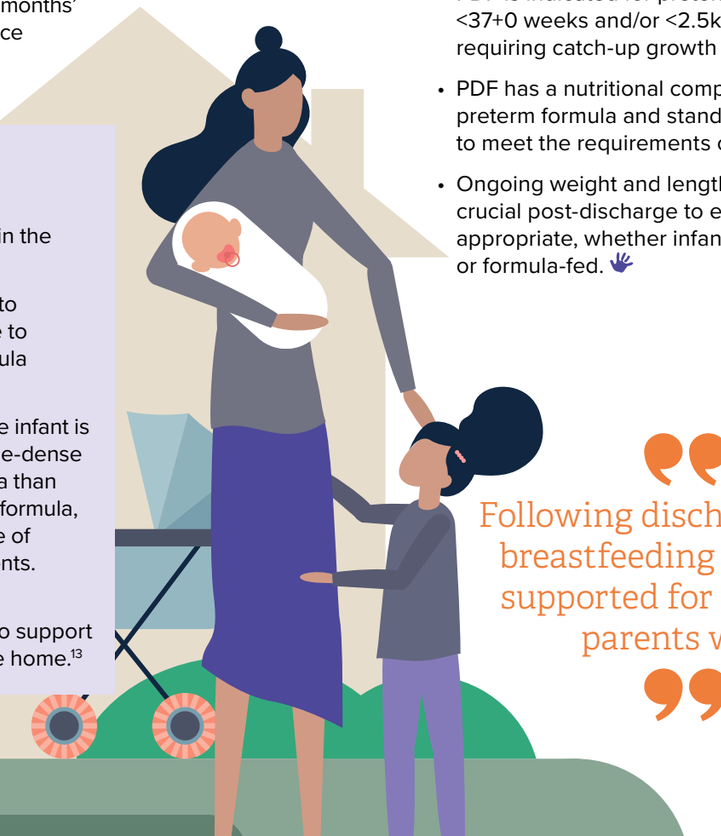
The infant's growth should be monitored frequently using the UK Neonatal Infant Close Monitoring growth chart,[10] including plotting both length and weight. PDF should be gradually transitioned over to a standard term formula, possibly in combination with supplementation of specific nutrients when:

- Weight-for-length is optimal, or the infant is maintaining their weight along the same centile.[11] Both quantity and quality of growth should be considered. Weight gain of 15-20g/kg/day until term and 25-30g/day thereafter can also be used as a guide.
- An infant has reached their birth centile (i.e. after catch-up has been completed and in proportion with their length). Infants need to find their individual genetic potential, which may be different to their size in utero, and this should be considered.[12]
- Weight gain is disproportionally faster than length gain.

If growth is still a concern at three months corrected age (12 weeks), a Dietitian referral should be made for further nutritional assessment/management.[1] The use of a PDF may be extended to between 6 to 12 months' corrected age where there is evidence of improved body composition at six months of age.[3]

Practical tips for discharging infants' home on a PDF

- ✓ Monitoring growth is essential in the first few months of life.
- ✓ Ensure that advice is provided to parents on when is appropriate to transition onto a standard formula to avoid over-feeding.
- ✓ Consider the volume of feed the infant is taking; infants fed on less calorie-dense formulas may take more formula than those on a more calorie-dense formula, which may determine the intake of energy, protein and micronutrients.
- ✓ Provide advice regarding safe preparation of infant formulas to support feed preparation away from the home.[13]



ADDITIONAL VITAMIN AND MINERAL SUPPLEMENTATION

Infants born <34 weeks and/or <1.8kgs should continue with full multivitamin supplementation until they are 6 months corrected age whether receiving fortified or unfortified breast milk or PDF. At 6 months, families should follow the Department of Health guidelines.[14]

Current recommendations suggest iron supplementation for any infant <1.8kgs and term infants born <2.5kgs.[14] Iron supplements should be regularly reviewed when the infant is taking fortified breast milk or PDF, as BMF and PDF vary in iron content. This needs to be considered if feeds are changed once the infant is at home.[14]

SUMMARY

- Following discharge home, breastfeeding should be supported for as long as parents wish.
- The use of BMF on prescription post-discharge can be considered for ongoing nutritional support to aid growth and maintain breastfeeding.
- PDF is indicated for preterm infants born <37+0 weeks and/or <2.5kgs and for those requiring catch-up growth at discharge.
- PDF has a nutritional composition between a preterm formula and standard term formula to meet the requirements of preterm infants.
- Ongoing weight and length monitoring are crucial post-discharge to ensure growth is appropriate, whether infants are breast-fed or formula-fed.

> "Following discharge home, breastfeeding should be supported for as long as parents wish."

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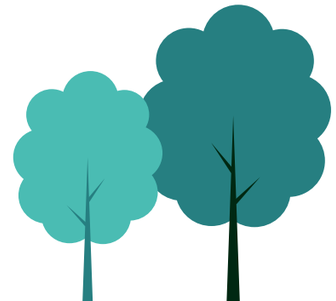

NUTRICIA ACADEMY
Feed your mind

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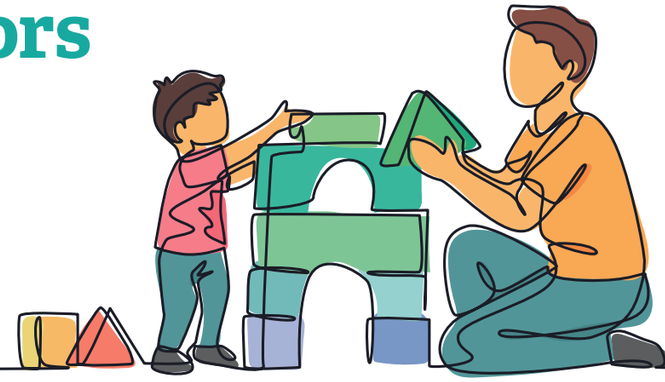
From **surviving** to **thriving** in childhood cancer **survivors**



Over the past 60 years, the number of childhood cancer survivors (CCS) has increased significantly in high-income countries (HIC) because of advances in both supportive care and treatments.[1] For all childhood cancers combined, 5-year survival increased from 30% in the 1960s to now exceeding 80% in most HIC.[2] Despite this success, CCS are at risk of developing a myriad of physiological, psychosocial and neurocognitive late effects, that may begin well before the end of the cancer treatment.[3] Additionally, CCS are at significantly higher risk of developing non-communicable diseases (NCD), including diabetes mellitus, metabolic disease, osteoporosis and cardiovascular disease earlier in life, compared to same-age peers.[1,4,5]

Historically, nutrition interventions in paediatric oncology have focused on the prevention and treatment of undernutrition (mainly manifesting as weight loss), while promoting healthy growth by optimising energy intake for survival. However, with increased survival rates and growing rates of overweight and obesity during childhood,[6] there is a need to pay more attention to nutrition status for longevity (thriving) to reduce the burden of NCD and improve the quality of life of CCS.[7] Looking forward, dietitians, along with other health care professionals, need to address modifiable risk factors such as dietary habits and sedentary lifestyles both during treatment and beyond.

