SMALL TALK

PAEDIATRIC NUTRITION UPDATE INTENDED FOR HEALTHCARE PROFESSIONALS ONLY | SPRING 2022

FALTERING GROWTH

Best practice sharing, tools and audit results

• TEMPLE Tools on Inherited Metabolic Diseases • ARFID: Support for Paediatric Patients
• Congenital Hyperinsulinism: Diagnosis and Management

EDITORS

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WELCOME

to our spring edition of Small Talk focusing on **faltering growth**

The collaboration between specialist centres and local services in the management of patients is fundamental in providing optimal patient care. By sharing clinical experience and joint ways of working, we can provide beneficial continuity for patients and their families, even in a pandemic! In this edition of Small Talk, you will find best practice sharing by healthcare professionals in specialist areas of dietetic management.

The edition starts with an article exploring the outcomes of a survey by the dietetic cardiology team at Great Ormond Street Hospital (GOSH), giving great insight into their work with local services, and recommendations for how a tertiary service can work with local teams.

A working group within the British Inherited Metabolic Disorders Group (BIMDG) have shared a unique view from their work on the TEMPLE (Tools Enabling Metabolic Parents Learning) modules.

We also explore the role of a dietitian in the management of avoidant restrictive food intake disorder (ARFID), by specialist dietitian Michelle Simpson, as well as an article by Annaruby Cunjamalay sharing her expertise on the management of patients with congenital hyperinsulinism.

In addition we've included three interesting case studies exploring the clinical rationale and decision-making process in the management of patients with a range of nutritional challenges.

We aim to include a comprehensive mix of content to help with your Continued Professional Development and, as always, we welcome any comments, feedback or contributions to future editions.

Best wishes

Vicki

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NUTRICIA
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Cardiac Infants: a Survey of How Feeding can Best be Supported by Outpatient Services

Brittany Rothman Highly Specialist Paediatric Dietitian - Cardiology
Catherine Kidd Highly Specialist Paediatric Dietitian - Cardiology & CICU

Infants born with congenital heart disease (CHD) are known to be a nutritionally vulnerable group, often presenting with malnutrition, feeding difficulties and growth failure prior to surgery.[1] An estimated quarter of patients prior to surgery can present with a weight for height <-2 SD and mean weight for age -1SD as well as 30% may cross down 2 percentile bands.[2] Improved nutrition pre-operatively is correlated with improved post-operative outcomes such as length of intensive care unit (ICU) stay, mortality and morbidity.[3]

The Great Ormond Street Hospital (GOSH) cardiac dietetics team currently provide a cardiac outpatient service to support pre-surgical infants and interstage single ventricle infants, in line with the Delphi consensus 'Nutritional Pathway for Infants with Congenital Heart Disease before Surgery'. These guidelines direct nutritional goals for this vulnerable group based upon diagnosis and growth history. We also support cardiomyopathy and chylothorax (non-congenital) patients. Patients are either looked after solely by GOSH dietitians, by their local dietitians, or care is shared between our service and the local team; this is individual to the patient rather than consensus or protocol driven.

The overall aim of this survey was to collect information from local dietitians to further develop our outpatient service that supports pre-surgical infants. We hoped this would allow us, as a tertiary referral centre, to better support local community services and the cardiac infants for which it cares. We considered the following main points:

1. Current outpatient dietetic services available in the community
2. Identify vulnerable cardiac infants that require tertiary centre input for optimal nutrition management
3. Awareness of Delphi guidelines and confidence in the use of Delphi guidelines
4. Ways to improve current service provision and support local services

METHOD

An anonymous survey created on SurveyMonkey was circulated (August-October 2020) to various NHS trusts, specialist groups (Paediatric Critical Care Society), social media platforms (Facebook and Twitter via BDA paediatric groups) and local dietitians whom we frequently liaise with. This survey was circulated via email, with some follow-up via telephone for additional information and reminder emails sent to collect further feedback, comments and to increase response rate. The survey was sent to (*n*=79) individuals and consisted of 16 questions including multiple choice answers and 'free text' boxes.

RESULTS

Current cardiac services available in the community

DEMOGRAPHICS

A response rate of 67% was achieved; Table 1 shows the locations services had covered:

Table 1

AREAS COVERED		
Bedfordshire	Greater London	Surrey
Berkshire	Hertfordshire	Sussex
Central London	Norfolk	Wessex &
Derbyshire	Oxfordshire	Channel Islands

WORK SETTING

96% of the respondents work within paediatrics only and 4% of the services covered both adults and paediatrics.

Survey results shown in Figure 1 indicate that respondents covered a variety of settings including: home-enteral feeding (HEF), outpatient services, general patient services and inpatient care.

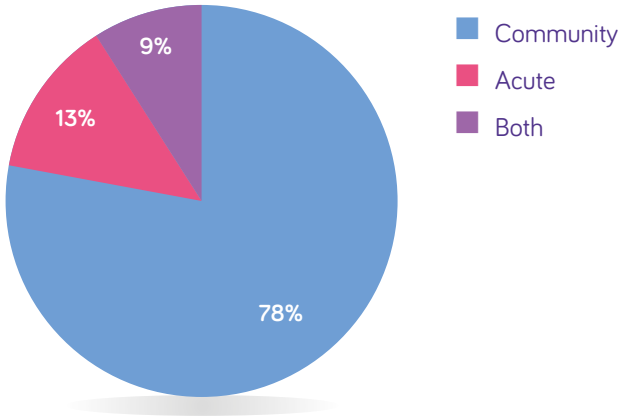


Figure 1 Area of Work Setting

REFERRAL CRITERIA FOR LOCAL TEAMS

Respondents were asked if there are referral criteria that would prevent acceptance of a cardiac infant on their caseload (i.e. fluid restriction/diagnosis/joint care/non-tube fed patient). Thematic analysis of the responses suggested the main exclusion criteria listed below:

- Non-tube fed patients
- Specialist diagnosis or have a secondary specialist diagnosis
- Frequent input, monitoring or follow-ups at specialist hospital
- Adequate growth
- Short term use of tube feeding (<4 months)
- Higher risk nutrition diagnosis based on Delphi guidelines
- Level of experience of staff: areas may be covered by locum dietitians
- Not under care of acute paediatrician or consultant
- Fluid restricted

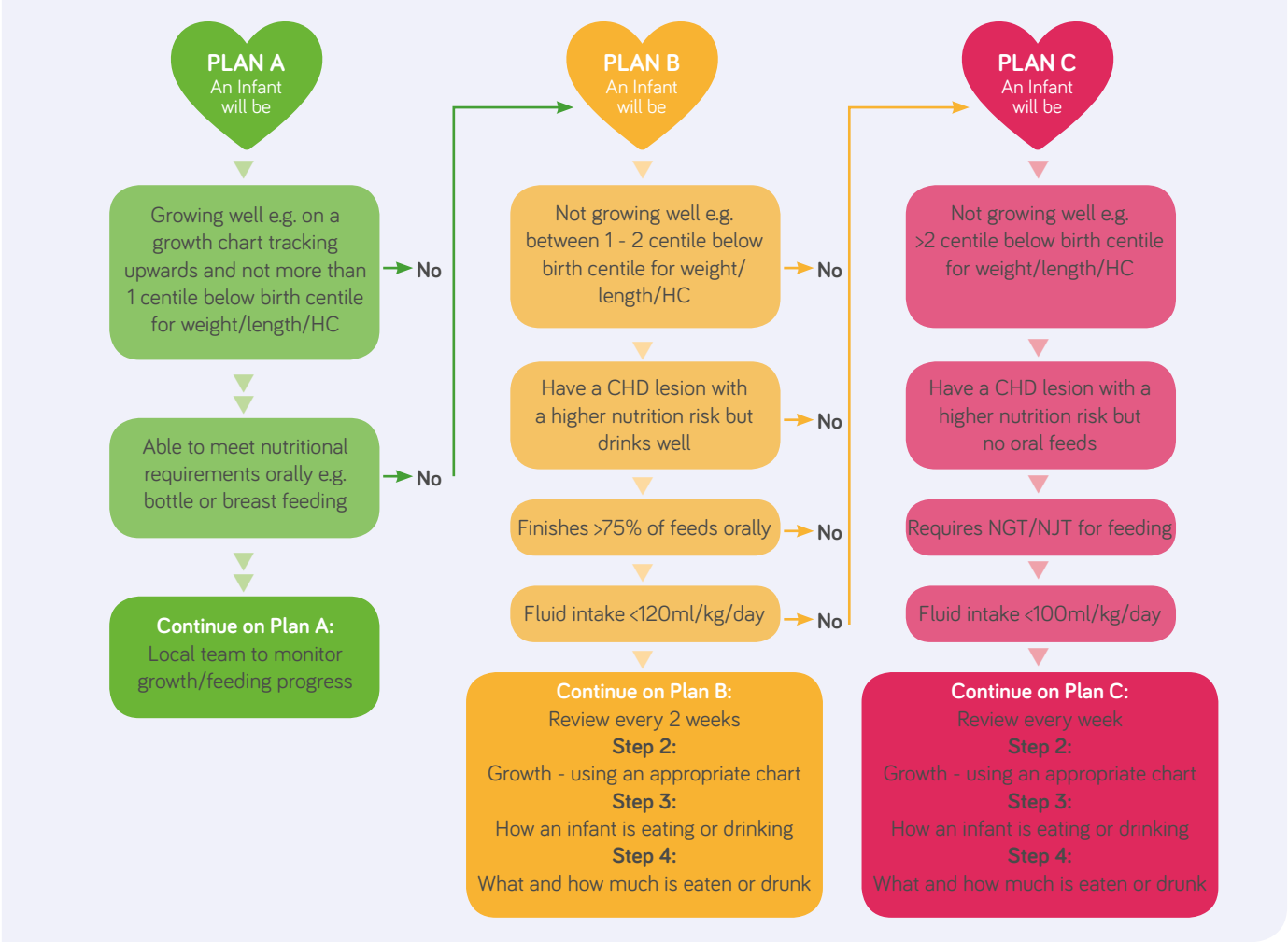


Figure 2: Choosing a Nutrition Care Plan: A, B, or C

Identify vulnerable cardiac infants that require additional input for optimal nutrition management

We wanted to identify the most vulnerable cardiac patients according to the Delphi guidelines, by determining where input and support may be most needed. In addition, we wanted to determine what the most common cardiac diagnosis is of patients being referred or reviewed in the community, as well as waiting times and frequency of patient reviews compared to the recommended frequency of review.

