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## Specific author contribution:

Professor Konstantinos Gerasimidis – planning the study; revision of the manuscript; final approval; agreement to accountability.

Anna Walsh – planning and conducting the study; data interpretation; drafting the manuscript; revision of the manuscript; final approval; agreement to accountability.

Omowunmi Bamkole – data interpretation and analysis; drafting the manuscript; revision of the manuscript; final approval; agreement to accountability.

# Abstract

Blenderised tube feeding (BTF) has become an increasingly popular method of nutrition support to long-term tube-fed patients mostly children. This study surveyed perceptions and experiences on BTF shared on YouTube. From 71 videos analysed, attitudes toward BTF were mostly positive (91%) and included psychosocial benefits and improvements in gastrointestinal symptoms; no differences between caregivers and healthcare professionals were observed. Very few speakers (8%) felt there was a lack of support regarding use of BTF in schools and from healthcare professionals, since it is not part of the standard clinical management protocols. The most commonly used food items in blends included tips on recipes for blends, storing feeds and ensuring nutritional adequacy. Analysis of YouTube content on BTF was considerably positive and suggests that BTF is feasible and safe way to provide nutrition to tube fed patients.

(Word count: 150)

Key words: Nutrition support, enteral nutrition

# What is known:

- Blenderised tube feeding (BTF) has become widespread amongst patients on long-term enteral nutrition, mainly children.
- There is scarce quality evidence on the benefits of BTF and lack of experience or training limits its use.

## What is new:

- How and where patients receive information regarding BTF.
- What information is shared by BTF users' on video platforms.
- There are substantially more positive than negative experiences on the use of BTF both by healthcare professionals and carers of users.
- Better training and more support on the use of BTF is required by healthcare professionals.

(Word count: 88)

#### Introduction

Blenderised tube feeding (BTF) has become an increasingly popular mode of nutritional support to people requiring long-term enteral nutrition, particularly those on gastrostomy feeding.<sup>[1, 2]</sup>

There is sparse data from controlled intervention trials which have explored the effectiveness of BTF on patients' clinical and nutritional outcomes, safety, and quality of life. Few studies have also investigated the perceptions, attitudes and experiences of those who use BTF, but have found a largely positive response.<sup>[3-6]</sup> These studies reported fewer gastrointestinal (GI) symptoms compared to commercial formula.<sup>[4, 5, 7, 8]</sup> Patients who used BTF considered it to be more natural, enjoyed eating the same meals as their family, tolerated it better than formula and were better able to maintain their body weight.<sup>[7, 9, 10]</sup>

Studies have shown that BTF is viewed positively by healthcare professionals (HCPs) too, but a lack of evidence, education and practical training regarding BTF and practices around its delivery, means that some are reluctant to recommend it.<sup>[10-12]</sup> It is therefore possible that BTF has become more widespread amongst patients who require EN or their carers due to dissemination of information and practical tips across social media and video platforms.

YouTube is a video platform on which healthcare information has been widely broadcasted and shared amongst patients, on topics ranging from pregnancy to gallstone disease.<sup>[13-15]</sup> It is estimated that over 80% of those with access to the internet find healthcare information online.<sup>[13-17]</sup> It offers a channel through which perceptions, attitudes, experiences and practices of BTF users, caregivers and HCPs can be disseminated independently of scientific evidence.<sup>[16, 17]</sup> This study aimed to analyse YouTube content on perceptions, attitudes, experiences and practices on BTF from patients, caregivers and HCPs.

## Methods

A YouTube search strategy was carried out on the 19th May 2020 in Glasgow, UK. Search terms included "Blenderised Diet", "Blended Tube Feeding", "Blended Diet", "Real Food Blends for Tube Feeding", "Natural Tube Feeding", "Home Tube feeding", and "Homemade Blended Tube Feeds" (See Figure, Supplemental Digital Content 1, which shows the search strategy). Boolean operators or term truncations were avoided as such search strategies are less likely to be used by lay people and the general public.

Only the videos from the first page of each search were included. Videos were included if they were relevant to BTF with narrative or text which expressed a monologue for

the video, had acceptable sound quality and were in English. Speakers could be from multiple backgrounds including patients, caregivers and HCPs.

Videos were excluded if they lacked relevance to BTF, such as by promoting blenderised diets for weight loss, or if they did not contain any narration, written description or a speaker since no perspectives or opinions regarding BTF could be expressed. Videos focused on commercial formula, or promotion or advertisement of a commercial blended food product were also excluded.

