Multi-agency practice for developing a blended diet for children fed via gastrostomy


Abstract

The administration of a blended diet via a gastrostomy tube to children with complex needs is an evolving area of practice. Healthcare professionals must provide guidance, promote best practice and optimise patient safety where patients and families choose a blended diet in preference to the prescribed commercial feed. The Aneurin Bevan Health University Health Board in Newport, Wales, took a collaborative approach, by working with parents as equal partners, to enable a child with complex needs to receive a blended diet at school. The development of a protocol and risk-assessed approach enabled the delivery of bespoke flexible care that met the holistic needs of the child and family and improved the child’s quality of life. The initiative also led to positive outcomes for the school and wider community.

Keywords

blended diet, child health, community children’s nursing, complex care needs, enteral feeding, multi-agency working

FAMILIES IN the UK who use home enteral tube feeding for their children have shown growing interest in the use of blended food via a gastrostomy device as an alternative to commercially prepared feeds. Blended diet for enteral feeding via a gastrostomy tube is defined as homemade everyday food blended to a smooth ‘single cream’ consistency (Brown 2014).

The practice has been adopted in the United States and parts of Europe for a number of years (British Dietetic Association 2015), but the evolving interest in it in the United Kingdom as an alternative to the standard commercial feed recommended by a dietician has been driven by families via social media. There are numerous websites and online parents’ forums which aim to support parents and carers on the use of blended diets.

There is little published evidence available on the benefits or risks of a blended diet, although anecdotal reports from families suggest a beneficial effect. The reported benefits from changing to this method of feeding include reduced gastro-oesophageal reflux, improved bowel function and an improvement in mood, hair and skin condition (Klek et al 2011, Pentiuk et al 2011) However, there are also potential adverse effects such as increased risk of infection, tube blockage and compromised nutritional intake.

A recent rapid review of the evidence indicates there is a need for further studies to understand the benefits and outcomes of a blended diet and the experiences of families (Coad et al 2017).

Aims

This article describes the approach taken by a health board to support a family who chose to administer a blended diet to their child in the community setting, while also exploring the wider effect of this initiative for the child, family, educators and on professional practice.

Understanding the concerns

When a parent of a preschool child with complex health needs informed the healthcare team that she had been administering a blended diet at home and wanted a carer to administer it when her child started school, it raised several issues for practitioners.

Aneurin Bevan University Health Board delivers care in the acute and community setting across five local authority sectors, and for the health board to agree to such an approach it was important to understand the risks and benefits to the child, the professionals and the organisation fully.

The use of a blended diet for children with health needs is contentious, and at the time
of the request health professionals in the UK were not supporting or encouraging the use of a blended diet due to lack of evidence or a professional consensus.

The Parenteral and Enteral Nutrition Group (PENG) of the British Dietetic Association was not recommending the practice, though it recognised that professionals had a duty of care to patients and carers who wished to pursue this method of feeding, and developed a risk assessment tool to guide healthcare practitioners in areas to consider (PENG 2016). Nurses were concerned, however, about the potential risk to themselves as they would be working outside manufacturers’ guidance and be non-compliant with professional codes of conduct and practice.

There are numerous anecdotal reports from parents of the potential benefits of a blended diet as an alternative to commercial feeding; the mother of the preschool child with complex health needs described the positive effect it had on her child physically, emotionally and socially. Important elements of this initiative were taking a rights-based approach in the assessment of need, treating a child equally irrespective of health need and supporting a child’s right to access education.

For this initiative to become a reality, a collaborative approach was essential, and education colleagues were keen to work in partnership to enable the child to access the blended diet at school.

Considering the issues
The health board is accountable, in the context of a patient quality and safety assurance framework, to ensure that any system that it funds is lawful and clinically safe. In Wales the Welsh Risk Pool Service (WRPS) supports the quality and safety agenda for patients and staff by undertaking effective risk management and clinical assessments (Shared Services Partnership 2012).

The WRPS indemnity arrangements for maintenance of NHS core activities recognise that the delivery of healthcare is evolving and requires different and innovative approaches; the indemnity arrangements need to be sufficiently flexible to meet the needs of the service to ensure the highest level of patient safety and quality. Therefore, the principle applied by the WRPS is that training a person or organisation that is external to NHS Wales falls within the scope of the indemnity arrangements where there is evidence that the training is undertaken in furtherance of the NHS core activities or there is a benefit to the wider public sector.

It was fitting that the new Nursing and Midwifery (NMC) code (NMC 2015) was published at the time of the initiative as it outlines the changing role and expectation of nurses and the importance of prioritising people and practising effectively (Box 1).

Developing a governance framework
Having reviewed the history, evidence and expert opinion in the use of blended diets for children with complex health needs, and following executive team approval for the initiative, professionals from health and education were brought together to gain a consensus of support and commitment to enable the child access to a blended diet at school.

A solution was made possible through the development of a protocol and governance framework, which incorporates a pathway of professional approval and documentation of professional discussion. This makes clear that all risks have been highlighted and discussed with the family and reinforces the family’s wishes and choice, a risk assessment and a multi-agency care plan, which clarifies everyone’s individual responsibilities.