Table 2

Most commonly seen cardiac diagnosis	
Ventricular septal defect (VSD)*	Atrial Septal Defect (ASD)*
Tetralogy of Fallot (TOF)*	Hypoplastic left heart syndrome (HLHS)*
Patent ductus arteriosus (PDA)*	Post-surgical infants
Single ventricle	Cardiomyopathy
Heart failure	Pulmonary stenosis
Coarctation	Transposition of great arteries
HEF patients with cardiac background	Post-surgical cardiac infants

*Higher nutritional risk conditions

WAITING TIMES AND RESPONSE TO REFERRALS IN THE COMMUNITY

According to the Delphi guidelines, once cardiac pre-surgical infants are categorised into plan A, B, C, there are recommended guidelines for follow up as seen in Figure 2 above.[4] Respondents were asked for average waiting times for clinics in the community.

The average waiting times for the patients seen in the services are shown in Figure 3.

The majority of the respondents answered that patients could be seen in 0-1 month. Where answers stated 'other', thematic analysis indicated patients may be seen within 1-2 weeks of hospital discharge if meeting any of the following criteria:

- Urgent referral
- Under the age of one year- old
- HEF patients
- If deemed routine or non-urgent patients may be seen within 6-18 weeks

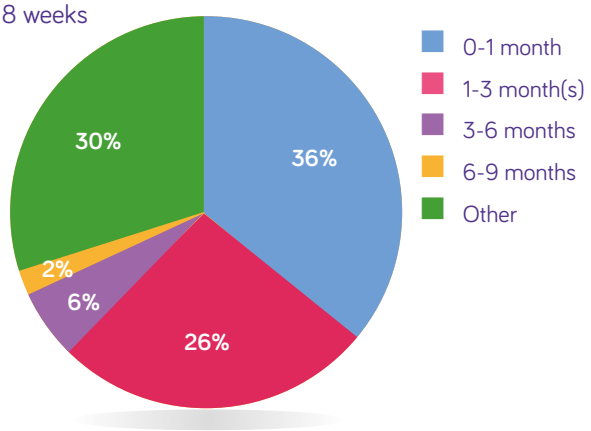


Figure 3 Average waiting times for patients seen in services

Compared to the Delphi guidelines, if patients were not deemed urgent, the recommended time for review could be exceeded. Further seen from the above data collection, there are higher risk nutritional diagnosis patients being referred in the community, which is important to identify as delayed consultation with a dietitian may exacerbate further nutritional deficits. It is noteworthy that this survey was conducted during the COVID-19 pandemic, which may have significantly impacted waiting times.

FREQUENCY OF REVIEW OF CARDIAC OUTPATIENTS
Respondents were asked how often patients are being reviewed or seen within the services, results are shown in Figure 4.

If answers indicated 'other', thematic analysis showed most common responses:

- Monitoring is dependent on growth, age and if the patient is tube fed
- Based on the clinical need
- Variable wait times: 1-3 months
- Dependent on capacity of dietitian
- As considered necessary by the dietitian, telephone reviews could be offered if more input is needed more frequently
- Level of support needed by family

MANAGEMENT OF CARDIAC INFANTS IN THE COMMUNITY
Local services were asked what the current barriers may be when seeing cardiac infants within the community. The most common barriers listed were:

- Fluid restrictions: teams struggle to have updates of fluid restrictions and are unable to reach calorie requirements due to this
- Unable to manage regularity of reviews due to widespread caseloads and non-funded services
- Lack of multidisciplinary input: local dietitians working in isolation find it difficult accessing specialist information
- Conflicting guidance: receiving outdated fluid allowances from the team and variation in nutrition practice
- Time restrictions
- Unknown guidelines for nutritional requirements

Other: lack of information sharing, unknown guidelines for requirements and conflicting information or guidance

Awareness of the Delphi guidelines and confidence in the use
The Delphi guidelines were published in April 2018 and disseminated by:

- Providing copies of the guidelines to the paediatric groups
- Publishing a Clinical Nutrition article
- Endorsement by the British Dietetics Association (BDA)
- Completing editorials in Dietetics Today
- Study day presentations
- Including them within the cardiac chapter of Clinical Paediatric Dietetics and Paediatric Dietetic Pocket Guide

57% of respondents were not aware of the guidelines; 43% were aware as shown in Figure 5.

Respondents were also asked how confident they felt using the Delphi guidelines in their practice. Results are shown in Figure 6.

Ways to improve current service provision and support local services
56% of respondents did not feel the GOSH dietitians needed to be involved and care could be managed locally, 44% indicated other (Figure 7).

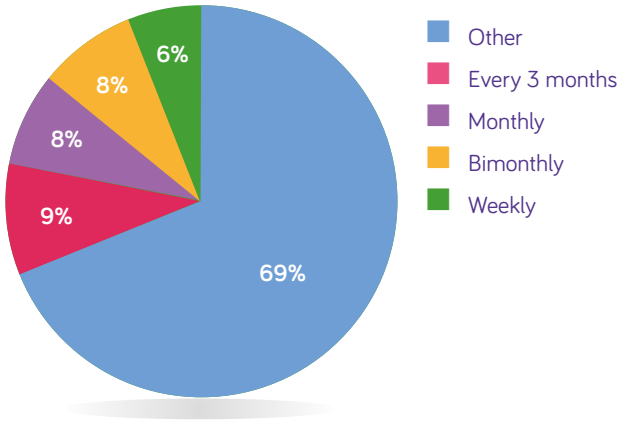


Figure 4 Frequency of patient reviews

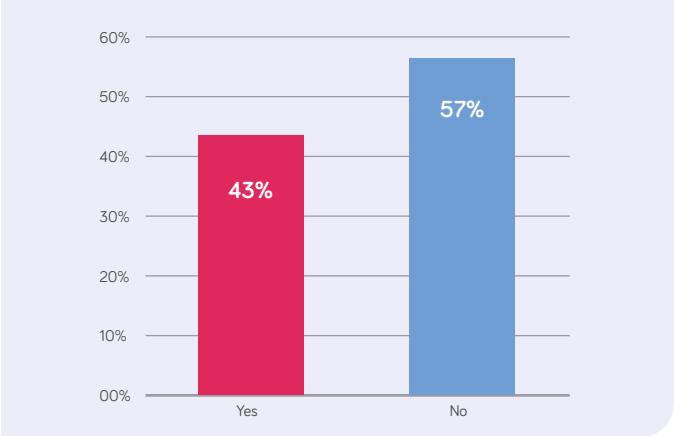


Figure 5 Awareness of the Delphi guidelines used as reference.

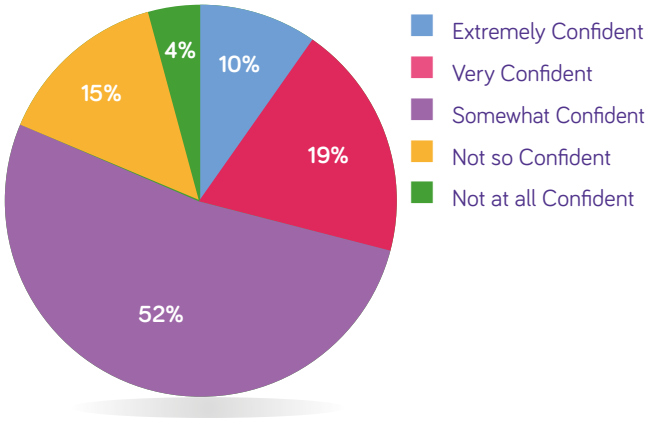


Figure 6 Confidence in using Delphi Guidelines

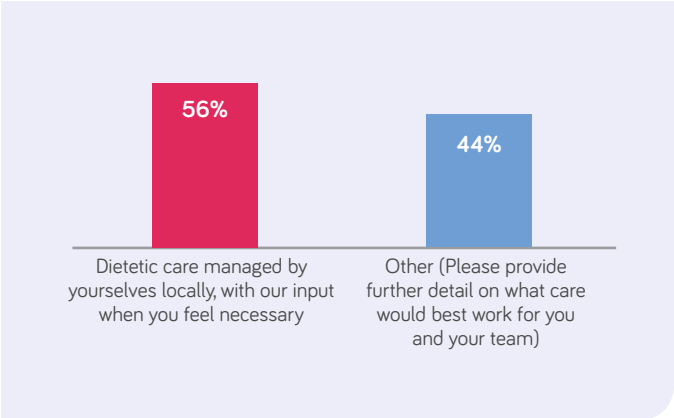


Figure 7 How do you feel these patients should best be managed?

Where respondents indicated 'other', respondents would prefer if GOSH kept dietetic care for:

- Patients that require more frequent input and review (weekly or biweekly)
- Safeguarding cases: joint care with the GOSH team
- Shared care for complex conditions
- Any patients with poor cardiac function, fluid restrictions and concerns with growth

What can the services do to help local dietitians in the community?

- Adequate handovers: sufficient information, indicating nutritional goals of the team as well as realistic expectations for growth in infants and any medical treatment or input in the community i.e. nutrition goals/long term expectations of growth and medical treatment
- Good communication: letters or emails to indicate any changes i.e. fluid restrictions, treatment and concerns
- Updated contact list of dietetic teams and health professionals involved which can be done annually
- Provide updated guidelines for these cardiac infants being discharged
- Provision of study sessions (via Zoom) or webinars which involve: Delphi guidelines, complex case studies, patient information leaflets or resources

Conclusion

Local dietitians are vital stakeholders in managing care for cardiac infants. As such, we are extremely grateful for the time taken by local dietitians to complete this survey. We have so far made a number of changes to our current service based upon the survey results with the following improvements:

1. Provision of a discharge 'pack' to local dietitians, including:
   a Copy of the Delphi guidelines
   b Most recent dietetic entry
   c. Medical discharge summary. This includes a feeding discharge 'template,' which has helped ensure that the cardiac dietitians standardise information provided on discharge. This includes: current anthropometry and target weight, fluid restriction, current feeding plan, GOSH follow up provision, contact details for GOSH dietitians, medical and nursing teams
2. Provision of study sessions and webinars which involve: discussion of the Delphi guidelines and complex case studies

The responses from this survey indicate that further data collection is needed to determine if there has been an improvement in awareness of the guidelines once changes in service have been made. As a tertiary centre we would like to work collaboratively and support teams in reviewing cardiac infants both preoperatively and postoperatively. We would also hope to further develop patient information such as leaflets and educational videos, which can then be shared with community healthcare professionals.