#### Data Extraction

Data from the videos were initially recorded in large, free hand text onto a database (Microsoft Excel, 2020). The free text was broken down into provisional codes, which were then standardised into similar keywords or phrases and then collated into themes. Speakers were classed as either a HCP if they stated they were a qualified medical professional, nurse, dietitian, nutritionist and nutritional therapist; or a patient or caregiver if they were the primary users or caregiver to the patient being tube fed.

#### Statistical analysis

Summary statistics are presented as counts and frequencies. Chi squared test was carried out to determine whether there were significant differences in perceptions between different speaker types and patient conditions using SPSS (IBM® SPSS® Statistics 26).

#### Results

#### Sample characteristics

One hundred and twenty videos were identified, after the removal of duplicates, and 71 of those were eligible and used for downstream analysis. All the videos were created on personal accounts. The median (IQR) number of views for the videos was 1449 (397-4800), video duration was 6 minutes (4-12) and number of subscriptions per channel was 186 (55-839).

From the 71 speakers, 21 (30%) were HCPs and 50 (70%) were either a patient (n=3) or a direct carer to the patient (n=47). Thirty-eight (55%) of the speakers discussed the use of BTF for certain conditions; these were classified either as a neuromuscular condition (n=32), commonly cerebral palsy, or a surgical condition (n=6). Thirty-three (45%) either did not specify a condition or they were a HCP. Seventy speakers originated from the USA and one speaker was from the UK.

### Attitudes towards BTF

Across the 71 videos, a total of 148 views on BTF were expressed; 134 were positive and 14 were negative. The positive views were categorised into: Psychosocial Benefits, Improvements in GI Symptoms, Physiological Benefits, and Convenience (Figure 1). The negative views included Lack of Community Support and Nutritional Inadequacy.

#### Psychosocial Improvements

Psychosocial improvements were reported 62 times (46%). BTF increased feelings of normalisation (n=22) (Figure 1); this was either stated directly or implied through quotes such as 'BTF brought back the joy of cooking' and 'BTF allows the speaker and patient to enjoy smells of food'. Other psychosocial improvements included increased patient wellbeing, with speakers commenting that the 'patient appears happier' and has an 'improved mindset and attitude to feeding'. Speakers also mentioned their perception that BTF is more natural and healthier than commercial formula, and that BTF promoted gut healing and a more diverse intestinal microbiome. These improvements were equally expressed by both patients/carers and HCPs (p=0.671).

## Improvements in Gastrointestinal Symptoms

There were 34 mentions (25%) of an improvement of GI symptoms, most commonly reduced vomiting and reflux (Figure 1). Improvements in GI symptoms did not differ between patients/carers and HCPs (p=0.327).

#### Physiological Benefits

There were 19 views (14%) on physiological benefits; these were improvements in patient skin tone, nail and hair growth, height, weight gain, fewer hospital admissions and infections, improvements in patient energy levels and increased oral intake (Figure 1). More carers said there were physiological benefits with BTF compared to HCPs but there was no significant difference between these proportions (p=0.069).

#### Convenience

Fifteen speakers (21%) felt that BTF was equal to, or more convenient to use than commercial formula (Figure 1). This was because they felt it was quick to set up, there were more options available and it meant that going out for meals was easier. However, five speakers perceived BTF to have a higher risk of clogging, found BTF more time consuming and thought it was less convenient. There was no significant difference between the proportion of patients/carers who expressed that BTF was equal to or more convenient than commercial formula and the proportion of HCPs who expressed this (p=0.341).

### Lack of Community Support

Six speakers (8%) felt there was a lack of support regarding use of BTF in schools and from HCPs since it is not part of the standard clinical management protocols. However, four caregivers recommended contacting a dietitian or medical professional for information about BTF, for example, to calculate patients' nutrient requirements or to seek advice on recipes. Five speakers described or recommended the use of other sources such as government guidelines, online forums and nutritional tracking applications to aid BTF.

## Nutritional Inadequacy

Nutritional inadequacy caused by BTF was another concern quoted by three speakers (4%). One caregiver expressed that it is difficult to reach the calorie requirement while maintaining an appropriate volume during blending. Two HCPs mentioned their concerns regarding the risk of nutritional inadequacy while using BTF.