> There is growing evidence that early weight gain during cancer treatment persists into survivorship.

Excess weight gain

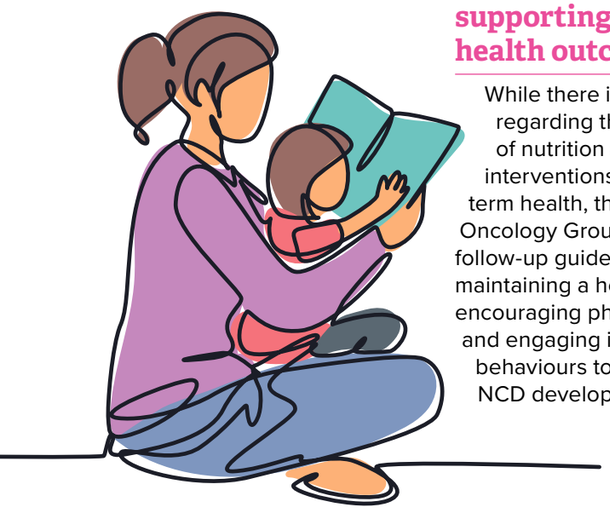
There is growing evidence that early weight gain during cancer treatment persists into survivorship, now seen in up to 40-50% of patients: particularly those treated for Acute Lymphoblastic Leukaemia (ALL), lymphomas, some sarcomas, brain and spinal cord tumours, and cancers treated with cranial/abdominal radiotherapy or those receiving total body irradiation.[8-11] The potential mechanisms behind this trend include poor dietary habits, sedentary lifestyle or impaired mobility, alterations in leptin and adiponectin, growth

hormone/pancreatic insufficiency, glucocorticosteroid use during treatment, and changes in the composition of the gut microbiota.[9,11,12] The risk of treatment-related late effects, such as NCDs, are higher in CCS who are overweight and obese[13], while data suggests that earlier onset overweight/obesity is positively associated with a higher risk of developing a secondary malignancy in adulthood.[14,15] Interestingly, secondary malignancy is becoming the most common cause of death beyond 30 years after initial diagnosis in CCS.[16,17]

Factors influencing excess weight gain in CCS

Paediatric cancer patients undergoing treatment commonly experience side effects, such as nausea, vomiting, mucositis and changes in smell or taste that can significantly impact dietary intake and can contribute to altered food habits, including learned food aversions.[18] Furthermore, these factors can adversely impact parent/child feeding dynamics, contributing to negative feeding practices, such as parents placing pressure on the child to eat, or threatening nasogastric tube insertion.[19] It has been shown that these maladaptive feeding behaviours are difficult to reverse and likely to persist into survivorship.[20] While it is known that CCS have poor diet quality, low adherence to dietary guidelines, picky eating, and poor self-regulation of dietary intake relative to healthy peers,[20-24] it is likely that a lack of holistic nutrition support during treatment, as well as maladaptive feeding behaviours, influence the development of overweight and obesity. Difficulties in managing cravings, preference for high-energy foods, an urgency to eat, selective eating and parenting behaviours should therefore be addressed when planning interventions.[25]

It is important to highlight that there remains a cohort of patients where intensive nutrition support remains a priority to prevent malnutrition, both during and beyond treatment; certainly in more intensive, high-risk treatment protocols, such as those used for neuroblastoma, osteosarcoma and rhabdomyosarcoma.[26] However, it is important that clinicians remain vigilant, and once nutrition goals (i.e. catch-up growth) have been achieved, advice should focus on healthy eating principles to avoid excess weight gain or fat mass accumulation, during and beyond treatment.[27]



Role of the dietitian in supporting long-term health outcomes in CCS

While there is limited evidence regarding the influence of nutrition and lifestyle interventions on CCS' long-term health, the Children's Oncology Group long-term follow-up guidelines[28] recommend maintaining a healthy weight, encouraging physical activity, and engaging in healthy eating behaviours to reduce the risk of NCD development in later life.

Despite these recommendations, there is limited understanding of how nutrition interventions/education can be effectively integrated into survivorship and follow-up services. Furthermore, to date, there is no consistency in the delivery of nutrition interventions/education after active treatment, with the most significant barrier being a lack of funding to support dietitians in the long-term follow-up service of CCS.[29,30]

With CCS reporting lack of awareness of their increased risk of later health problems,[31] dietitians are in a unique position to promote a better understanding of the risks, as well as dietary and lifestyle considerations required for optimal long-term health. Emphasis should be placed on enhancing dietary quality through positive eating behaviours while increasing intakes of fruits, vegetables, and whole grains (fibre) to improve health outcomes.[32,33] Consideration should be given to body composition aiming to maintain optimal fat-free mass, rather than focusing on body mass index alone.[27] Furthermore, in the absence of specific guidelines to optimise bone health, dietitians should provide advice on how to improve diet quality with particular focus on calcium and vitamin D supplementation as per national guidance.[34]

From surviving to thriving in CCS

In the past decade, an increasing number of studies have investigated the role of diet or lifestyle interventions for CCS.[35-37] However, contention remains around the most optimal time to deliver interventions. Benefits of delivering interventions during treatment include reinforcement of healthy dietary principles and leveraging health awareness as a 'teachable' moment.[38] However, 'preventative' dietary and lifestyle interventions delivered during treatment must accommodate for symptoms that arise, for example due to chemotherapy and radiation therapy, and thus may not be appropriate or deemed a priority.

Most studies have focused on interventions during maintenance chemotherapy or after completion of treatment. For example, a recent programme showed an increase in parent confidence in providing nutritious foods to CCS using an online, parent-led intervention which focuses on behaviour change strategies to restore healthy eating practices in survivors.[39] It is evident that further research on delivering diet and lifestyle interventions is needed to enhance health outcomes for CCS (thriving). This would also help guide practice and provide evidence to ensure appropriate levels of staffing across the cancer continuum are achieved.

Conclusion

Childhood cancer survivors are increasing in number due to improved treatment protocols and supportive care, including nutrition provision. This positive outcome is tempered by the recognition that CCS have a high burden of chronic health conditions in later life. Dietary interventions need to reflect these changes, with greater emphasis on diet quality, diversity, and positive eating behaviours to prevent excessive weight gain and obesity, all important for long-term health outcomes (thriving). The promotion of adequate intakes of micronutrients, e.g. calcium and vitamin D, is also necessary. Dietitians play a key role in facilitating this journey; however, to date, they have had limited opportunities to do so due to inadequate funding in CCS. Due to the heterogeneity of CCS' needs, and the complexity of factors contributing to poor nutrition/lifestyle, a multifaceted, patient-centred approach is necessary. Meanwhile, more research is needed to determine the most effective interventions and the most optimal timing during the cancer continuum, to best support long-term health in CCS.