FOR A FULL REFERENCE LIST, PLEASE SEE **PAGE 25**

Acknowledgement Thanks goes to the following teams for the ongoing support: GOSH cardiac and ICU dietetics team, managing clinical lead and survey respondents for helping to share this vital information and for the ongoing support for education and service improvement.

Development of Educational Teaching Packages (TEMPLE) on Inherited Metabolic Diseases for Parents and Health Professionals

Professor Anita MacDonald Consultant Dietitian in Inherited Metabolic Disorders, **Karen van Wyk** Clinical Specialist Dietitian, **Pat Portnoi** (retired) Specialist Dietitian, **Rachel Skeath** Paediatric Metabolic Dietitian

BACKGROUND

Inherited metabolic disorders (IMDs) are rare, chronic, lifelong conditions which can cause physical and psychological dysfunction; some are life-limiting. They may be detected by newborn screening or present with clinical symptoms. Management is complex and requires close monitoring particularly during times of acute illness due to the risk of metabolic decompensation. A subgroup of IMDs are managed through dietary modification with or without medications.

The diagnosis of a metabolic disorder is unexpected and involves a lot of uncertainty about the future. The names of the conditions are long and will be unfamiliar to families. Parents commonly look to the internet for clarification, but this risks accessing inaccurate or misleading information. There is limited material available that is reliable and written for the non-expert. Clear and straightforward educational resources that can be given to families at the time of diagnosis are essential.

Drs Wendel and Burgard from Germany, in 2013 developed a set of modular teaching slides for healthcare professionals to use with parents/caregivers following the diagnosis of an IMD. This teaching package entitled TEMPLE (Tools Enabling Metabolic Parents Learning) helped medical doctors ensure that any teaching was delivered in a consistent and standardised manner using materials produced by considered methodology. It was very detailed, covering a range of IMDs and even gave health professionals guidance on the best seating plans for the clinic room. The material produced was comprehensive, but potentially not in a suitable format to give out to parents and carers who may not have medical, metabolic and biochemical knowledge.

Formation of a working group

In 2014 Nutricia purchased the rights to TEMPLE and the British Inherited Metabolic Disorders Group (BIMDG) of Dietitians formed a small working party to review the original teaching package, addressing the identified need for educational resources. Core working group members throughout the development of the paediatric TEMPLE resources were: Rachel Skeath, Karen van Wyk, Pat Portnoi and Anita MacDonald.

TEMPLE modules

TEMPLE modules were written for the IMDs in which dietary modification is central to management. Modules were initially prioritised and developed for each of the IMDs detected by newborn screening in the UK. Additional modules have been written since these and there are now 23 different modules available (Table 1). Most of the modules are available in an A5 teaching booklet and online slides. Some of the rarer conditions are available in online format only from the BIMDG website https://www.bimdg.org.uk/site/temple.asp and https://www.nutricia.co.uk/hcp/resource-centre/tools-enabling-metabolic-parents-learning.html

IMD Condition	Colour	Booklet	Online
Amino acid disorders			
Phenylketonuria (PKU)		✔	✔
Homocystinuria (HCU)		✔	✔
Maple Syrup Urine Disease (MSUD)		✔	✔
Tyrosinaemia type I (HTI)		✔	✔
Tyrosinaemia type II (HTII)		✘	✔
Organic acidaemias			
Glutaric aciduria type I (GAI)		✔	✔
Methylmalonic aciduria (MMA)		✔	✔
Propionic aciduria (PA)		✔	✔
Isovaleric acidaemia (IVA)		✔	✔
Urea cycle disorders			
Citrullinemia		✔	✔
Arginino succinic aciduria (ASA)		✔	✔
Ornithine transcarbamylase deficiency (OTC) deficiency		✘	✔
Arginase deficiency		✘	✔
Carbohydrate disorders			
Galactosaemia		✔	✔
Glycogen Storage Disease Type Ia		✔	✔
Glycogen Storage Disease Type Ib		✔	✔
Glycogen Storage Disease Type III		✔	✔
Fatty acid oxidation disorders			
Medium Chain Acyl-CoA dehydrogenase deficiency (MCADD)		✔	✔
Very long chain acyl-CoA dehydrogenase deficiency (VLCADD)		✔	✔
Long chain acyl-CoA dehydrogenase deficiency (LCHADD)		✔	✔
Carnitine palmitoyltransferase I (CPTI) deficiency		✘	✔
Carnitine palmitoyltransferase II (CPT II) deficiency		✘	✔
Carnitine acyl carnitine translocase (CACT) deficiency		✘	✔

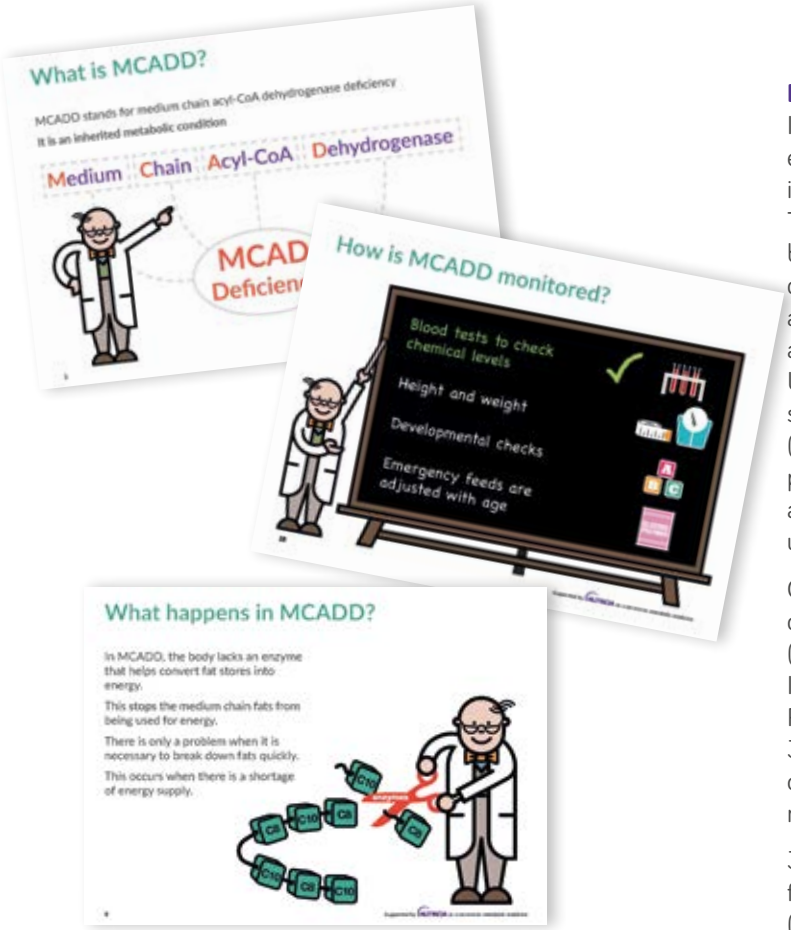
Online downloadable slides available from BIMDG website: https://www.bimdg.org.uk/ and https://www.nutricia.co.uk/hcp/resource-centre/tools-enabling-metabolic-parents-learning.html

Figure 1 Guidance for downloading TEMPLE slides from BIMDG website. Click on the 'Education' section as indicated.

The TEMPLE module philosophy

The TEMPLE slides and booklets are designed as a resource for dietitians or healthcare professionals, providing clear, core introductory information suitable for parents and caregivers of newly diagnosed infants or children. It was considered central to uphold the philosophy of the original teaching package and standardise the format and content of the educational material.

The TEMPLE modules enable a structured approach to the initial visit with simplified text and colourful graphics to help the dietitian or healthcare professional explain each condition. It is intended that the healthcare professionals give further individualised teaching together with a patient specific management and monitoring plan. Parents/caregivers can take home the TEMPLE resources from their clinic appointment and refer to them again later to gain a better understanding of the condition. They can also be used to help explain the condition to others such as extended family members, child minders, nursery workers, school staff and other interested parties.



TEMPLE module design and production

Each TEMPLE module was developed according to a rigorous process, with wording and format agreed by all the team members. They were checked for consistency with other modules and reviewed by an IMD physician. Initially the group had one face to face meeting each year, with the remainder conducted by evening telephone conferences. In the last three years, the project has continued with video or phone conferencing. Approximately five modules were developed each year, with some updates completed as necessary to standardise information. The date of the most recent version of each individual TEMPLE module is listed on the BIMDG website.

Format of each TEMPLE module

The slides and booklets include the following:

- The name of the condition and guidance about its pronunciation
- An explanation of the condition
- Pathophysiology and biochemistry
- Function and metabolism of relevant nutrients according to the condition e.g. protein, fat or carbohydrate
- Clinical outcome with and without treatment
- Method of diagnosis
- Dietary management and other medical treatment
- Illness management
- Monitoring
- Genetics
- Summary

Evaluation of TEMPLE

In April 2020 the working group designed a short survey to evaluate the use of TEMPLE with parents and caregivers of infants/children newly diagnosed with a metabolic disorder. The aim of the survey was to obtain feedback on the TEMPLE booklets, how they were used and determine if any improvements could be made. The survey (a 10 question SurveyMonkey) was available on the National Society for Phenylketonuria (NSPKU) and Galactosaemia Support Group websites. Metabolic Support UK also encouraged parents and caregivers to complete the survey. There were 61 responses, but unfortunately only 56% (*n*=34) had read the booklets. Many responses were not from parents/caregivers of newly diagnosed infants or young children and so did not meet the criteria of the survey, but they gave useful feedback.

Of the 61 responses, 18% (*n*=11) were parents/caregivers of children ≤1 year, 33% (*n*=20) 1-5 years, 10% (*n*=6) 6-11y, 36% (*n*=22) ≥11y, and in 3% (*n*=2) the age was not specified. The main IMDs represented in the survey were galactosaemia 46% (*n*=28), PKU 25% (*n*=15), HCU 7% (*n*=4), MCADD 7% (*n*=4) and VLCADD 3% (*n*=2). There were single responses from parents/caregivers of children with 7 other conditions and one respondent did not name any condition.

35 respondents said they received the booklets from the following sources: support groups 37% (*n*=13), dietitians 29% (*n*=10), doctors 21% (*n*=7) and nurses 6% (*n*=2). A further 9% (*n*=3) received the booklets from multiple sources.