## Most commonly mentioned foods for BTF

The most commonly mentioned foods used for BTF in the videos were collected and classified according to their food group (Figure 2). The most popular food group was vegetables (n=46), whilst carrots (n=16) and chicken (n=11) were the most popular food items. Speakers often used or recommended supplementing blends with micronutrients (e.g. vitamin D); 18 of 50 caregivers (36%) mentioned the use of supplements in feeds, while only three of 21 HCPs (14%) mentioned supplementation, primarily if there were nutritional deficiencies (p=0.092). Four caregivers also mentioned use of commercialised blended feeds to supplement their home-made blended feeds (p=0.197).

#### Recommendations, facts and experiences from speakers

Recommendations and practical tips relevant to the preparation and provision of BTF were mentioned by different speakers and categorised into Gastrointestinal Considerations with BTF, Supplementation, Recipe Ideas, Feeding Considerations, Transitioning to BTF, Blending Tips, Equipment Suggestions, and Storage Ideas. These included ways to create nutritionally adequate recipes, store blends for future use and achieve the required viscosity of blends for BTF (See Table, Supplemental Digital Content 2, which shows practical tips on the use of BTF).

## Discussion

This study analysed YouTube speakers' perceptions, experiences and practices of BTF by patients or their caregivers and HCPs. The most commonly reported benefits of BTF were

psychosocial improvements, including feeling more normal and increased patient happiness. BTF was considered to be healthier and more natural by speakers and one caregiver described how "the process of receiving different nutrients more gradually each day and according to what is in season was more natural than receiving the same complete nutrition at every meal". This observation is in agreement with previous research<sup>[18]</sup> which found that 43% of patients who used BTF considered it to be more natural than commercial EN.

Caregiver satisfaction was a reported improvement by both caregivers, patients and HCPs. A study amongst British dietitians<sup>[11]</sup> found that 74% expected to see caregiver involvement as a major benefit of BTF, and this may be a contributing factor in the decision to transition to BTF for paediatric patients. Improvement of quality of life is now being considered an important patient reported outcome both in research and routine clinical practice.

Other improvements included the perception that BTF can improve gut health; whilst the speakers did not provide any scientific evidence for this. Recent research<sup>[3]</sup> found that patients who transitioned to BTF had an increase in bacterial richness and diversity, particularly firmicutes, several of which are beneficial fibre fermenters, while the abundance of potentially harmful proteobacteria decreased.

A quarter of speakers in this study mentioned that BTF improved their gastrointestinal issues. This is a well reported improvement, observed in other studies, and may improve feeding tolerance in such patients.<sup>[1, 3, 4, 8, 18]</sup> A major factor in the hesitance of HCPs toward recommending BTF are concerns of nutritional inadequacy.<sup>[11, 12]</sup> However, this concern was only raised by two HCPs and one patient/carer. More research is required to determine whether nutritional inadequacy is a reasonable concern for BTF.

As shown by previous research, there is little professional guidance regarding BTF and likewise speakers reported barriers to accessing official information on BTF.<sup>[11, 12]</sup> It is likely that many users turn to media platforms to gain information regarding BTF and perhaps a sense of community. The most commonly used foods were described, and reportedly chosen due to nutritional value and suitability for blending (carrot, chicken, spinach, nuts). It is not widely known what information BTF users' receive to guide their practice and as evidenced by this study, there is a wealth of practical experiences to draw upon. It might be useful that some of these are taken into consideration to inform future clinical practice guidance, particularly in the absence of any quality evidence. There remains an unmet need for more quality randomised controlled trials to study the effectiveness of BTF in improving patients' nutritional and clinical outcomes and safety, as well as quality of life. There is also a need to improve professional training and accessibility of BTF resources for HCPs.

This study has some limitations. The views in this study were self-reported, therefore results only reflect personal perceptions and experiences based on anecdotal evidence. The video analysis process was carried out by a single researcher therefore interpretation of codes and themes may have been in part subjective. Videos created on use of BTF likely express positive aspects of BTF and may introduce a positive bias towards opinions. A standardised approach, similar to the ones used in systematic reviews, was not applied to the search strategy and so results may vary if carried out by others. YouTube results may also differ depending on multiple factors such as the date of the search, searcher's location, or language settings.