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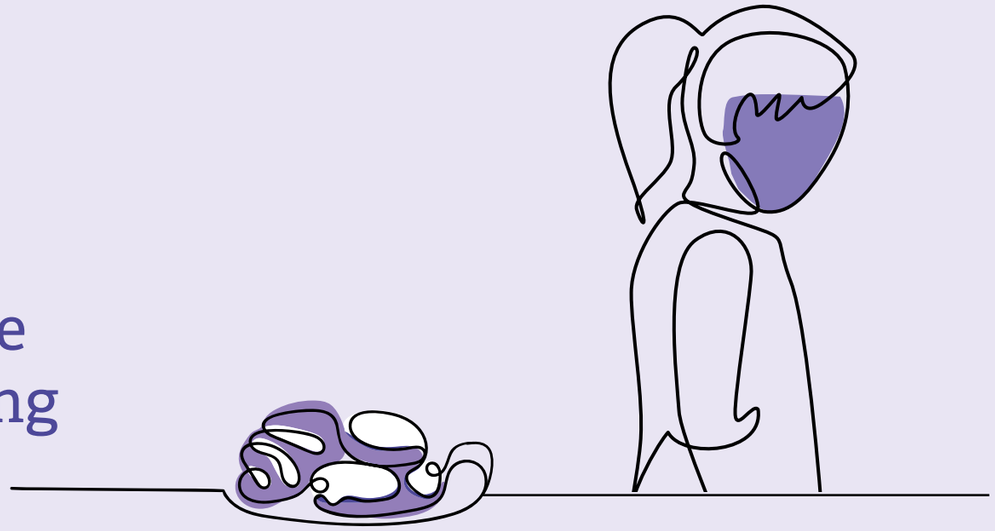
SARAH FULLER
Clinical Lead for CAMHS and Research Dietitian

A case of **Avoidant Restrictive** Food Intake Disorder (ARFID) leading to **faltering growth**



Case presentation

Sofia is a 10-year-old girl who was referred to the paediatric urgent referral clinic at her local hospital via her GP. Sofia's parents were worried that she was still wearing clothes for girls aged 6-7 years, and her younger sister was taller than her. Sofia complained of pains in her tummy and was only passing stools once a week.

History

Sofia's parents reported that when they started the weaning process she was not interested in weaning and had a small appetite. A normal toddler diet was established by the age of one year, but she would only eat very small portions. However, when Sofia started nursery, she began to refuse the foods she used to enjoy and, over the subsequent months, her diet became further restricted. For example, taking one brand of strawberry yoghurt, white bread with margarine, biscuits, crisps, strawberry fruit pouches, chicken nuggets and potato waffles, and she would only drink water. Her parents had sought help from the health visiting team who had given reassurance that Sofia was eating enough food to maintain her growth if she had one protein, one dairy, carbohydrates and one fruit portion in her diet. Sofia's family had been advised to give her a multivitamin and mineral supplement, so she had been taking a strawberry gummy for five years. Sofia would only eat bread and butter when at school and her family could only go out to restaurants, cafes, or family members' houses if they took her accepted snacks.

Examinations: Sofia's blood results showed that she was deficient in iron, calcium, vitamin D, vitamin A and vitamin B12. The paediatrician admitted her to the ward for further investigations, to rule out an organic cause for her poor growth and to consider nasogastric tube (NGT) feeding.

Dietetic assessment: This was the first time Sofia and family had seen a dietitian. Sofia's weight was 18kg (<0.4th centile) and she was 125cm (2nd centile). Sofia's family presented her red book, which indicated that the last measurements were at the age of 7 years, when her weight was 20kg (>9th centile) and height 122cm (50th centile). Previous measurements highlighted that prior to her 6th birthday she tracked on the 25th centile for weight and 50th centile for height. Her diet history was as follows:

- Breakfast: 2 rich tea biscuits or a strawberry yoghurt
- Morning snack: fruit pouch
- Lunch: ½ -1 slice white bread with margarine and a small handful of crisps
- Afternoon snack: 2 rich tea biscuits
- Evening meal: 2 chicken nuggets and one potato waffle with ½ small strawberry yoghurt
- Drinks: 3 cups of water flavoured with strawberry squash.

Diagnosis – Avoidant Restrictive Food Intake Disorder (ARFID)

ARFID is an eating disorder not motivated by weight or shape concerns, but motivated by other reasons that may include sensory sensitivities around the smell, look, or texture of food, feelings of anxiety after a choking or vomiting episode, or a lack of interest in food and not feeling hungry.[1] This may cause someone to restrict their intake or avoid certain foods or textures.

Management

Sofia was prescribed oral nutritional supplements (ONS) to support growth. Sofia's family felt she may take a strawberry drink as she liked this flavour, therefore Fortini Smoothie Multi Fibre (2 x 200ml bottles/day) was prescribed (providing 300kcal and 6.8g protein/bottle) and one Fortini Creamy Fruit pot per day providing 150kcal and 3g protein/pot (equating to 750kcal and 16.6g protein/day). With gentle support from her parents over the next five days whilst in hospital, Sofia learned to drink her Fortini Smoothie Multifibre and eat ½ a pot of the Fortini Creamy Fruit. She was discharged from the ward with an urgent referral to the local Child and Adolescent Mental Health (CAMH) team and was followed up in the dietetic clinic. No paediatrician follow-up was deemed necessary as all organic causes for Sofia's presentation were ruled out on the ward. It was agreed to follow-up by phone with the dietitian.

Outcome

Sofia was reviewed by phone one month after her discharge from hospital and Mum reported that she was able to drink both Fortini Smoothie Multi Fibre bottles and eat a whole pot of Fortini Creamy Fruit each day. She had just returned from the GP surgery and had gained 2kg, and her weight was now 20kg (<0.4th centile). Sofia was very happy as she was able to return to her swimming class with her friends and had more energy.

Sofia received treatment by her local CAMH Service for ARFID, which included messy play sessions with the occupational therapist and anxiety management work with the psychologist. These interventions helped Sofia further expand her diet.

Sofia continues to have a lack of interest in food but has learned to eat and take her supplements at set times during the day. She also understands that she must continue this to keep her energy levels up and be able to enjoy school and swimming lessons.

Four months after discharge from the ward, Sofia attends an out-patient clinic, she continues to make good progress and has started to grow in height again. She is now 23kg (>0.4th centile) and 128cm (>2nd centile).

Discussion

The diagnosis of Avoidant Restrictive Food Intake Disorder (ARFID) was classified by the American Psychiatric Association back in 2013.[1] For some, there is a clear reason why they develop ARFID, such as a choking or vomiting episode, but for others there is no one reason, but many overlapping factors. In the case of Sofia this diagnosis was made by the multidisciplinary team in CAMHS – which included a mental health dietitian, occupational therapist, and psychologist. This diagnosis can be defined by several parameters but for Sofia the following were met:

- Significant failure to achieve expected growth and,
- significant nutritional deficiency and,
- a lack of interest in eating and drinking.