69% (*n*=18/26) of parents/caregivers said that the booklets helped them understand the condition and 85% (*n*=28/33) said they would recommend the booklets to others. Evaluated from 34 responses, booklets were used to educate family (56%, *n*=19), friends (24%, *n*=8), child minders, nursery and schools (27%, *n*=9), and GP/other health professionals (15%, *n*=5).

The parents/caregivers responded that they found the TEMPLE booklets easy to read, contained accurate information, had helpful graphics and enabled them to learn about the condition. As over one third of respondents were parents/caregivers of older children, this indicates an interest in the development of similar resources for older age groups.

Availability

Dietitians and other healthcare professionals can order copies of the TEMPLE booklets from Nutricia. They are available free of charge. The online slides are accessible from the BIMDG website https://bimdg.org.uk/site/temple.asp and https://www.nutricia.co.uk/hcp/resource-centre/tools-enabling-metabolic-parents-learning.html.

The PKU module is available through the NSPKU website and the Galactosaemic Support Group distribute the galactosaemia module to their members.

The Future

The TEMPLE resources are being adapted and used in many countries throughout the world. Teams in the USA have produced short teaching videos using much of the format written by the BIMDG-Dietitians group. They have also been translated into other languages.

Discussions are now taking place to develop TEMPLE modules for adults starting with maternal PKU. Further modules will be developed according to patient need and priority. The convenience of online educational material has been recognised during the COVID-19 pandemic and endorses the potential value of TEMPLE modules as an accessible, reliable resource for use with patients and families.

Acknowledgements

We would like to recognise the help and support of Diana Webster, Rychelle Winstone, Ewan Forbes and Heidi Chan in this project.

It would also not have been possible without the considerable support of the Nutricia team who provided artwork, financial and administrative support.

Disclaimer

The artwork was produced by Nutricia with specific guidance provided by the working group. Although these resources have been supported by Nutricia, the project has been led by dietitians. TEMPLE has not been used to advertise any commercial products. The graphics were carefully chosen to avoid any direct association with commercial products.

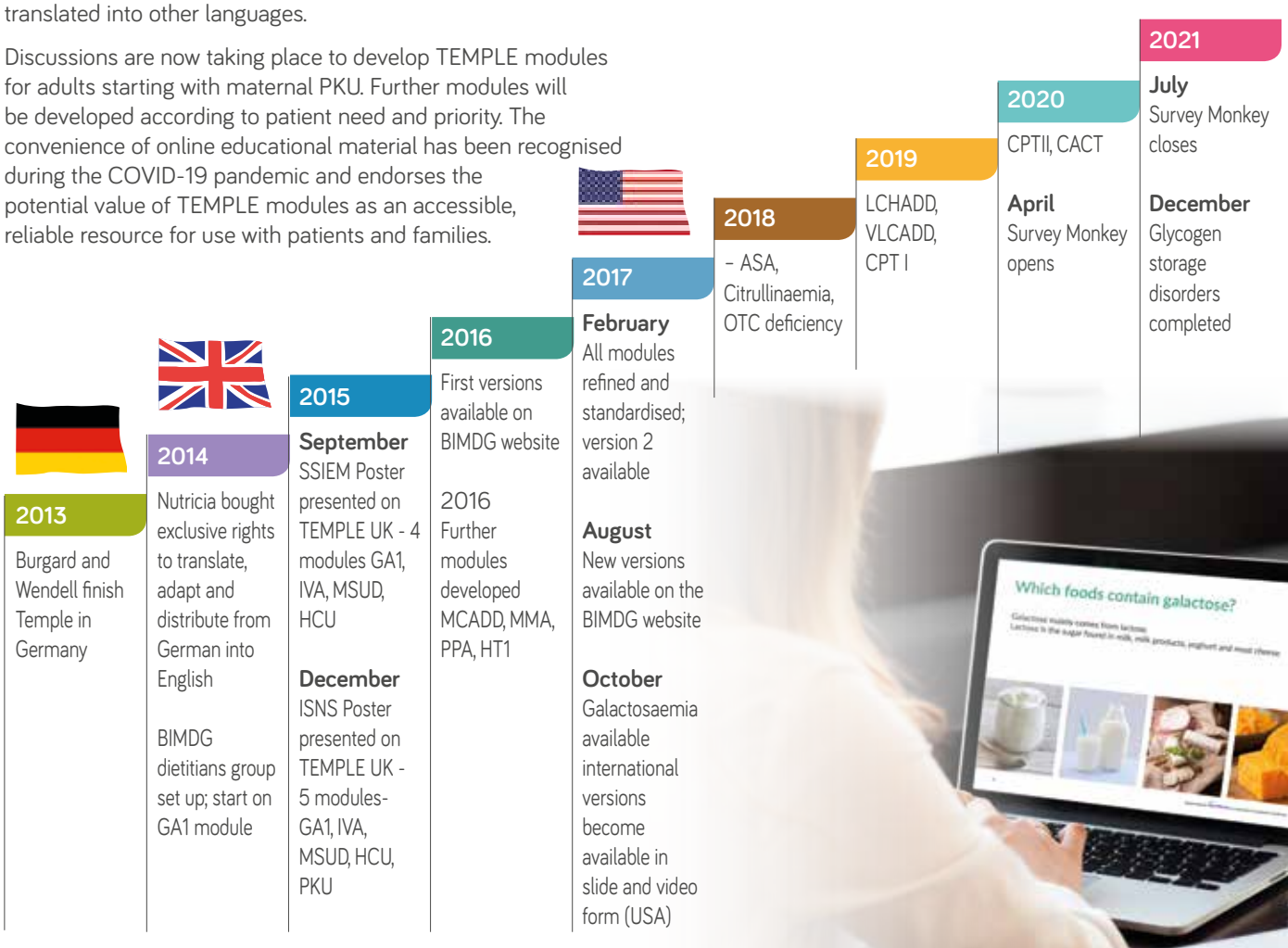


Figure 2 TEMPLE timeline

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WHEN CALORIES COUNT AND SO DOES TOLERANCE

NUTRINI PEPTISORB ENERGY

The energy dense peptide feed designed to meet higher nutritional requirements in children from one year of age.

- Extensively hydrolysed 100% whey protein
- Excellent compliance[1]
- Excellent GI* tolerance[1]
- Easy to use, convenient and well accepted[1]

This information is intended for Healthcare Professionals only.

Nutrini Peptisorb Energy is a Food for Special Medical Purposes for the dietary management of disease related malnutrition in children from one year onwards with malabsorption and/or maldigestion, and must be used under medical supervision.

[1]Data on file (2016). ACBS trial, n=(7), Nutricia Ltd.
*Gastrointestinal

Accurate at time of publication, February 2022.

NUTRICIA
Nutrini Peptisorb Energy

The Use of Nutrini Peptisorb Energy in a Child with a Complex Enteral Feeding History

Debbie Evans Paediatric Dietitian

DIAGNOSIS:
Complex medical needs stemming from prematurity

Background

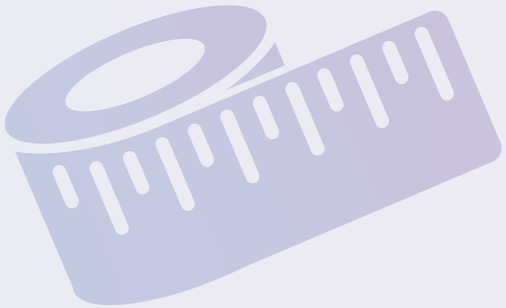
Baby X was born at 24+6 weeks at a birth weight of 785g (25th - 50th percentile). He suffered with bronchopulmonary dysplasia, chronic lung disease, an intraventricular haemorrhage and necrotising enterocolitis requiring surgery. He was transferred to our Special Care Baby Unit (SCBU) at 42 weeks gestational age on 165ml/kg, 17.5% Aptamil Pepti Junior with a weight between the -4SD <0.4th percentile and 0.4th percentile. Paediatric dietitians were involved from the outset and continued to monitor regularly after discharge at 5.5 weeks corrected age. All ages mentioned in this article are corrected for prematurity.

Management

At 10 weeks Baby X was fed on a combination of Expressed Breast Milk (EBM) and Aptamil Pepti Junior. Oral feeding was not progressing and Baby X continued to require top ups via a naso-gastric (NG) tube. He suffered with multiple respiratory illnesses, gastro-oesophageal reflux (GOR) and high stoma losses.

During a ward admission, the Paediatrician changed his feeds to Neocate LCP and his stoma losses significantly reduced so feeds were switched to Neocate LCP. At 7 months, a video fluoroscopy showed an unsafe swallow and oral feeds were stopped. GOR and respiratory infections continued to be problematic so feeds were administered via a feed pump and a thickener was added. At 12 months, Baby X had his stoma reversed and button gastrostomy placed. At 1 year his weight continued to be <0.4th percentile and his length <9th percentile.

Neocate Junior was introduced at 14 months but changed back to Neocate LCP at 17 months as Neocate LCP was better tolerated by baby X. At 19 months Neocate LCP was concentrated to meet Baby X's nutritional requirements for catch up growth. Toleration was variable so concentration was reduced to the standard dilution. This coincided with the first Covid lockdown. By 20 months, Baby X wanted to join in with family meals so his Speech and Language Therapist (SaLT) allowed small quantities of International Dysphagia Diet Standardisation Initiative (IDDSI) level 4 solids. A second video fluoroscopy was done at 22 months and Baby X was allowed to eat an increased volume and frequency of solid food. By 2 years, Baby X had reached 9th percentile for weight. His length continued to follow the 9th percentile.



Infatrini Peptisorb feeds were successfully introduced from 2 years 6 months and Baby X started nursery a month later. Baby X became increasingly active so bolus feeds were started at nursery. Baby X moved on to Nutrini Peptisorb Energy feeds from 2 years 9 months.

Baby X is now 3 years old. His weight is on the 25th percentile as is his length. He currently has 570ml of Nutrini Peptisorb Energy as 5 unequal feeds. He has three meals and two snacks of IDDSI level 3 solids and small amounts of thickened water. His regimen is described in Table 2 overleaf. His third video fluoroscopy has been postponed until spring 2022. Table 1 summarises his dietetic history.