### Conclusion

The perceptions, experiences and attitudes of YouTube® speakers on BTF were overwhelmingly positive. Experiences provided by video creators have indicated that BTF is a viable option to provide to patients on long-term EN. Clinical trials are required to direct guidelines and practices so HCP and patients can use BTF safely and effectively.

#### References

- Batsis ID, Davis L, Prichett L, et al. Efficacy and Tolerance of Blended Diets in Children Receiving Gastrostomy Feeds. Nutr Clin Pract. 2020;35(2):282-8.
- Bennett K, Hjelmgren B, Piazza J. Blenderized Tube Feeding: Health Outcomes and Review of Homemade and Commercially Prepared Products. Nutr Clin Pract. 2020;35(3):417-31.
- Gallagher K, Flint A, Mouzaki M, et al. Blenderized Enteral Nutrition Diet Study: Feasibility, Clinical, and Microbiome Outcomes of Providing Blenderized Feeds Through a Gastric Tube in a Medically Complex Pediatric Population. JPEN J Parenter Enteral Nutr. 2018;42(6):1046-60.
- Hron B, Fishman E, Lurie M, et al. Health Outcomes and Quality of Life Indices of Children Receiving Blenderized Feeds via Enteral Tube. J Pediatr. 2019;211:139-45 e1.
- Maddison J, Taylor J, O'Neill M, et al. Outcomes for gastrostomy-fed children and their parents: qualitative findings from the 'Your Tube' study. Dev Med Child Neurol. 2021.
- 6. Epp L, Lammert L, Vallumsetla N, et al. Use of Blenderized Tube Feeding in Adult and Pediatric Home Enteral Nutrition Patients. Nutr Clin Pract. 2017;32(2):201-5.
- Johnson TW, Spurlock AL, Epp L, et al. Reemergence of Blended Tube Feeding and Parent's Reported Experiences in Their Tube Fed Children. J Altern Complement Med. 2018;24(4):369-73.
- Schmidt SB, Kulig W, Winter R, et al. The effect of a natural food based tube feeding in minimizing diarrhea in critically ill neurological patients. Clin Nutr. 2019;38(1):332-40.
- 9. Coad J, Toft A, Lapwood S, et al. Blended foods for tube-fed children: a safe and realistic option? A rapid review of the evidence. Arch Dis Child. 2017;102(3):274-8.
- 10. Breaks A, Smith C, Bloch S, et al. Blended diets for gastrostomy fed children and young people: a scoping review. J Hum Nutr Diet. 2018;31(5):634-46.

- 11. Armstrong J, Buchanan E, Duncan H, et al. Dietitians' perceptions and experience of blenderised feeds for paediatric tube-feeding. Arch Dis Child. 2017;102(2):152-6.
- Eustace K, Cole L, Hollaway L. Attitudes and Perceptions of Blenderized Tube Feed Use Among Physicians and Advanced Practice Providers. JPEN J Parenter Enteral Nutr. 2021.
- Lee JS, Seo HS, Hong TH. YouTube as a source of patient information on gallstone disease. World J Gastroenterol. 2014;20(14):4066-70.
- Yuksel B, Cakmak K. Healthcare information on YouTube: Pregnancy and COVID 19. Int J Gynaecol Obstet. 2020;150(2):189-93.
- 15. Ozsoy-Unubol T, Alanbay-Yagci E. YouTube as a source of information on fibromyalgia. Int J Rheum Dis. 2021;24(2):197-202.
- 16. Madathil KC, Rivera-Rodriguez AJ, Greenstein JS, et al. Healthcare information on YouTube: A systematic review. Health Informatics J. 2015;21(3):173-94.
- Sampson M, Cumber J, Li C, et al. A systematic review of methods for studying consumer health YouTube videos, with implications for systematic reviews. PeerJ. 2013;1:e147.
- Hurt RT, Edakkanambeth Varayil J, Epp LM, et al. Blenderized Tube Feeding Use in Adult Home Enteral Nutrition Patients: A Cross-Sectional Study. Nutr Clin Pract. 2015;30(6):824-9.