For children like Sofia, ONS are useful to increase the energy and protein density of the diet as well as the micronutrient content, which in this case was needed to support catch-up growth. As Sofia was able to manage a strawberry yoghurt and a fruit pouch, prescribing Fortini Smoothie and Creamy fruit were logical choices. Fibre was also considered important for Sofia who had a low fibre intake and a tendency to constipation (passing stool once/week). Fortini Smoothie Multi-Fibre provided 5.6g of mixed fibre - ~35% or 1/3 of her daily needs according to the European Food Safety Authority (EFSA) recommendation of 2019 (7-10 years = 16g/day).[2] In addition, a 200ml supplement was preferred over a compact format to support her hydration and bowel movements.

Conclusions

Sofia, a 10-year-old with a late diagnosis of ARFID, had poor growth, low nutrient status and constipation due to restrictive eating habits. Following dietetic intervention using nutrient enriched ONS with fibre (Fortini Multifibre Smoothie and Fortini Creamy Fruit) along with support from the local CAMH service, Sofia achieved catch-up growth and became less restrictive in her behaviour. ONS are a useful tool to support growth in children with ARFID, but these children also require MDT support. Sofia is now able to go to school with energy and enjoy her swimming lessons, which for her are the most important things!

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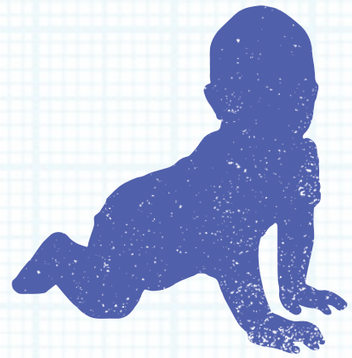
Nutrition support principles for children with congenital heart defects

Introduction

Congenital heart disease (CHD) is the most common congenital abnormality affecting 9 per 1000 live births. The advances in surgical techniques have improved survival rates but growth failure following cardiac surgery is common and associated with increased risk of mortality.[1,2] In the last ten years there has been a focus on trying to improve growth amongst infants with CHD, before and after surgery, to reduce poor outcomes as well as improving longer term metabolic outcomes.[3]

Improving nutrition outcomes in infants with CHD with the early use of nutrient energy dense infant feeds

A nutrition pathway to support growth in infants before surgery using nutrient energy dense infant formula, in combination with breastmilk or standard infant formula, in the first few weeks of life[3], has been shown to improve growth at 4 and 12 months of age.[4] However, despite the use of nutrient energy dense feeds, some infants and children will continue to experience growth failure. A recent study used machine learning to better understand possible causes of undernutrition in children with CHD one-year after surgical repair. Important predictive factors for poor weight gain were found to be having a low weight-for-age at the time of surgery and 1 month following surgery. Persistent thinness was associated with the length of time spent in hospital and the type of infant formula used. Finally, shortness was influenced by height-for-age z-score following surgery, and at the point of discharge, along with the duration of aortic clamping time during cardio pulmonary bypass time.[5] Other factors associated with poor growth in post-surgical repair is the ongoing need for medication to support cardiac function[6], suggesting there may be increased requirements due to reduced cardiac function or poor intake due to a lack of appetite.[7] Feeding difficulties due to early life experiences and lack of normal feeding[8,9] in children with CHD is also very common, often contributing to selective eating patterns, sensory issues, and a lack of appetite.[10]

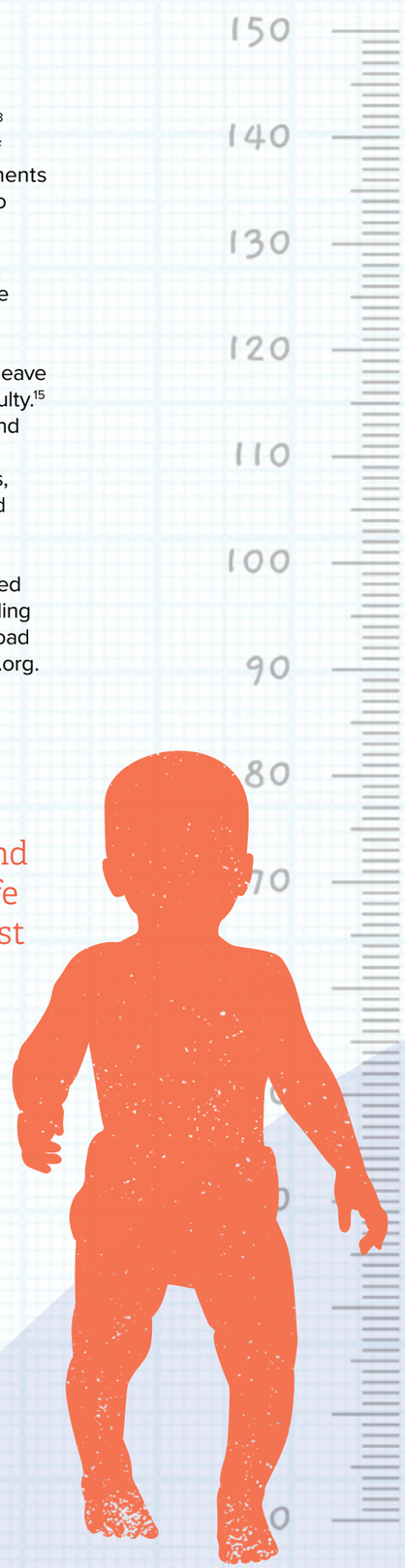


Why is it important to know this?

Most infants with CHD are born around the 25th–50th centile.[2] Children who are tracking along a lower centile line, i.e. 2nd centile (<-2 z-scores), may not be achieving their growth potential. As such, using dietary recall methods or a food diary is important to better understand whether children have i) reduced or low intake of energy, ii) increased losses through ongoing gastrointestinal symptoms, or iii) increased requirements. Many young children will be on a nutrient energy dense feed at the age of 1 year or 10kg, therefore, switching to an age-appropriate oral nutrition supplement is often required. In these circumstances, it is useful to start with options that have a similar macronutrient composition to the nutrient energy dense feed, i.e. a 1kcal/ml oral nutritional supplement (such as Fortini 1.0), as these are likely to be better tolerated. Children with CHD often experience delayed gastric emptying with increased risk of gastro-oesophageal disease (GORD).[11,12] As energy and protein density impact gastric emptying, symptoms of GORD can be exacerbated, increasing the risk of feeding difficulties.[12,13] As children get older, the use of 1.5kcal/ml oral nutrition supplements may be useful between meals to boost nutrient intakes.

For parents of children with CHD, feeding and mealtimes can be the cause of significant distress[14,15], especially as, following cardiac surgery, up to 9% of children will leave hospital with a new feeding difficulty.[15] Mealtimes are often a battleground as many children with CHD have problematic mealtime behaviours, selective or restrictive eating, and oral processing dysfunction.[13] To try and better support families of children with CHD, we co-designed a series of recipe books and feeding information[16], available for download at www.congenitalheartnetwork.org.uk/nutrition.

> Poor growth beyond the first year of life is common amongst children with congenital heart defects (CHD).



What are some of the practical ways to offer nutrition support?