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Table 1 Dietetic history

Corrected age	Weight centiles	Feed	Dietetic considerations and challenges
Birth	25th-50th percentiles		
42 weeks gestation – 24 weeks	-4SD <0.4th to -5SD <0.4th percentiles	Aptamil Pepti-Junior +/- EBM bolus feeds	High stoma losses, frequent respiratory infections & significant GOR
24 weeks – 14 months	<-4SD <0.4th percentiles	Neocate LCP via pump at 7 months	Frequent respiratory infections & significant GOR
14 – 17 months	2nd to <9th percentiles	Neocate Junior via pump	Vomiting/GOR, loose stools
17 months – 2 years 6 months	<9th – 25th percentiles	Neocate LCP via pump feeds. Solids	Timing of feeds & solid food
2 years 6 months – 2 years 9 months	9th-25th to <9th percentiles	Infatrini Peptisorb via pump & as bolus feeds. Solids	Adapting regimen for nursery. Increased tiredness affecting meal times
2 years 9 months - 3 years	<9th to 25th percentiles	Nutrini Peptisorb Energy pump & bolus feeds. Solids	

Figure 2 Nutrini Peptisorb Energy regimen

0700	20 tsp breakfast. Sips of thickened water
0930	50ml bolus feed of Nutrini Peptisorb Energy. ~15 min break then second 50ml bolus feed of Nutrini Peptisorb Energy
1030	Up to 20 tsp yoghurt or fruit puree with thickener
1230	20 tsp lunch. Sips of thickened water
1330	50ml bolus feed of Nutrini Peptisorb Energy. ~15 min break then second 50ml bolus feed of Nutrini Peptisorb Energy
1530	Bite & dissolve snacks
1600	100ml Nutrini Peptisorb Energy via pump at ~250ml/hr
1730	20 tsp dinner. Sips of thickened water
2130	200ml Nutrini Peptisorb Energy via pump at ~250ml/hr
0000	160ml Nutrini Peptisorb Energy via pump at ~250ml/hr 3 x week when dad is available (70ml per day)

IMPORTANT NOTICE: Breastfeeding is best. Foods for special medical purposes should only be used under medical supervision. May be suitable for use as the sole source of nutrition from different ages, and/or as part of a balanced diet from 6 months onwards. Refer to label for details.

Discussion

Baby X had a turbulent first two years of life with multiple illnesses in addition to surgeries. Feeding was challenging and consistent weight gain was not achieved until he was over 14 months. He benefited from reduced exposure to infections during the Covid lockdowns.

As faltering growth was a concern for Baby X, his paediatrician and parents were reluctant to risk possible feed intolerances when he was well between infections. Prior to transfer to SCBU Baby X was trialled with Infatrini Peptisorb so at 2 years 6 months this was considered by his parents and medical care team as more likely to be tolerated than Nutrini Peptisorb. The transition from Neocate LCP to Infatrini Peptisorb went well and a further transition to Nutrini Peptisorb Energy three months later was readily accepted.

Baby X has benefited from a 1.5Kcal/ml peptide based feed in the form of Nutrini Peptisorb Energy. It has been a challenge for both Home Enteral Feeding (HEF) dietitians and parents to find a regimen that fitted in with nursery, prioritised meals and snacks whilst giving sufficient feed required to meet his nutritional requirements.

This case shows the need for a range of paediatric feeds to meet the needs of complex infants and children. Nutrini Peptisorb Energy is an extremely useful addition to the extensively hydrolysed feed range within the Nutricia portfolio.

The Management of Appropriate Food Intake in an Infant with Previous Nasogastric Tube Feeding and Severe Reflux

Gemma Callaghan Specialist Paediatric Dietitian

DIAGNOSIS:

Suboptimal weight gain

Symmetrically small < 0.4th centile

Soft distinctive features

Gastroesophageal reflux

Food aversion following previous severe reflux and previous Nasogastric tube (NGT) feeding

Symmetrically small, dysmorphic features such as asymmetry of face and large ventricles

Tests and Screening:

TORCH screen at birth, *De Lange gene studies, chromosomal breakage studies* ***nil identified at present.***

Baby B was born at 33 weeks' gestation via C-section due to Intrauterine growth restriction (IUGR). Baby B had a low birth weight (1350g) and suffered respiratory distress syndrome after birth requiring high flow oxygen for 2 days. Baby B spent 6 weeks in the neonatal unit before being discharged home in July 2019 on Nutriprem 2.

Baby B had an initial assessment with a dietitian in September 2019 following consultant referral. Baby B's weight had dropped below the 0.4th centile from the 2nd centile whilst length remained below 0.4th centile. Dietetic assessment revealed that Baby B was unable to meet the target volumes needed for weight gain instigating the need for a higher energy formula milk. Concerns raised over hydration status, growth faltering and severe reflux led to an inpatient stay at this point.

Nutrition plays a fundamental role in determining growth of individuals in the first two years of life. Ward admission allowed feed observation, optimisation of reflux medications and the commencement of NGT feeding. In the weeks later, the multi-disciplinary team on the children's ward were reassured by achievement of target volume, improved reflux and subsequent weight gain leading to Baby B's discharge home safely with NGT feeding. At 6 months corrected age the NGT was removed to encourage oral dietary intake to support growth through baby-led weaning.

Weaning was a struggle for Baby B who became aversive to anything entering his mouth. Baby B required desensitisation techniques to aid oral dietary intake requiring regular involvement Speech and Language Therapy (SLT) and dietetics. High calorie high protein food fortification was key to Baby B obtaining essential nutrients when purees became accepted (10 x teaspoons) at mealtimes.

Dietitians continued to encourage the introduction of solids before milk, but intake remained the same at one year of age and so nutritional supplementation was necessary to support Baby B's growth and nutrition. Baby B's nutritional requirements were calculated, see Table 1. Dietetic prescription for Fortini Multi Fibre in both Unflavoured and Chocolate flavours was requested and trialled.

Table 1 Baby B's Nutritional Requirements

Estimated Average Requirement (80 x 6.3kg @120-150% = 605-760kcal)
Total fluid requirement (120ml x 6.3kg = 760ml/d-1L)
Protein requirement (14.5g per day)

On dietetic review, it was clear that volume remained an issue. Baby B was managing a maximum of 400ml (100ml four times daily) despite mums efforts to increase to his target of 600ml per day to meet requirements for weight gain given his poor intake of solids. At this stage it seemed entirely appropriate to look at the more nutritionally dense compact version of this. Baby B was weaned on to a 125ml Fortini Compact Multi Fibre (300kcal, 7g protein and 3g of dietary fibre/125mls bottle) with the aim to meet nutritional requirements and allowing the dietary intake of solids. As Baby B preferred the chocolate flavour of Fortini Multi Fibre dietetic prescription was requested for Fortini Compact Multi Fibre Chocolate-Caramel flavour.

At dietetic review, I was delighted to hear that the compact size of the supplements prescribed made achieving the desired volume easier for the family, subsequently reducing anxiety around feeding and mealtimes. The versatility of this product makes it a great way of fortifying porridges and puddings with extra calories, protein, vitamins, and minerals. I educated Baby B's nursery and parents on recipes using the supplement. At home, Baby B's volume of food intake improved and vomiting reduced, reflecting nicely in weight gain and an overall better daily routine.

Baby B has continued to manage well with Fortini Compact Multi Fibre Chocolate-Caramel at the volume of 375ml per day. (see Table 2 overleaf). In the short term, the improved dietary intake alongside the Fortini Compact Multi Fibre ensures Baby B is meeting his nutritional needs. Currently Baby B is reviewed bimonthly to check his weight, blood results, clinical appearance, and dietary intake in order to identify any nutritional deficiencies at the earliest opportunity. Baby B's weight is on the 0.4th centile and height proportionally on the 2nd centile.

Continued on page 14 ▶

Table 2: Real life example of daily intake using Fortini Compact Multi Fibre Chocolate-Caramel

Breakfast routine	10-20 spoons porridge/Weetabix/ overnight oats with 125ml Fortini Compact Multi Fibre Chocolate-Caramel
Mid-morning eating routine	Finger foods-crisps, wotsits, 50ml Fortini Compact Multi Fibre Chocolate-Caramel and 50ml water
Lunch time	10 spoons puree veg and 50ml water 10 spoons of chocolate caramel Delight or mousse recipe made with 125ml Fortini Compact Multi Fibre Chocolate-Caramel
Mid-afternoon eating routine	Snacks like yoghurt, crisps and 50ml water
Evening eating routine	10 spoons of puree veg mash, gravy, and 10 spoons chocolate mousse made with 75ml Fortini Compact Multi Fibre Chocolate-Caramel
Supper/night time eating routine	100ml full cream milk and a biscuit

In this case all parameters improved using this product; weight gain was achieved as well as volume of dietary intake. Baby B now has regular daily bowel movements without the need for medications. Fortini Compact Multi Fibre Chocolate-Caramel was a suitable choice for Baby B due the high-energy content and nutritional value. At present this helps to bridge the gap between nutritional intake and requirements orally without the need for nasogastric feeding. The compact size aids compliance and its tasty flavour ensures it can easily be added to foods to enhance energy protein value of the meal. The parents are aware that it may be necessary to discuss and instigate a referral for a gastrostomy placement if nutritional intake remains inadequate in the future.

IMPORTANT NOTICE: Fortini Compact Multi Fibre is a food for special medical purposes for the dietary management of disease related malnutrition and growth failure in children from one year onwards, and must be used under medical supervision.

Diary Dates

9th International Conference on Nutrition and Growth (N&G 2022)
17-19 March 2022.
Digital event
https://nutrition-growth.kenes.com/welcome-message/

The Nutrition Society Spring Conference 2022
Nutrition, immune function, and infectious disease
4-5 April 2022
Royal Society of Edinburgh
https://www.nutritionsociety.org/events/spring-conference-2022-nutrition-immune-function-and-infectious-disease

WAO & BSACI 2022 UK Conference
25-27 April 2022
Edinburgh International Conference Centre (EICC)
https://www.bsaci.org/wao-bsaci-2022-uk-conference/

Nutricia Conference. Dietary Management of Inherited Metabolic Disorders (DMIMD).
27-28 April 2022
Royal College of Physicians, London.
Contact for further details: jmassociates1@me.com

Nutrica: KetoConference
In collaboration with Manchester Ketogenic Service.
10 May 2022
The Edwardian Manchester, A Radisson Collection Hotel.
Contact for further details: jmassociates1@me.com

Please note that these events are still scheduled to take place at the time of printing. However, variations may occur depending on how the COVID-19 situation develops.