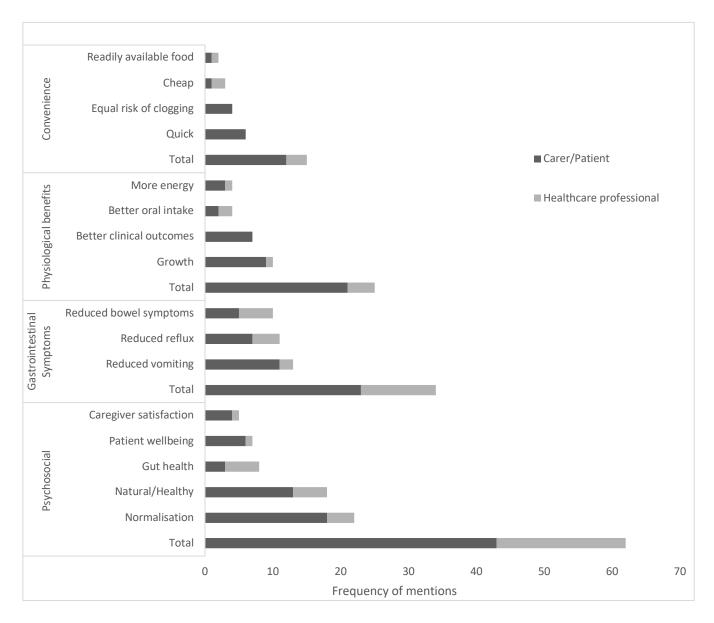
# Figure legends

**Figure 1**: Number of positive attitudes towards BTF expressed by the YouTube speakers, categorised into Psychosocial, Gastrointestinal (GI) symptoms, Physiological benefits, and Convenience, with subcategory breakdown by Speaker types.

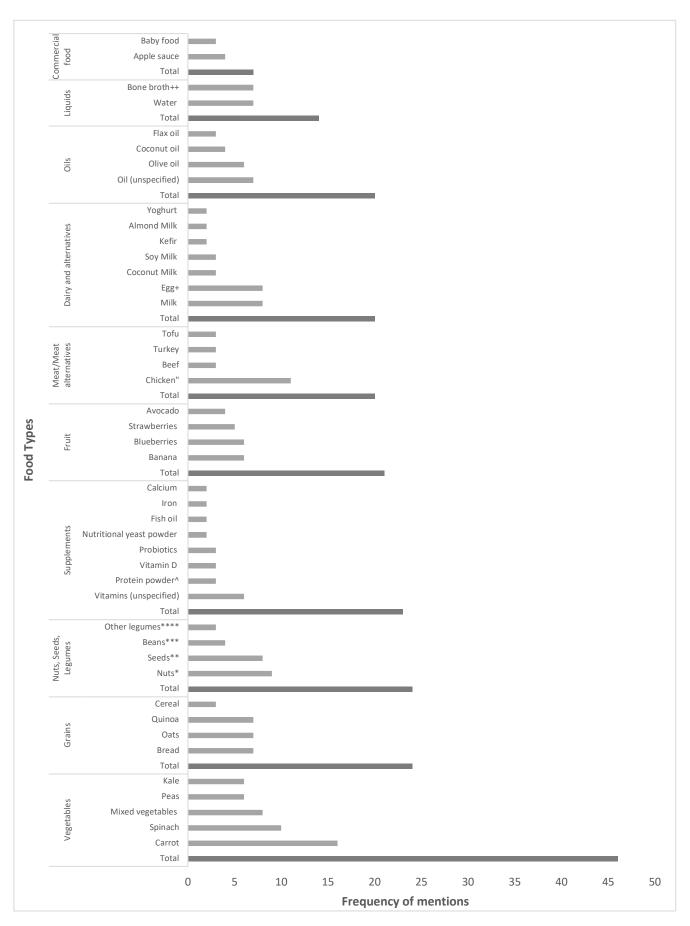
**Figure 2**: Most commonly mentioned food groups used in blends by the YouTube speakers, subcategorised into specific food items.

- ++ including beef, chicken
- + including powdered, scrambled, boiled
- " including drumsticks, breast, roasted, pre-prepared
- ^ including whey
- \* including almond, peanut butter, soaked, walnut butter
- \*\* including sunflower, chia, flax, linseed, pumpkin
- \*\*\* including black, kidney, soy
- \*\*\*\* including chickpeas, lentils.