1. Offer favourite foods and appropriate portion sizes at mealtimes.
2. Limit mealtimes to around 15-20 minutes.
3. The latest advice is to include nut butters as part of complementary foods. Foods can be enriched at mealtimes with nut butters (i.e. three times a day), this can be in hot meals including breakfast porridge or as a between meal snack. Careful consideration is required if there is a history of nut food allergy or a family history of nut allergies.
4. Offer oral nutrition supplements as a bedtime drink and as part of breakfast.
5. Be creative with how oral nutrition supplements can be used, i.e. as a dessert and using neutral flavoured options in foods.
6. In children with low appetites, it may be better to avoid snacks, although some children will do better with small snacks and small meals – each child will require a personalised approach.
7. Avoid adding cream, butter, extra cheese, oils, and fats to meals as the increased fat content may increase symptoms of GORD and nausea.
8. Offer regular follow-up, ideally every 3 months, to track growth and provide families with much needed encouragement and support.

Conclusion

Children with CHD are medically complex, with poor growth which is associated with poorer outcomes. Children growing along a low centile line will require additional nutrition support to promote catch-up growth, i.e. an extra 300-500kcal per day. The use of nutrient energy dense feeds for infants and oral nutrition supplements for young children can help achieve these goals but should be provided in a way that does not impact on intake of food at mealtimes.

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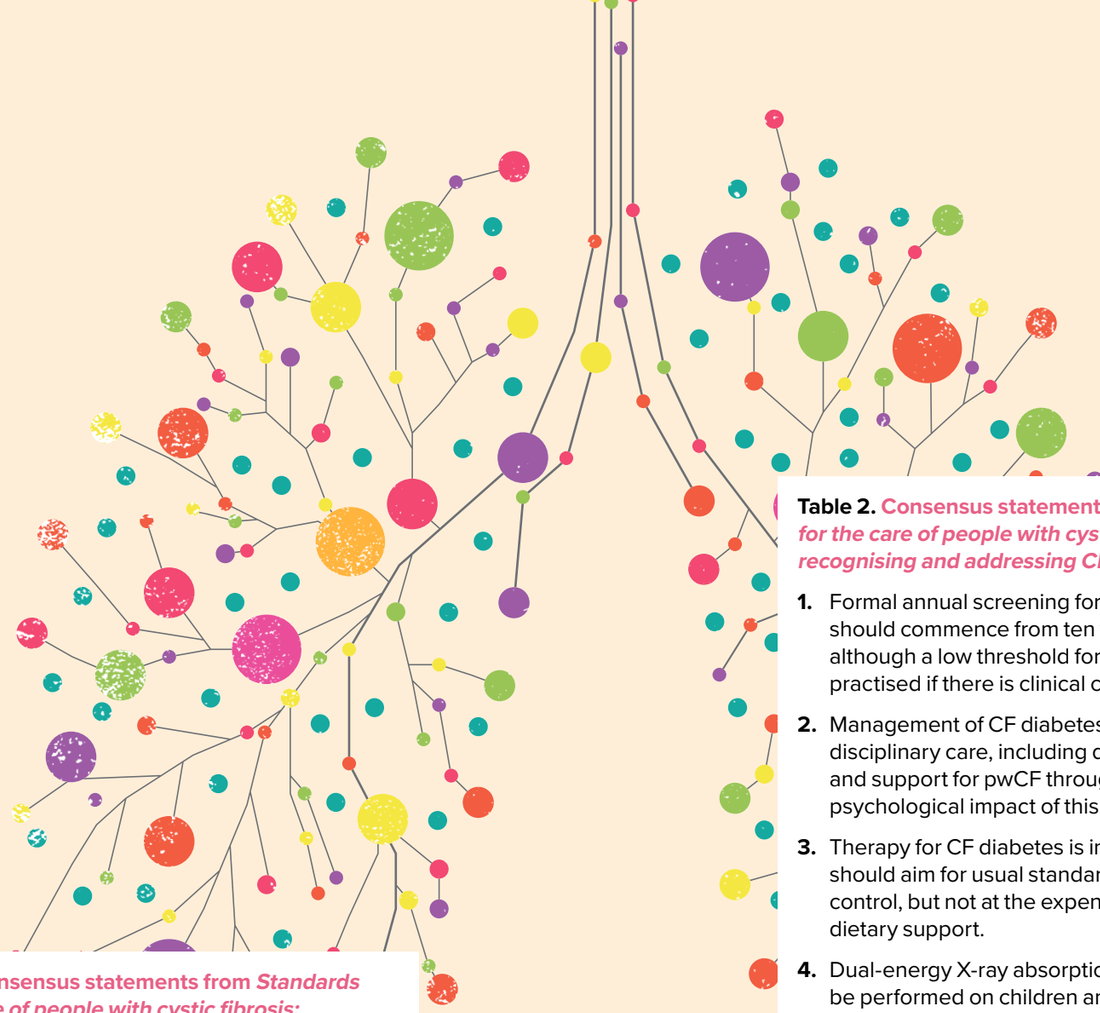
NUTRICIA ACADEMY NA
Feed your mind

BY JACQUI LOWDON
Clinical Specialist Paediatric Dietitian,
Cystic Fibrosis

A summary of the European Cystic Fibrosis Society (ECFS) standards series



Recently, a series of four papers have been published updating the European Cystic Fibrosis Society (ECFS) standards for the care of people with cystic fibrosis (pwCF). The first paper (Castellani et al, 2023) "A timely and accurate diagnosis" outlines the development of newborn bloodspot screening (NBS).[1] Countries with well-established NBS programmes are now reaping the benefits of early diagnosis, allowing pwCF to achieve excellent nutritional status, one of the basic principles underpinning CF care.

The second paper (Southern et al, 2023) discusses the changes in CF care, highlighting significant developments over the past two decades.[2] The first three sections of this paper discuss the essential components of ensuring good health: achieving excellent nutrition, maintaining airway health, and promoting exercise. Models of care are considered, including remote care, and the last section covers the management of medications. This review includes a consensus on 28 statements, with seven focused on nutrition (Table 1).
The nutrition section includes infant feeding, supporting good eating habits, dietary content and eating behaviours, pancreatic enzyme replacement therapy (PERT) and maintaining good nutritional progress.

Table 1. Consensus statements from *Standards for the care of people with cystic fibrosis: establishing and maintaining health*[2]

1. Whenever breast feeding is possible, it should be encouraged and supported for infants with CF.
2. Infants with CF presenting with meconium ileus are at risk of both short and long-term nutritional deficits and require early support from the CF team.
3. Support from a specialist CF dietitian is essential.
4. The CF team should encourage healthy feeding behaviours early in life to promote a good relationship with food and a positive body image.
5. Pancreatic enzyme replacement therapy should be initiated if there is clinical evidence of pancreatic insufficiency.
6. Nutritional status should be monitored at each clinic visit.
7. For people on Cystic Fibrosis Transregulator Modulator (CFTRm) therapy, special consideration should be given to the need for salt and vitamin supplementation.

> "Whenever breastfeeding is possible, it should be encouraged and supported for infants with CF."