BDA Diagnosis and Management of Cow's Milks Allergy in Infants and Children Course
6–7 June 2022
BDA Office, 3rd Floor, Interchange Place, 151-165 Edmund Street, Birmingham, B3 2TA
https://www.bda.uk.com/ems-event-calendar/diagnosis-and-management-of-cow-s-milks-allergy-in-infants-and-children22.html

The 53rd ESPGHAN Annual Meeting
22- 25 June 2022
Copenhagen, Denmark
https://www.espghan.org/our-organisation/Annual-Meeting

EACCI Hybrid Congress
"Common origins of allergy and chronic inflammatory diseases - One Health approach"
1-3 July 2022
Prague, Czech Republic
www.eaaci.org

The 9th Congress of the European Academy of Paediatric Societies "Shaping the Future of Child Health"
7–11 October 2022
Barcelona, Spain
https://eaps2022.kenes.com/

SAVE THE DATE
Nutricia Study Day
2-3 November 2022
Keep an eye out for further details

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The Fortini Range are Foods for Special Medical Purposes for the dietary management of disease related malnutrition and growth failure in children from one year onwards, and must be used under medical supervision.

*Product can be provided to patients upon the request of a Healthcare Professional. They are intended for the purpose of professional evaluation only.

This information is intended for Healthcare Professionals only. Accurate as of Oct 2021.

Infatrini Peptisorb Use in Optimisation of Reflux Management in Complex Patients

Heather Grant Paediatric GI Dietitian

DIAGNOSIS:
Congenital Myotonic Dystrophy and Associated Foregut Dysmotility

Background

Baby T was referred to the GI team by the Neonatal team. She was born at 29 weeks and referred at 14.5 weeks (3.5 weeks corrected age), has chronic lung disease secondary to prematurity and had been diagnosed with congenital myotonic dystrophy. Congenital myotonic dystrophy is an autosomal dominant neuromuscular disorder with multisystem involvement that within the neonatal and infancy period can be very challenging. It presents with a variety of clinical features and systemic effects (neurology, respiratory, cardiac) that include common GI issues such as reflux and risk of aspiration, feed and suck difficulties, constipation and diarrhoea.[1] Baby T was likely going to require life-long ventilation and because of the other effects, there would be a direct impact on the options for, and response to, dietetic intervention.

Assessment and recommendations

On initial assessment Baby T has upper GI dysmotility, with reflux significantly impacting the ability to progress with enteral feeds. At the time of referral, Baby T was meeting over 50% of the requirements from parenteral nutrition (PN). Enterally, she was receiving maternal expressed breast milk (MEBM) as hourly boluses. Baby T was born on the 75th centile for weight, while currently sitting on the 91st centile. Her length plotted on the 25th centile. She was vomiting most days and had very variable stooling (0-8 x per day). Muscle coordination was poor, making oral inappropriate at present.

She was referred with the aim of answering:

1. What feed choice would provide optimal symptom management?
2. How could feeds be progressed to enable enteral autonomy?
3. Does Baby T require jejunal feeding?

Each of these questions relates to Baby T's reflux management together with the recognition that she has a long-term illness. The goals of intervention were to minimise symptoms and reduce the impact of reflux through medical and nutritional management. At the time of review, she had already been established on good dosing of proton pump inhibitor and a prokinetic.

Having been dependent on PN for >3 months a priority goal was to facilitate a route off PN. Whilst jejunal feeding may be indicated, there were some interventions to trial prior to moving to jejunal feeding as a treatment for foregut dysmotility.

We agreed to implement the following interventions under close monitoring:

1. Continuous pump feeds with Infatrini Peptisorb for 18 hours with the addition of a Farrell* valve system into the circuit
2. Maintain MEBM use as 6 x 1 hourly boluses
3. Reduce volume of PN to meet 30% total PN requirements

Rationale for recommendations

Jejunal feeding was considered as delivery of enteral feeds resulted in vomiting, posseting and perceived distress periods. This may be an appropriate intervention in this scenario or in the future, but there were some clear feed choice and delivery changes that would precede a move to jejunal feeding. This is supported by the ESPGHAN 2019 position paper where a trial of continuous gastric feeds, hydrolysed or elemental feeds and trialling at least 1 prokinetic drug to promote oral or gastric feeding prior to jejunal feeding is recommended.[2]

Pump feeding allows slow delivery and advancement of feeds that can maximise tolerance, however our local policy does not support EBM use in enteral pump feeds due to fat and mineral losses that are known to occur.[3] The addition of the Farrell bag to the circuit allows for decompression, which can have a beneficial impact on feed tolerance.

Infatrini Peptisorb was selected as a feed that was higher in energy (1kcal/ml vs approximation of 0.67kcal/ml for EBM) to allow total volumes required to be reduced enterally, which would in turn reduce the amount of PN needed. The hydrolysed component would be of additional benefit not only as a pre-jejunal feeding consideration, but with the potential for optimising gastric emptying with extensively hydrolysed whey if using formula feeds for gastric feeds.[4,5] Baby T required multiple courses of antibiotics for intercurrent illness and with a predisposition to altered stooling, the presence of enhanced Medium Chain Triglycerides (MCT) content within Infatrini Peptisorb (50% MCT) and the osmolality under 400mOsm/kg increased confidence of optimised tolerance.

*The FARRELL bag is a closed enteral decompression system intended to allow excess gas to be removed from the stomach (gastric distention/bloating) and to prevent the loss of tube feeds, medication and stomach contents

Table 1 Response to interventions

Age	Weight	Phase
14.5 weeks (3.5 weeks corrected)	75th-91st centile	PN meeting approximately 50% requirements 11ml hourly MEBM x 3 - 5kcal/kg Switched to 75% of enteral feeds as Infatrini Peptisorb via pump - 46kcal/kg
16 weeks (5 weeks corrected)	75th centile	PN discontinued 19ml hourly MEBM x 3 - 5kcal/kg 20 hour pump feed Infatrini Peptisorb - 95kcal/kg and 95% of target energy provision
22 weeks (11 weeks corrected)	50th-75th centile	60ml MEBM x 3 14 hour pump feed Inatrini Peptisorb - 75kcal/kg
28 weeks (17 weeks corrected)	50th centile	120ml MEBM x 3 gravity bolus - 23kcal/kg 12 hour pump feed Infatrini Peptisorb - 60kcal/kg and 72% of total energy provision

As Baby T coped very well with this regime the Infatrini Peptisorb was able to be advanced with PN stopping 10 days later. There were no further vomiting or concerns regarding her reflux, with stools remaining variable. Her weight tracked the 50th centile in the weeks and months that followed which minimises the generation of excess fat stores. The 18-hour feed plan was able to be condensed in stages to achieve a 12 hour overnight pump feed and 3 x 120ml EBM bolus feed through the day and small oral tastes.

Infatrini Peptisorb can be a good option in the management of reflux and upper motility issues within a caseload of children with complex needs. It allows a low volume option for oral and enteral feeding with a degree of hydrolysis, MCT component and osmolality that aims to optimise tolerance of gastric feeds.

FOR A FULL REFERENCE LIST, PLEASE SEE **PAGE 25**

How Paediatric Dietitians can Support Children and Young People with Possible Avoidant Restrictive Food Intake Disorder (ARFID)

Michelle Simpson RD, Lead Paediatric Specialist Eating Disorders Dietitian

INTRODUCTION

As a paediatric dietitian in a varied, busy DGH I had many referrals for "fussy eating" and for the majority of cases, a child's dietary intake could be significantly improved by increasing parental knowledge and confidence about their child's selective eating. However, there are always children who do not respond to this treatment plan, and attend clinics for long periods of time, with no real improvement. Recently, within my role as Lead Specialist Eating Disorders Dietitian in the local Child and Adolescent Mental Health Services (CAMHS) I have been tasked with supporting the team with children with Avoidant Restrictive Food Intake Disorder (ARFID), and I can see that in retrospect many of the children with selective eating had what we now class as ARFID.

AIM

Over the past 3 years, the knowledge, awareness and funding opportunities for ARFID has grown, however, there can be inconsistency in the care pathways across the country. The aim of this article is to increase the confidence of paediatric dietitians managing ARFID traits in general paediatric clinics, by highlighting resources available to support the child and their parents instead of being referred for specialist input, or whilst waiting to be assessed.

WHAT IS ARFID?

ARFID is classified within the eating disorder diagnoses in DSM-5 (Diagnostic and Statistical manual of Mental disorders 5th Edition) and International Classification of Disease- 11 (ICD-11) see Table 1.

Table 1 ARFID diagnosis according to the DSM-5

According to the DSM-5, ARFID is diagnosed when:
1 An eating or feeding disturbance (for example, an apparent lack of interest in eating or food; avoidance based on the sensory characteristics of food; concern about aversive consequences of eating) is manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following: - Significant weight loss (or failure to achieve expected weight gain or faltering growth in children) - Significant nutritional deficiency - Dependence on enteral feeding or oral nutritional supplements - Marked interference with psychosocial functioning
And when,
2 The eating/feeding disturbance is not better explained by lack of available food or by an associated culturally sanctioned practice
3 The eating/feeding 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
4 The eating/feeding disturbance is not attributable to a concurrent medical condition or not better explained by another mental disorder
5 The eating/feeding disturbance occurs in the context of another condition or disorder, the severity of the disturbance exceeds that routinely associated with the condition or disorder and warrants additional clinical attention.

THE ROLE OF A DIETITIAN IN ARFID

A large part of the diagnostic criteria includes assessment of nutritional adequacy and growth. Therefore, dietitians are an integral part of the assessment and treatment MDT. Paediatric dietitians are skilled in assessing growth and development in children and young people as well as providing essential input about concerns with failure to achieve expected growth potential or significant weight loss. As the only registered professionals within the NHS who can assess age-specific nutritional adequacy of dietary intakes and provide specific dietary advice, we can support the restoration of physical health including weight, height, and correction of nutritional deficiencies wherever possible. We also have expert knowledge of enteral feeding and different nutritional supplements available to support existing accepted food repertoires.

ARE THERE TYPICAL ARFID PATIENTS?

Although there are no "typical ARFID patients" because each child and young person often has a complex history, there are effects on their quality of life that are often shared. ARFID patients are often unable to eat at friend's houses, school or out at restaurants because, for example, they find it difficult to eat in the same way as their peers, or are affected by busy environments. If the driver behind the eating difficulty is sensory, or is fear of aversive consequences (such as choking), the ability of the patient to try new foods is often greatly reduced and associated with a great amount of anxiety. Therefore, identifying the driver of the eating difficulty is key, so that treatments to improve the quality of life for these children and their families can be put in place.

