

The Use of Blended Diet with Enteral Feeding Tubes

Dr Sarah Durnan and Alisa Kennedy

Questions to the Floor

- Children, Adult or mixed caseload?
- Do you have patients on your caseload on blended diet?
- Do you have a trust policy in place or have sought trust guidance to support enterally feeding blended diet ?

Objectives

- The controversies of blended diet
- Emerging Research
- The BDA Policy Statement Review 2019
- Samples from the new statement
- Questions

Antecedents

‘Use of Liquidised Food with Enteral Feeding Tubes’ BDA Policy Statement (2013)

- ‘does **not** recommend’
- ‘Use of liquidised food increases the likelihood of feeding tube blockage and increases the risk of gastric infection.’
- Practice Toolkit (2015)
- ‘a retrograde step’

‘It’s Just Food, Blended’ Exploring Parents’ Experiences of Choosing Blended Diet for Their Tube-fed Child

Dr Sarah Durnan, Specialist Dietitian, Dr Alex Toft, Dr
Helen Flaherty and Professor Jane Coad

Literature Review

| Author and Year | Study Details |
|------------------------|--|
| Pentiuk et al 2011 | Uncontrolled Cohort Study, questionnaire design |
| Gallagher et al 2018 | Uncontrolled Cohort Study, questionnaire design |
| Johnson et al 2017 | Electronic survey of US Parents of tube-fed children |
| Armstrong et al 2017 | Survey of UK Dietitians |
| Johnson et al 2015 | Survey of US Dietitians |
| Novak et al 2009 | Professional Round Table |
| Brown 2014 | Professional experience piece |
| Thomas 2017 | Professional experience piece |
| Johnson 2013 | Individual Case Report |

The voice of the parent was largely missing!

Aim and Objectives

Aim:

This research aimed to generate rich data and a deep understanding about individual parents' experiences of choosing blended diet to feed their long-term tube-fed child.

Objectives:

- To explore the reasons why parents first consider an alternative to commercial formula.
- To understand the benefits of blended diet as perceived by parents who use it to feed their tube-fed child.
- To explore how individual parents have been supported by professional in their choice to use blended diet.
- To identify challenges experienced by parents following their choice to use blended diet.

1) To explore the reasons why parents first consider an alternative to commercial formula

- Parents primary motivation was the Health and Wellbeing of their child
- Unacceptability of other treatment options
- Parental assessment of wider risk posed to the child

*We were coming to that place, the option of last resort. We had tried everything and she's not getting better. Now what I have to consider as a parent is; not just the nutrition of my daughter but the health and safety of her because whilst she was on these [commercial] formulas she would vomit, and she would aspirate on that vomit. **Nathan***

2) To understand the benefits of blended diet as perceived by parents who use it to feed their tube-fed child

- Rapid improvement of previously debilitating symptoms
- Reduction in medications
- Improved growth
- Perception of improved appearance and health
- Happier child

'Once I'd started I actually felt that I'd been let down by the professionals; not telling us about it [blended diet]... I just think what might she have been like? If she'd been on proper food at that point would she have been in hospital all that many times and could I have kept a job down instead of packing in work to care for her?' Emily

- Inclusion in social aspects of food
 - Family meal times
 - Special Occasions
 - Inclusion of wider family members
- A plethora of smaller choices
 - Personalisation
 - Variety
- ‘Real Food’ rather than medicine
 - ‘I can be his Mum rather than his nurse

‘When this idea, the blended diet came of real food it somehow changed things and made things... actually this is more how like life should be, it brought some normality to a household that’s been so entrenched with medical stuff.’ Fiona

3) To explore how individual parents have been supported by professionals in their choice

- Inconsistent
 - No one profession seemed more or less supportive
 - Different experiences with members of the same profession
 - Changing attitudes toward blended diet
- Continued focus on risk is perceived to be unhelpful
- Parents want advice on food from their dietitian

*My friend, I remember her telling me how great her dietitian was. She's been given really good nutritional advice about foods to try and why and they've gone through all the benefits of this food versus that. Whereas I have to go online, I have to read something and decide whether that is right or wrong. I would like to have someone who can cut through all of that for me and give me some advice about food. My poor dietitian is just so worried that she is not giving me any advice really so I've had to go and make guesses myself. **Marie***