Table 2. Consensus statements from *Standards for the care of people with cystic fibrosis (CF): recognising and addressing CF health issues*[3]

1. Formal annual screening for glucose intolerance should commence from ten years of age for pwCF, although a low threshold for screening should be practised if there is clinical concern.
2. Management of CF diabetes requires multi-disciplinary care, including diabetes specialists, and support for pwCF through the significant psychological impact of this diagnosis.
3. Therapy for CF diabetes is insulin based and should aim for usual standards of glycaemic control, but not at the expense of high-nutrient dietary support.
4. Dual-energy X-ray absorptiometry (DXA) should be performed on children and adults with CF, who are at risk of low mineral density, for example: low Body Mass Index (BMI), low FEV1*, history of steroid therapy, history of hypogonadism.
5. Bisphosphonates should be considered for pwCF with significant osteoporosis on DXA scan despite standard therapy (adequate nutrition, physical activity, and calcium/vitamin D supplementation).
6. CF teams should take active measures to minimise the risk for pwCF developing renal compromise or stones, including routinely assessing for acute kidney injury and chronic kidney disease, modifying potentially nephrotoxic treatments, and ensuring adequate hydration.
7. Constipation and Distal Intestinal Obstruction Syndrome are common comorbidities and CF physicians should routinely assess if pwCF are experiencing symptoms suggestive of these conditions.
8. Screening for colorectal cancer in pwCF should commence at an earlier age than the general population.

**Force Expiratory Volume 1*

Whilst the first two papers focus on "timely and accurate diagnosis" and "establishing and maintaining a healthy life", the third (Burgel et al, 2024) examines the potential challenges that pwCF encounter. Early identification and timely intervention in CF specific health issues is essential.[3] Complications covered include CF diabetes (CFD), CF liver disease (CFLD) and CF bone disease. Again, there is a consensus on 28 statements, with eight focused on nutrition (Table 2).

The fourth paper (Southern et al, 2023) "Planning for a longer life"[4] builds on the issues covered in the previous three papers. It explores the challenges that pwCF now face, due to an increased life expectancy.

Following on from this series, an update on the nutritional care of infants, children and adults with CF has been published (Wilschanski et al, 2024).[5] In summary, supplementation of vitamins and PERT have mainly remained the same, whilst sections on pregnancy, CFD, CFLD, CF bone disease, probiotics, nutrition, and mineral supplements have been extended. New sections include nutrition after organ transplantation and nutrition with highly effective modulator therapies. Some recommendations from the new guideline have been summarised below.

Nutritional assessment and monitoring

Since the 2016 guidelines,[6] there has been a growing body of evidence demonstrating that body composition is central to a comprehensive nutritional status assessment. The new guidelines contain a complete section summarising the literature and recommendations on methods of body composition assessment.

Bone disease

A more detailed section on bone disease is included, with recommendations on when to repeat the DXA scan, e.g. depending on the presence of risk factors and the previous results.

Probiotics

Since the 2016 nutrition guidelines were published, studies have not observed benefits from using probiotics/synbiotics on nutritional status, pulmonary function or quality of life (QOL), whilst reported benefits to the gastrointestinal (GI) system are conflicting. The authors therefore concluded that, due to the low quality of evidence, they cannot advise on their use to improve clinical outcomes in CF at present.

Lung transplant (LT)

LT remains the ultimate therapy for end stage lung disease in CF. Post LT, BMI recovery, or an improvement in BMI 1 year post LT, might be associated with better survival, especially in the more malnourished pwCF.[7] Consequently, it is recommended that nutritional support should aim for maximal BMI recovery.

Cystic Fibrosis Transregulator Modulator (CFTRm) therapy

The effect of CFTRm on body weight and BMI varies according to the type of CFTRm used and the genetic mutation of the pwCF.[8] For example, those who commenced on Elexacaftor-Tezacaftor-Ivacaftor (ETI) experienced the most significant increase in body weight and BMI. Therefore, appropriate dietary advice should be provided prior to commencing CFTRm, including discussions about possible weight gain and any resultant body image concerns. To date, there is limited data on the effects of CFTRm of body composition. Further studies are required to examine the effects of different CFTRm therapies and the long-term implications.

GI symptoms appear to improve after commencement of CFTRm but should be closely monitored.[9]

Reports suggest that CFTRm also alters plasma fat soluble vitamin (FSV) status.[10,11] Therefore, routine monitoring of FSV levels, especially vitamin A, following commencement of CFTRm therapy is recommended.

In addition, variable effects on blood pressure and plasma lipid profiles have been noted in patients on CFTRm.[12] As the "CF legacy diet" previously encouraged a high fat, high salt intake, it is now recommended that pwCF on ETI maybe at risk of hyperlipidaemia and hypertension, and therefore, lipid profiles should be checked annually on CFTRm and advice provided accordingly. Blood pressure should also be monitored at least every three months after commencement of CFTRm and annually thereafter. Although this may be more pertinent in the adult population, as paediatric dietitians we need also to be considering the long-term health of our pwCF.

Good nutritional status remains of paramount importance in CF care. The very first ESPEN-ESPGHAN-ECFS guidelines on nutrition care for pwCF was published in 2016.[6] This series is an update of the guidelines, including the benefits and challenges that are faced by pwCF as we make advances in care.

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Ask The Experts

Do you have a question for our expert?

Email **resourcecentre@nutricia.com** and your question might be answered in our next edition!

Dr Luise Marino

Nutrition support principles for children with congenital heart defects

Q. What % of infants (roughly) that you see in your practice require (or are prescribed) a nutrient energy dense formula before and after surgery?

In our experience the majority (55%) of infants with Congenital Heart Defects (CHD) will require a nutrient-energy dense feed (including extensively hydrolysed) before and after surgery, with the remainder given a combination of nutrient energy dense feed and breastmilk (30%), or standard infant formula (15%). For those infants who are undernourished, nutrition support is required until catch-up growth has been achieved (i.e., back to their birth centile or one centile line below).

Breeana Gardiner

From surviving to thriving in childhood cancer survivors

Q. What key areas do you discuss with children and families as they near the end of treatment?

The areas that I focus on with children and families, as they near the end of treatment, will be very much dependent on the individual child's clinical and nutrition status, as well as their needs and priorities.

Important areas to address are any dietary restrictions or dietary modifications that may have arisen during their cancer treatment leading to nutrient deficits or adverse changes in eating behaviours. My aim is to move them towards normalising meal patterns and routines, emphasising the importance of maintaining a healthy balanced diet for long-term health and recovery. Dietary quality is another important focus area – here I encourage increasing or maintaining their intake of fruits, vegetables, and whole grains (fibre) to help establish life-long healthy eating habits. I will also look at their calcium and vitamin D intakes and encourage dietary sources (or supplementation for vitamin D), following national guidance to optimise bone health. In addition (depending on the child), I may discuss the importance of maintaining a healthy weight, encouraging a healthy lifestyle with physical activity to reduce the risk of later life disease.

Finally, in those children that are tube fed, I introduce the concept of transitioning from the tube feeds to eating orally (in agreement with the multidisciplinary team). For this I will develop a plan, together with the child and family, aiming to ensure the child meets their full nutritional needs as they gradually transition.