ARFID ASSESSMENT TOOLS

The PARDI assessment tool identifies and divides the possible drivers behind the eating difficulty into 3 main groups; sensory sensitivities, fear of aversive consequences and disinterest, which then helps formulate treatment options. This takes about 60-90 minutes to complete in an appointment that is not easily included in a busy paediatric clinic. Using the shorter PARDI-AQ as a screening tool may help highlight where the driver is, as well as confirm the need for referral to a specialist ARFID clinic.

Table 2 Possible treatment options for each driver[1]

Low interest in food or eating	Sensory-based avoidance	Concern about aversive consequences
Psychoeducation	Psychoeducation	Psychoeducation
Structure/routine	Sensory diet	Graded exposure
Learning/habit acquisition	Desensitization	Cognitive Behavioural Therapy
Arousal regulation/ attention	Discuss management strategies	Anxiety management strategies
Family interventions	Family interventions	Family interventions

HOW PAEDIATRIC DIETITIANS CAN SUPPORT CHILDREN AND THEIR FAMILIES WITH SUSPECTED ARFID:

1 Nutritional Assessment

Blood tests are important in diagnosing micronutrient deficiencies, however, the analysis of a 3-5 day food diary can be very useful in addition to, or instead of blood tests. The food diary should include food intakes in other locations other than just the family home (e.g. whilst at grandparents or childcare), and will help to identify supplementation needs. The evidence available at the current time indicates blood test requests for the following vitamins and minerals: vitamin C, vitamin A, thiamin, vitamin B_{12} and vitamin D, B_2, zinc, iron[2-10]

2 Nutritional Support to Ensure Adequate Growth and Development

Children with ARFID may require some additional nutrition to support their growth and development. This may include the following:

- Educating parents and young people on what constitutes a balanced diet in children. Often the need for snacks and "puddings" are undervalued by parents striving for a healthy diet
- Supplementation with vitamins and minerals if needed (for example, liquids, sprays, tablet presentations)
- Food fortification, for example using full fat dairy products, smoothies with ground almonds and skimmed milk powder
- The use of prescription Oral Nutrition Supplements (ONS) (for example neutral flavour compact ONS, smoothie or juice style ONS made into ice lollies or jelly, calorie supplements in liquid intakes such as ketchup, milkshakes etc). When using concentrated calorie supplements start with 1ml and increase by 1-2ml increments every other day until the required amount
- The use of tube feeding, to either top up dietary intake or as sole source of nutrition

REASSURANCE OF PARENTS & CARERS

Many children and young people have strong preferences and dislikes when it comes to food and eating. This is entirely normal and appropriate. Many children will be 'fussy' eaters and have particular habits when it comes to food and eating, such as not wanting food to touch, wanting to use certain crockery and cutlery, not liking certain foods, or only wanting to eat a preferred food over and over again. Many children also go through stages of not wanting to eat or eating more or less in response to feeling upset, worried, angry or overwhelmed. This often resolves itself in time without intervention. With some adaptations and a supportive family approach, these preferences and phases can be managed and accommodated without too much difficulty. Young people who are growing, developing, thriving and functioning are unlikely to have ARFID. Parents should be reassured if this is the case that their child's nutrition is good enough. Children with ARFID are likely to have had difficulties with food and eating from a very young age (with the exception of Fear of Aversive Consequences' which can occur suddenly), and parents or carers may benefit from referral and further assessment, alongside signposting to the following helpful books and websites.

- Food Refusal and Avoidant Eating in Children - A practical guide for parents and professionals by Gillian Harris and Elizabeth Shea
- ARFID; Avoidant Restrictive Food Intake Disorder - A guide for parents and carers by Rachel Bryant-Waugh (2019)
- Helping Children Develop a Positive Relationship with Food by Jo Cormack
- www.ARFIDAWARENESSUK.org

REFERRAL FOR SPECIALIST ARFID ASSESSMENTS

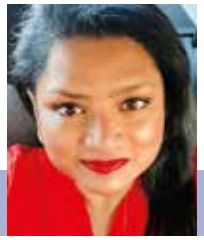
Specialist ARFID services are usually commissioned within local CAMHS Eating Disorders Teams, therefore a direct referral to them is needed. The CAMHS team will need a recent set of anthropometric measurements and any blood tests you have done so they can triage the urgency.

The referral criteria are based on the diagnostic criteria above, often with close attention to effects on psychosocial functioning and physical health. It is important to remember that these services within CAMHS are primarily mental health services, and often continue to need support from physical health services such as paediatrics. The diagnostic criteria include exclusion criteria around other physical and mental health disorders that may have associated eating difficulties that are not ARFID. This could be a very grey area within this speciality, and there needs to be further collaborative work so that children and young people who may slip through the ARFID net are supported such as children with eating difficulties associated with congenital conditions.

BDA POSITION PAPER ON A DIETITIAN'S ROLE IN ARFID

Keep an eye out for the BDA Position Paper on ARFID that a working group of dietitians are developing. This will provide more help with the commissioning of services, with a toolkit to follow with more detailed information and signposting of this condition.

FOR A FULL REFERENCE LIST, PLEASE SEE **PAGE 25**



The Management of Congenital Hyperinsulinism

Annaruby Cunjamalay Highly Specialist Paediatric Endocrine Dietitian

Introduction

Congenital Hyperinsulinism (CHI) is a rare but potentially serious condition that presents soon after birth. The estimated incidence is 1:40,000 births, with the highest incidence rate of 1:2500 births found in consanguineous parents.[1] CHI is characterised by the overproduction of insulin secretion from pancreatic β-cells. The risk of brain injury results from insulin action stopping the body from using alternative fuels for the brain to use instead of glucose. It is therefore essential to make a rapid diagnosis and commence immediate management, to prevent severe hypoglycaemic brain injury associated complications such as epilepsy, cerebral palsy and other neurological damage or death.[2]

The aim of treatment is to avoid any episodes of hypoglycaemia. For CHI, hypoglycaemia is less than 3.5mmol/litre. In the absence of ketone bodies, infants with CHI are constantly reliant on the circulating blood glucose as the fuel for normal neurological functioning, hence the importance of maintaining the blood glucose concentration above 3.5mmol/litre.

CHI is often missed as it is difficult to identify, with non-specific symptoms such as abnormal feeding, irritability, jitteriness, and lethargy. Despite advanced treatment, the evidence suggests that approximately a third of children with CHI have some degree of brain injury.[3]

Some of the neuro-developmental problems are often only evident at school age when higher-order cognitive functions have developed; these children present with problems such as attention-deficit/hyperactivity disorders plus learning problems.[4]

Hypoglycaemic brain injury has a lifelong devastating effect on the child and the family which consequently has a long-term socio-economic impact on the National Health Service (NHS).

The Potential Symptoms of CHI?

A child usually starts to show symptoms within the first few days of life, although very occasionally symptoms may appear later in infancy. Symptoms of hypoglycaemia can include floppiness, shakiness, poor feeding, and sleepiness, all of which are due to the low blood glucose levels. Seizures can also occur due to low blood glucose levels. If the child's blood glucose level is not corrected, it can lead to loss of consciousness and potential brain injury.

Transient Hyperinsulinism

Transient hyperinsulinism hypoglycaemia occurs when increased insulin production is only present for a short duration and often resolves in the first few weeks or months of life. It is found in conditions such as:

- intrauterine growth retardation
- infants of diabetic mothers or uncontrolled gestational diabetes
- infants with perinatal asphyxia/stress

More research is needed to understand why transient hyperinsulinism occurs.

Genetics

There are several known genetic causes of CHI, which can be inherited in an autosomal recessive or dominant manner. Genetic testing and identification of parental origin can be useful in assessing the likelihood of focal and diffuse CHI early in the treatment.

Histology

There are two subtypes of CHI, focal and diffuse. The management of diffuse and focal disease are different. Focal disease can be cured if the lesions are located accurately and are surgically removed. However, diffuse disease will require the removal of almost the entire pancreas, a subtotal pancreatectomy (95%) which then increases the risk of other long-term effects, such as diabetes or pancreatic insufficiency. As a result, oral enzyme replacement therapy with meals is an option, although it still carries a risk of developing insulin dependent diabetes. Occasionally hypoglycaemia can occur after surgery for diffuse disease, however, usually in a milder form which is more responsive to medical management.[5]

How is CHI Diagnosed?

CHI is typically diagnosed through detailed blood and urine tests that are taken whilst a child's blood glucose level is low. If the patient's blood glucose level does not fall sufficiently low during the initial period, they may have a diagnostic fast, all fluids will be gradually reduced for a period until they become hypoglycaemic (3.0mmols/l or less for a very short period of time only). Once the diagnosis has been reached glucose is given intravenously to bring the blood glucose level back to normal.

Once CHI is confirmed, medical treatment to stop insulin production is commenced. Blood samples are also sent for genetic analysis as the results of these help to determine whether a child will need an 18-F-DOPA Positron Emission Tomography (PET) scan.

18-F-DOPA PET Scan

A PET scan gives very detailed, three-dimensional images of the body. It works by injecting an isotope called 18-F-DOPA, which is able to identify the area of the pancreas where excessive insulin is being produced and the treatment recommended by the doctor will depend on the results of the scan.[6]

Table 1. Criteria for Diagnosing CHI

Serum glucose	<3.0 mmol/l
Serum insulin	Detectable at the point of hypoglycaemia
C peptide	Elevated at the point of hypoglycaemia
Free fatty acids	Low
Beta hydroxyburarate (ketones)	Nil
Ketones	None in the urine
Cortisol	May be low at the point of hypoglycaemia
Growth hormone	May be high

It is important to estimate the glucose requirements to maintain euglycemia. A normal hepatic glucose production rate in a full term newborn is 4-6mg/kg/minute, however, in CHI patients this figure can be much higher.[7] The Glucose Infusion Rate (GIR) is helpful at diagnosis and as a useful indicator of the severity of CHI throughout the acute management.

The GIR for enteral feeds is as follows:
Total Carbohydrate (CHO) (g) x 100 (mg) | weight (kg) | 24 (hours) | 60 (minutes) = mg/kg/min

CHI Services in the UK

There are two specialist centres for CHI; one in the South of the country, which is Great Ormond Street Hospital (GOSH), London, and in the North, a joint service between the Royal Manchester Children's Hospital and Alder Hey Hospital in Liverpool. These two centres in the UK have the expertise to carry out the detailed repeated blood glucose monitoring needed to deliver treatment.