4) To identify challenges experienced by parents following their choice to use blended diet

- Getting Started
- Additional time and work
- Investment

‘My head was full of numbers and calculations and when I made it the whole kitchen was a mess it was like the Swedish chef had been at work it was everywhere and that was a challenge and I think it’s important for people to know it doesn’t stay like that you get your routine, you get your rhythm.’ **Olivia**

- Defending their choice
 - Respite
 - School
 - Hospital
- Peer Support

'I've tried to level with them as an equal, as a healthcare professional as well. I'm a sensible Mum, I'm not some quack but I think sometimes I'm viewed as this spear heading, single woman campaign, a lentil feeding, sandal wearing type crusader which I'm not I just want to feed him normal food.'

Laura

Strengths and Limitations

Strengths

- Valuable insight and understanding of parents experiences which has been missing from the literature to date.
- Rigorous Methodology
- Array of experiences
- Diversity of opinion
- Wealth of experience

Limitations

- A biased group
- Exclusion of non English speakers and those with communication difficulties
- Excluded parents using blended diet for <1 year

Implications for Practice

General Home Enteral Feeding

- Consider the language used
- Allow parents flexibility

The Decision to Try Blended Diet

- When should we discuss Blended Diet with Parents?
- Holistic assessment of Risk
- Potential to alleviate feelings of isolation and exclusion

Supporting Parents who have chosen Blended Diet

- Good communication with the MDT
- Continued focus on risk is unhelpful
- Advise on food
- More support initially
- Support needed depends on how they blend

Blended Diet BDA Toolkit and Professional Statement Development

Policy Statement Review 2019

- Joint funded by the PENG and Paediatric Specialist Groups
- Led by:
 - Dr Sarah Durnan – representing paediatric group
 - Ailsa Kennedy- representing HEF PENG
- Other Core Group Members:
 - Sian Thomas- Consultant Nurse Child Health, Aneurin Bevan Health Board.
 - Denise Kennedy-Senior Children's Dietitian, First Community Healthcare
 - Ruth Stanley- Lead Paediatric Gastroenterology Dietitian, RVI, Newcastle
 - Lucy Constable -Paediatric HEF Dietitian, Exeter
 - Sarah Donohoe- Community Paediatric Dietitian, South Tees NHS Trust
- With guidance from Naijia Qureshi –Head of Education and Professional Practice and Tom Embury Policy Officer at the BDA
- Review by a wider group of stakeholders including:
 - Dietitians
 - Medical and Nursing Professionals
 - Researchers
 - Patients and Parents

The Review Process

Phase 1

- **March 2019**- The current Position Statement (2013) and Practice Toolkit (2015) was circulated for critique amongst the wider group. Development of a core working group of six registered dietitians, and 1 specialist nutrition nurse.

Phase 2

- **1st April 2019**-First Meeting of the Core Group- Division of sections to review among core group members-Task and Finish approach.
- **1st May 2019**- Circulation of draft statement to the Wider Group- Feedback Collated

Phase 3

- **23rd May 2019**- Second Meeting of the Core Group- Second draft
- **10th July 2019**- Discussion at the BDA Council Meeting
- Feedback collated and Legal advice sought

Phase 4

- Final discussion and ratification at the BDA council meeting on **6th November 2019**

Sample of Policy Statement

The purpose of this statement is to:

- Create a culture where tube-fed individuals and their families and/or carers feel able to openly and honestly discuss the feeding plan they follow or plan to follow with the dietitians involved in their care.
- Create a culture where dietitians feel supported professionally, to offer blended diet as an option- to tube-fed individual where they deem it appropriate and feel able to raise the topic of blended diet with their patients and other healthcare professionals.

Sample of Policy Statement

A shared decision-making approach to care, alongside employer's clinical governance procedure should be followed by the dietitian. The dietitian should ensure families receive the individualised information they need to enable them to make an informed decision. Planning and preparing blended diet requires a significant commitment and families should have realistic expectations of the labour and financial cost involved. The shared decision should be justified and clearly documented in the individual's records by the dietitian.

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