The Children Childhood and Leukaemia Group (CCLG) have some great resources about life after cancer which can be found here: cclg.org.uk under 'Our Publications: after treatment finishes'.

Lucy Upton

Navigating the journey from complementary feeding to milk reintroduction in infants with cow's milk allergy

Q. When advising parents on the introduction of other food allergens to their infants' diet, how much time do you suggest between the introduction of each new allergen?

As general guidance, I would suggest leaving 2-3 days between introductions, particularly between food allergens that may be more commonly associated with non-IgE-mediated allergic presentations, e.g. egg and soy. In practice, some families may choose to take a little longer between allergen introductions, but conversely, I find that some are happy to move on more quickly, especially with foods more commonly associated with IgE-mediated allergic presentations, such as peanuts and tree nuts.

Catherine Casewell

Nutritional management of preterm infant's post-discharge - 'The Graduates'

Q. What clinical parameters do you use in your unit to decide which infants require additional breastmilk fortification after discharge?

When infants are being prepared for discharge from our neonatal unit, breastmilk fortifier (BMF) will have been gradually weaned down to approximately 2% (half strength) while weight gain is monitored closely. We measure and plot the following parameters on a Neonatal Close Infant Monitoring (NCIM) chart: twice weekly weights for all infants and weekly head circumference, with length measurements monitored less frequently. These are reviewed with the team before deciding on the need for BMF on discharge home using the following criteria:

1. **If weight gain is increasing** by between 15-20g/kg/day in infants <2.0kgs, or 12-15g/kg/day in infants 2-2.5kgs, and increasing along their centile for 10-14 days prior to discharge, and aligning with appropriate length/head circumference centiles, then **BMF is discontinued prior to discharge**.
2. **Outside of these criteria, BMF will be continued on discharge** home and weaned off (as indicated) with the support of the outreach team and Dietitian. If BMF is required on discharge, the family will be provided with a supply and the infant will be monitored by the outreach team and Neonatal Dietitian. Further supplies will be obtained from their GP as required. Parents will also be provided with written instructions on preparation and storage of BMF on discharge.

On the unit, we encourage a Family integrated care approach with parents providing the majority of care. They will already be involved in preparing feeds, e.g. adding BMF to either 5ml of expressed breast milk (EBM), and giving it via syringe or teat prior to a breast feed, or to 25ml of EBM and offering it in a bottle before the rest of the feed.

DIARY DATES

30
APRIL 2024

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MAY 2024

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EAACI Congress 2024

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5-8
JUNE 2024

47th European Cystic Fibrosis Conference

Glasgow

2-5
JULY 2024

Nutrition Society Congress 2024

Belfast

3-5
OCTOBER 2024

BSACI 2024

Harrogate

21-22
OCTOBER 2024

Nutricia Annual Congress

Royal Society of Medicine, London

> The NHS quickly adapted to working remotely to keep alive the lifeline of services for patients and carers.

A DAY IN THE LIFE OF

A remote Specialist Paediatric Dietitian

Home working is a term laced with stereotypes such as working in pyjamas and waking up minutes before starting work. The pandemic catapulted many people into the confines of their makeshift home office. The NHS quickly adapted to working remotely to keep alive the lifeline of services for patients and carers. Virtual clinics, telephone calls and online MDTs became the norm and quickly formed the core elements of hybrid working.

Follow me into a day-in-the-life of a remote Dietitian

Not having to battle the beeping horns and endless lines of traffic means I can start the morning with a brew and log in for my 8.30am start. The lack of commute means I often start earlier and finish later – a genuine pitfall.

Each morning is the same, emails and clinic prep. I run four paediatric clinics a week covering general paediatrics, a special school, home enteral feeding caseload and two dedicated rapid-access cow's milk allergy clinics. Doing such a mixed caseload virtually would never have been something I envisioned when I started out as a Dietitian. I would often sit in face-to-face clinics waiting for the next patient, as DNAs (did not attend) were a common theme. The virtual clinics are very different – patients/carers can now access our NHS services without the burden of transport, parking or childcare, resulting in lower DNA rates.

Virtual clinics do have drawbacks – you no longer have the engagement of face-to-face contact and miss the patient involvement and interaction. Going from one call to another, the voices and clinical pictures merge into one. Which means, there is now an even greater importance for good documentation to recall patients when it comes to reviews, dealing with queries or MDT discussions. Interpreting anthropometry is difficult without seeing the patient. I rely heavily on up-to-date weights from over-stretched Health Visitors, school nurses and parents/carers. With a caseload of patients with varying neurodevelopmental problems, it's difficult to assess their weight distribution and whether the centiles paint the correct picture. A support network of school nurses, Health Visitors and Dietetic Assistant Practitioners are my eyes and ears who help inform my dietetic plans.

Once the clinic is over, it's lunchtime before I tackle the admin for the afternoon. There isn't the opportunity to lunch with colleagues and make close work friends, but you become virtual pen-pals. Even a quick social event isn't so quick...a 4+ hour round commute. I miss the banter in an office or hearing the latest gossip, celebrating a birthday or engagement and the office cake to accompany it.

My afternoon involves responding to letters and emails. I usually log off at 4.30pm, but the temptation to reply to one more patient is always there. Even in the later evening, you suddenly remember a task and feel the need to log on. The work-life balance sometimes sways in favour of work and I feel the need to prove that I am doing my hours.

Home working can be a great tool for our work-life balance; however, there is a danger that it can take over. After experiencing a 100% face-to-face role, 100% remote working and a hybrid role, I am leaning in favour of the latter. My work as a Dietitian still has the value of seeing patients, building rapport, recognising barriers and safeguarding concerns. However, home working provides the advantages of being able to work more efficiently, whilst lessening the financial burden of travel for patients/carers. It also has a cost-saving benefit, reducing the need for office space and potentially reducing DNA rates.

This is an emerging area, and I am sure the definition and role of home/hybrid-working will continue to evolve in the coming years and have a place in maintaining the balance between both our personal and professional lives.

Up2Date

Effect of oral nutritional supplements on outcomes in children presenting with, or at risk of, faltering growth in clinical settings: A systematic review and meta-analysis

Cawood AL et al. J Child Health Care. 2023;Jul 5:1367493523118518l. doi: 10.1177/1367493523118518l. Epub ahead of print.

In this systematic review, the authors summarised the evidence around oral nutritional supplement (ONS) use in children with, or at risk of, faltering growth (FG). The National Institute for Health and Care Excellence (NICE) definition was used to define FG, i.e. '*a slower rate of weight gain in childhood than expected for age and sex*' (NICE, 2017). The study aimed to systematically examine evidence from randomised controlled trials (RCTs) looking at the efficacy of ONS on a range of outcomes. Ten RCTs were included which assessed **changes in outcomes for children** receiving **ONS** compared to **controls.**

- **ONS** included those containing micronutrients and at **least two** macronutrients, consumed orally in hospital and/or community settings, with or without dietary counselling or usual dietary care.
- **Controls** were those who received their usual care, e.g. dietary counselling, usual dietary care (hospital food or food fortification), or placebo.
- **Outcomes** – included at least one of the following: anthropometrics, nutritional intakes, other clinical outcomes or acceptability.
- **Age range** – from 1 to 18 years.