The protocol provides guidance, promotes best practice, supports consistency and optimises patient safety where parents choose to administer a blended diet in preference to a prescribed commercial enteral feed.

The multi-agency care plan strengthens the governance arrangements and the role of healthcare staff to lead and deliver training and assessment of competencies to identified non-NHS care staff who administer the blended diet at school. The development of the protocol provided an assurance to staff that they had organisational support in management of risk, training and delegating of this procedure to non-healthcare professionals.

<table>
<thead>
<tr>
<th>BOX 1. Links to themes of the Nursing and Midwifery Council code</th>
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<tr>
<td><strong>Prioritising people</strong></td>
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<tr>
<td>» The importance of really listening to people.</td>
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<tr>
<td>» To put the interests of the people using nursing services first.</td>
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<td>» To work in partnership to ensure the delivery of effective care.</td>
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<td><strong>Practising effectively</strong></td>
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<td>» To assess need and deliver, or advise, on treatment to the best of one’s abilities on the basis of the best evidence available and best practice.</td>
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<td>» To be accountable for the decision to delegate a task within the other person’s scope of competence, making sure that they fully understand instructions.</td>
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Integrated working to meet the needs of child and family

A large number of professionals, including a dietitian, enteral feeding teams, community children’s nurses, a paediatrician, an additional learning needs coordinator as well as a multi-agency team, were involved in planning for the child to attend school.

The fundamental element in the success of this initiative was the willingness of education staff to work in partnership with healthcare staff to support the parents. It demonstrates how parents and professionals can work as partners and provide flexible care to meet the needs of the child and improve their quality of life.

Outcome for the child and family

Through the delivery of bespoke care the needs of the child and family have been met as agencies have reviewed practice and challenged boundaries.

The child has made significant progress physically and developmentally since receiving the blended diet at school.

‘Physically, she has progressed from bottom shuffling to walking with a frame, to walking holding one hand, to practically running independently. She can’t wait to go to school, is making progress in all areas of the curriculum and enjoys every activity presented to her,’ (Additional learning needs coordinator (Aln co)).

This is also supported by her parents, who report the difference it has made to the child in motivation and confidence.

‘This all seemed so impossible when there was talk of her going to school, but it’s amazing what has been achieved. If it wasn’t for the blended diet I don’t think she would be able to attend school, as she had such diarrhoea on a normal feed. She’s now motivated by the other children and is now able to walk, but it’s motivational for me also,’ (Mother).
Outcome for the school and wider community

Education colleagues understood and accepted from the outset the parents’ request to administer a blended diet at school and were supportive of the process at all stages.

‘All our parents who provide packed lunches make the decision on what to include in them, I felt this was the same. From a school point of view, blending school dinners seemed perfectly reasonable... although for [child’s name] a blended diet would necessitate a specific blender. Again, this seemed reasonable and I was prepared to purchase it,’ (Aln co).

The school was keen to ensure that a number of staff received training in the process, which has resulted in developing staff confidence and skill in managing a child with complex health needs.

‘Some staff were nervous at first... the nurses were so encouraging and reassuring, they gave the staff the confidence. We worked out a rota so all staff have regular experience of feeding so as not to forget the training. This system has worked well,’ (Aln co).

The initiative is viewed as an achievement for all involved. Not only has the child benefited from attending mainstream school, the school reports that her peer group benefit from observing and learning about meeting the needs of children with a disability.

‘There was initially some interest in the “tube feeding” from some children, who would come and have a look and ask questions, but this type of interest is encouraged here. We want to increase understanding of different needs. Now, hardly anyone bats an eyelid. It was always absolutely taken for granted by us at school hardly anyone bats an eyelid. It was always absolutely taken for granted by us at school’ (Class teacher).

Preparation of the blended diet is shown in Figures 1-3.

Discussion

Modern healthcare needs to develop innovative solutions to resolve complex situations. This has been demonstrated in this article through the development of a bespoke multi-agency care plan approach to enable healthcare professionals to manage safely children in receipt of a blended diet in the community.

A case study approach has provided a unique opportunity to observe and learn lessons from administering a blended diet to a child with complex needs at school.

It demonstrates how parents and professionals can work co-productively as well as equal partners to provide flexible care that meets the needs of the child. This has empowered the child and family and improved their quality of life. It has strengthened multi-agency relationships through working together to meet the needs of the child. And, by developing solutions to complex situations and challenging the barriers that sometime exist in professional practice, it has resulted in the delivery of safe, effective care in practice.

As a means of reducing variation in practice the protocol has been shared with other organisations in line with the principles of Prudent Healthcare (Public Health Wales 2016). It has enabled the development of an evidence base to inform future practice and has been a catalyst for a multi-centre study that is being undertaken in South Wales which will examine the risks and benefits of administering a blended diet to children via gastrostomy.

Conclusion

Enabling a child with complex care needs to access a blended diet in a school setting has created positive outcomes for the family, the education system and the healthcare team. Even though the initiative was triggered in response to an individual request, this area of practice is evolving and this article will have far wider implications for patients of all ages in receipt of home enteral tube feeding.

References