Medical Management of CHI

The aim of treatment is to avoid any episodes of hypoglycaemia and safe tolerance to fasting appropriate for age. The aim is to keep a child's blood glucose levels above 3.5mmol/l. This can be managed by using a formula with added glucose polymers in feeds alongside drugs that aim to reduce insulin secretion.

The aim is to keep a child's blood glucose levels above 3.5mmol/l.

Table 2. A Summary of the Drugs Used in CHI

Drug	Indications	Mechanism	Side effects/limitations
Diazoxide	Hyperinsulinism	Opens KATP channels and stabilises pancreatic beta cells	Fluid retention Rarely leucopenia and thrombocytopenia Taste changes Pulmonary hypertension - echocardiogram prior to commencement Excessive hair growth
Chlorthiazide	Hyperinsulinism	Acts synergistically with diazoxide by activating non KATP channels	Hyponatraemia Hypokalaemia
Nifedipine	Hyperinsulinism	Inhibits voltage gated calcium channels in the B-cell membrane	Hypotension
Sirolimus	Hyperinsulinism	rapamycin (mTOR) inhibitor, beta cell suppressor	Not used regularly within CHI due to its immunosuppressive side effects Used in rare cases when other treatment options have failed
Glucagon	Hypoglycaemia	Increased glycogenolysis/ gluconeogenesis	Nausea Vomiting Increased growth hormone Increases myocardial contractility Decreases gastric acid and pancreatic enzymes
Octreotide	Hyperinsulinism	Activates G protein coupled rectifier K channel	Suppression of growth hormones Delayed gastric motility Steatorrhoea Cholelithiasis Abdominal distention Hepatitis Hair loss

Blood Glucose Monitoring

The Multidisciplinary Team will teach parents about blood glucose monitoring and the medications their child is receiving prior to discharge. Upon discharge, the medical team will ensure that every child is given an individualised hypo plan, and an emergency regime is also explained by the dietitian. This is made up from using a powdered glucose polymer and is given to a child during periods of illness or when the child is unable to eat, feed or drink as normal. The emergency regime is designed to give an appropriate amount of CHO for the child's age based on average nutritional requirements, with the aim of preventing hypoglycaemia and allowing the child to be managed at home.

Dietetic Intervention

When a child is initially admitted to hospital, dietetic input can be difficult. The child can be fluid restricted due to medication, or they may need a high IV dextrose volume to maintain blood glucose; there is less fluid available for feeds which may prevent oral feeding. If infants are unable to meet their nutritional requirements from enteral feeds for more than 7 days, parenteral nutrition (PN) alongside enteral feeds should be considered. Breastfeeding is promoted and well supported by the MDT. Whilst infants are fluid restricted, mothers can express breast milk and latching on after feeds, or in between for comfort, should be encouraged if safe to do so.

As these infants are fluid restricted, it can be effective to use a high energy feed to meet their energy, carbohydrate, and protein needs for healthy growth. Alternatively, a standard infant formula can be concentrated with an added glucose polymer to meet their nutritional needs.

Infants with CHI will often require glucose polymers such as Vitajoule or Maxijul added to feeds to increase the carbohydrate concentration. Glucose polymers should be added in small increments to feeds, as this can cause an osmotic load and can predispose preterm babies to develop necrotising entercolitis.

It is important that each child is meeting an appropriate level of protein for their age. When a glucose polymer is added to a feed this can alter the protein to energy ratio and can have a negative effect on growth. The protein energy ratio should be between 7.5-12%. [7]

Children with CHI are likely to have feeding problems and are more likely to have food aversions,[8] have persistent feeding difficulties and many (75%) will require nasogastric (NG) tube feeding and a majority (93%) will require anti-reflux medications.[9] The use of multiple NG tubes may cause facial and oral sensitivity, further adding to the oral feeding experience. In addition, there can be side effects of the medication that cause further feeding difficulties.

An NG tube is inserted to deliver continuous feeds. If tube feeding is required longer term, a percutaneous endoscopic gastrostomy (PEG) is often used. We continue to encourage the child to feed orally to keep their oral motor skills and reduce the chance of long-term feeding problems by using concentrated feeds and by having regular follow ups. Further support from speech and language therapists can help children regain the desire to eat and drink by mouth.

Infants are discharged on bolus feeding in the day and continuous feeding overnight to help maintain blood glucose levels. At the start of an overnight feed and at the end, a bolus feed is given as the blood glucose levels can drop quickly after continuous feedings. Prior to discharge a unique feeding plan is devised for the infant. Infants with CHI undergo a 6 hour 'safety fast' to ensure they are safe to go home and maintain their blood glucose level. Normal weaning is encouraged at 6 months of age in line with the current Department of Health (DOH) recommendations.

A child with CHI may benefit from the use of uncooked corn-starch, a complex carbohydrate. This can be used to allow a longer fast period overnight. Uncooked corn-starch can help with blood glucose stability and slow digestion times which range from 4 - 9 hours. A dose of 5g/dose is recommended with a maximum dose of 2g/kg/dose. This is not recommended in children under 1 year of age due to the immaturity of intestinal amylase.[7]

In Summary

The management of CHI can be complicated, however, once infants with CHI are stable, a degree of normal life can be achieved. Brain function in CHI can be normal if hypoglycaemia has been diagnosed and treated quickly, although this can vary depending on the amount of damage caused before diagnosis and treatment. With increased knowledge and research, the outcomes for these children are continually improving.

FOR A FULL REFERENCE LIST, PLEASE SEE **PAGE 26**

Up$_2$ Date ...

Nutritional management of the critically ill neonate: A position paper of the ESPGHAN committee on nutrition

Moltu. S. J *et al*, ESPGHAN Committee on Nutrition *J Pediatr Gastroenterol Nutr* 2021;**73**:274-289

There is wide variation in the nutritional management of critically ill term neonates and preterm infants. Recommendations on when to initiate nutrition, which mode of feeding, energy requirements, and composition of enteral and parenteral feeds are needed. The European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) Committee on Nutrition (CoN) performed a systematic literature review on nutritional support in critically ill neonates with the aim of providing clinical recommendations during different phases of critical illness in preterm and term neonates.

The ESPGHAN-CoN acknowledges that there is insufficient data to determine the optimal composition and timing of nutritional support in preterm infants and term neonates who are critically ill. The following general recommendations can be followed cautiously:

1. Establish the diagnosis of the critical illness by assessing clinical and biological markers
2. Calculate theoretical energy and macronutrient needs during different phases of critical illness
3. Initiating the minimal enteral nutrition (MEN) within 48 h if feasible
4. To gradually advance nutrient intakes when the clinical state and the inflammatory response are resolving and consider to increase the target above estimated needs to cover cumulative deficits and promote catch-up growth during the recovery phase
5. Monitor and assess the phase of clinical illness every 24 h

This review calls for more research and appropriately powered trials to resolve uncertainties in this area. Both short and long term trials should be designed to consider differing levels of illness severity, account for heterogeneity in the populations, and be large enough to determine meaningful outcomes.

Impact of oral nutritional supplements (ONS) on growth outcomes and IGF-1 level in underweight older children and young adolescents (5-14 years) with short stature and no systemic disease: High versus normal calories density formula

Soliman. A *et al.* *Acta Biomed* 2021, 2021; **92** (4) e2021320

For children with moderate undernutrition the World Health Organization (WHO) currently recommends using nutrient-dense supplementary foods such as oral nutritional supplements (ONS) to meet the extra need for weight and height gain.

This controlled trial investigated the impact of oral nutritional supplements with a nutrient density of 1 cal/1ml (sONS) compared to 1.5 cal/1ml (cONS) in pediatric patients (5-14 years) with faltering growth. Patients were randomised to one of the two regimes for one year and anthropometric measurements such as weight, height and body mass index (BMI) and appetite and gastrointestinal tolerance were recorded every 3 months. In addition serum insulin growth factor 1 (IGF-1) was measured at baseline and after 1 year.

In the study both sONS and cONS significantly increased the weight gain per day (WGD), height, growth velocity (GV) and height standard deviation score (Ht-SDS) at one year. There was a significantly greater mean WGD and body mass index standard deviation score (BMI-SDS) and a significantly higher IGF1-SDS increase in the cONS compared to the sONS group at 12 months.

In conclusion, both sONS and cONS improved the growth of underweight children between 5 - 14 years. This study supported by others, has shown that the use of energy-dense, cONS are well tolerated by children with faltering growth and are associated with higher weight gain compared to sONS.

Percutaneous endoscopic gastrostomy in children: An update to the ESPGHAN position paper

Homan. M. *et al*, ESPGHAN Committee on Nutrition *J Pediatr Gastroenterol Nutr* 2021;**73**(3):415-426

Percutaneous Endoscopic Gastrostomy (PEG) tube insertion to deliver nutritional support to children that are unable to maintain adequate nutrition orally, has become a common dietetic practice. Feeding tubes have improved the transition to out-of-hospital care and improved quality of life for many families. In accordance with the official ESPGHAN policy of periodic review of Societal papers, the aim was to update the position paper with recently published data and opinions.

The ESPGHAN conducted a systematic review from 2014 to 2020 and consensus on the content of the manuscript and recommendations were made by the authors. In addition, expert opinions of the authors are expressed in the manuscript when there was a lack of scientific evidence.

This position paper confirms that PEG insertion is a safe, quick and effective method for children to support enteral nutrition in order to avoid malnutrition in chronic severe diseases. The best possible patient outcomes are achieved when a multidisciplinary approach is used. Morbidity and mortality are minimised and quality of life is improved when team decisions are taken on things such as indication for insertion, preparation before the procedure, follow up, managing complications, and optimal time for permanent removal of the gastrostomy tube.

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* AAF: Amino acid-based formula
† Observational study of real world evidence in The Health Improvement Network (THIN) GP database[1], n=148, Neocate Syneo vs Alfamino (Feb 2021)
‡ Systematic review and meta analysis of 4 randomised controlled trials[2], Neocate Syneo vs Neocate LCP (Nov 2020)
# Clinical journey endpoint measured as being asymptomatic and not requiring a hypoallergenic formula prescription for at least 3 months
§ As compared to all other AAFs on the UK market, comparison conducted in August 2021

21-047. Date of prep: February 2022.

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FALTERING GROWTH EDITION REFERENCES | SPRING 2022

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