Results:

Overall, 1116 children (average age 5 years; 59% male) were recruited within these studies, of which 52% received ONS. The mean intake of ONS was 412kcal, 16.3g protein, 395ml/day for an average of 116 days (~3.8 months).

Weight changes: ONS-feeding achieved superior weight gain compared to the controls. Of the ten studies included, six compared changes in weight (kg) over time – five of which reported greater increases in weight in the ONS-fed group vs controls; and two reported a statistically significant improvement in weight (when compared to dietary counselling) in children with a diagnosis of picky eating fed ONS for 90 days. The meta-analysis (4/10 studies) showed significantly greater increases in weight in the ONS-fed groups (mean increase of 0.4kg) compared to controls.

Height changes: ONS-feeding achieved superior height gain compared to the controls. The meta-analysis (3/10 studies) showed significantly greater increases in height in the ONS-fed groups compared to the control (mean increase of 0.3cm).

Body mass index (BMI) changes: ONS-feeding tended to achieve superior BMI compared to the controls. 4/10 studies reporting on BMI showed improvements in favour of ONS.

Body composition changes: no difference was seen between ONS-feeding compared to the controls. 3/10 studies reporting on body composition did not show any statistical significance between the groups.

Nutritional intakes: trend towards superiority in ONS-fed groups but not significant. 7/10 studies included nutritional intakes. There tended to be a higher intake of protein, energy and some micronutrients in the ONS-fed groups versus controls and one study reported a significantly improved appetite amongst the ONS-fed group.

Clinical outcomes, e.g. infection risk: trend towards superiority in ONS-fed groups. Infections – 2/10 studies compared incidence of upper respiratory tract infections and found it to be significantly lower in the ONS-fed group versus the controls. One study reported fewer bacterial infections 14 days post antibiotic therapy with ONS, but it was not significant.

Disease progression, e.g. remission: trend towards superiority in ONS-fed groups which was significant in those with cancers, but not in others. The disease remission rate was significantly higher amongst children diagnosed with malignant disease receiving ONS versus the control. Larger decreases in C-reactive protein (CRP) were reported amongst paediatric burn patients receiving ONS versus the control but it did not reach significance.

Acceptability: good overall, with up to 98% compliance in some ONS-fed groups. Gastrointestinal tolerance was included in 3/10 studies and all reported good tolerance. There was limited data on ONS liking reported in the studies. However, compliance was generally good in the 6/10 studies that included it as an outcome – 5 observed high compliance. Of these, 3 reported 98% compliance (range 94-100%) in the ONS-fed groups.

Summary:

ONS-feeding in children with FG was associated with **significantly greater gains in weight** (mean difference (MD) 0.4kg, 95% CI [0.36, 0.44]) **and height** (MD 0.3cm, 95% CI [0.03, 0.57]). The authors concluded that this was likely related to the improvements in nutritional intakes. In addition, there was a trend towards higher nutrient intakes, improved appetite, lower incidence of infections, improved remission rate in children with cancer, and generally high compliance to the prescribed dose.

This review provides evidence to support the use of ONS in the management of children with, or at risk of, FG.

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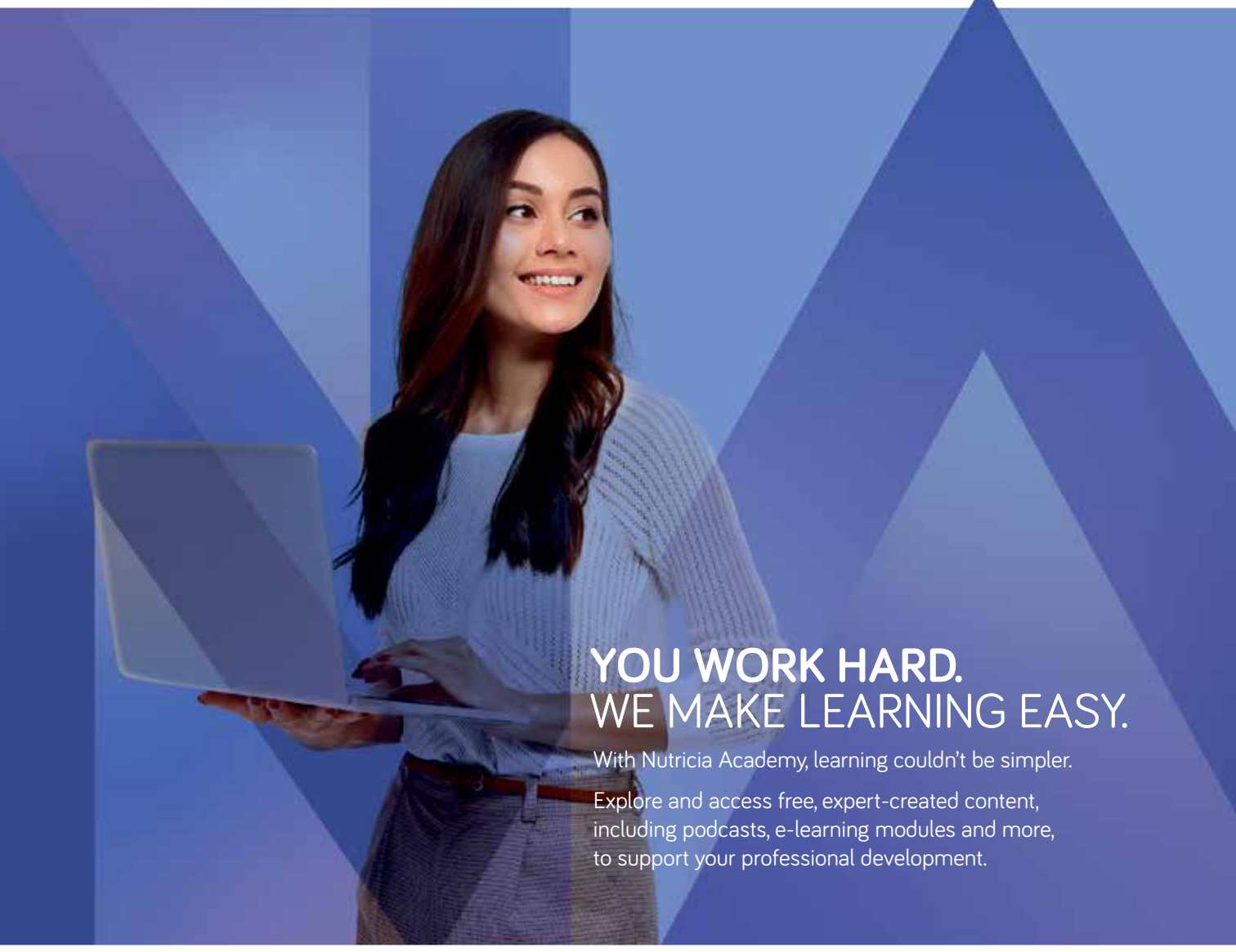

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