# Figure 1



# Figure 2

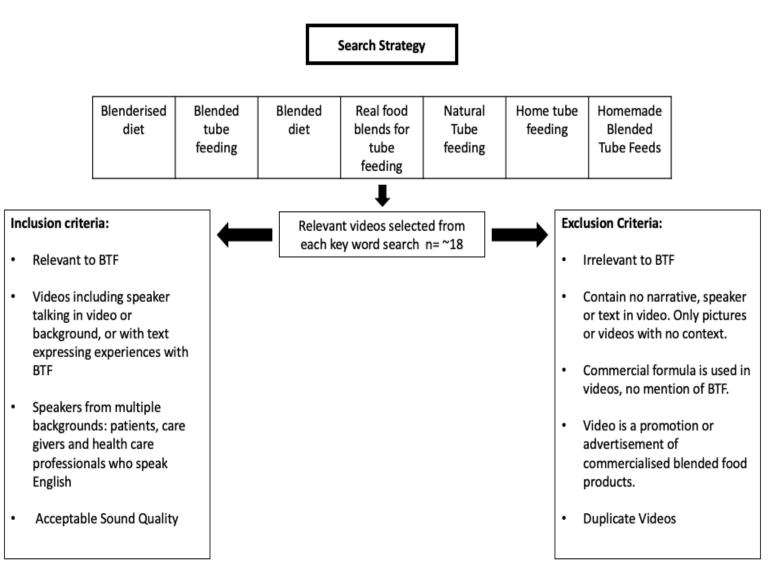


# Supplementary figure legends

Figure, supplemental digital content 1: Flow chart of search strategy.

**Table, supplemental digital content 2**: Recommendations and practical tips from the speakers based on speaker type based on anecdotal experiences from their use of BTF, and are not evidence based.

# Figure, Supplemental digital content 1



Table, Supplemental digital content 2

Category	Patient/Caregiver	Healthcare Professional
Gastrointestinal	Too much oil can cause further	
considerations	delayed gastrointestinal	
	emptying or symptoms.	
Supplementation	Add a multivitamin.	
		Supplement with
		commercial formulas.
	Supplements with probiotics a	are perceived to improve
	digestion and i	
Recipe creation	Follow government guidelines to create a balanced meal.	
•	Use mobile applications to create a balanced meal.	
	Protein powder can be used to	
	increase calories without	
	increasing the volume of blends.	
	Do not add cartilage o	r bone to blends.
	Give high calorie foods to reduce volume such as honey, coconut flakes, powders, whey and hemp.	
Feeding considerations	Medication should be given at	
	the start of feeds to promote	
	absorption.	
	Similar to commercial formulas,	
	blends should not be given	
	when hot.	
Transitioning to		Introduce new foods slowly
blenderised tube		to observe the patient's
feeding		reaction and identify any
		intolerances.
Blending tips	Use a very fine strainer when	
	dealing with seeds from berries,	
	tomatoes etc.	
	After blending, the volume can be up to 50% greater than the	
	initial volume, depending on the foods used, or if there are bubbles.	
		Leave the blend to sit for
		10-15 mins before feeding
		to remove air bubbles and
		reduce the volume of
		blend.
		Feeding methods depends
		on the viscosity of the
		blends – e.g. thicker feeds
		are more suitable for
		syringe feeding, whereas
		thinner feeds are more

		a sita bila fan ar war fa a din a	
		suitable for pump feeding	
		or gravity administration.	
	To blend bread more easily, it ca	To blend bread more easily, it can be toasted, or broken up	
	and soaked.		
		Warm and hot foods blend	
		more easily.	
		Blend with liquids such as	
		orange juice, milk, water.	
		Steaming ingredients adds	
		water and softens for an	
		easier blend.	
		Soak nuts seeds and lentils	
		before blending to soften	
		but ensure you throw out	
		soaking water.	
		Undercooked grains can	
		absorb a lot of liquid and make the feed become too	
		thick.	
Equipment	A very high-powered blender is		
	required.		
	Prime the tube before feeding to		
	remove air bubbles.		
	Oil the syringe before use (bolus		
	feeds).		
	Flush tube with water before		
	and after feeding to prevent		
	clogging and blockages.		
		Tube discolouration is	
		inevitable. Avoid staining	
		foods such as beets or	
		turmeric.	
Storing feeds	Use reusable pouches for on the		
	go, which can be put into the		
	dish washer. They can also be stored in ice tray and frozen into		
	cubes. Measure out one ounce		
	and once frozen, package		
	together in freezer.		
	Batch cook vegetable blends		
	and freeze in muffin tins. Once		
	frozen put into a zip lock bag		
	and use throughout the week.		