

Use of K.Yo as a supplementary source of nutrition for a tube fed child with drug resistant epilepsy

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K.Yo is part of the Vitaflo Keto portfolio of products for the dietary management of epilepsy and other neurometabolic disorders.



Patient details and medical history

Age:

6 years

Gender:

Male

Relevant family and social history:

Lives with mum, dad and older brother.

Diagnosis

- Sub-acute sclerosing panencephalitis (SSPE)

Relevant medical history

Previously fit and well child, achieving all milestones, nil past medical history until sudden onset of neurological decline with seizures (clonic, tonic-clonic, myoclonic and 1 episode status epilepticus), dystonic posturing, ataxia and cognitive impairment around 5½ years old. Trialled various anti-epileptic drugs (AEDs) with no significant improvement in seizure activity; at this point was referred as an inpatient for urgent consideration of ketogenic diet 3 months after his first seizure.

Further investigations including electroencephalogram (EEG), magnetic resonance imaging (MRI) and lumbar punctures showed to have evidence of measles antibodies in cerebral spinal fluid and a subsequent diagnosis of SSPE was made one month after commencing KD.

Medications

Levetiracetam, gabapentin, clobazam, clonidine, immunoglobulin infusions, ribavarin, melatonin. PRN: buccal midazolam, chloral hydrate, bisacodyl suppositories.



Dietetic assessment

Nutritional history:

Prior to the child's neurological decline, he ate a wide range of foods, textures and drank fluids. With the progression of disease and onset of seizures, he became less alert (post seizures/side effect of AEDs) and developed an unsafe swallow. A nasogastric tube was placed to meet nutritional requirements and he has since had a gastrostomy tube inserted as a long term route for feeding.

Relevant biochemistry:

Ketogenic blood screen checked prior to starting diet.

Anthropometrics:

On starting KD: Weight = 20kg (50th-75th centile),
Height = 118cm (75th-91st centile)

Daily estimated energy requirements and ketogenic diet prescription:

Daily energy requirement	1480kcal		
Classic ketogenic diet (CKD) ratio	Initial ratio 0.5:1 (\uparrow 0.5 increment as tolerated) Final ratio 2.5:1		
Macronutrients (based on 2.5:1 ratio)	140g fat	20g protein	36g carbohydrate
Micronutrients	RNI for all micronutrients		
Fluid	1500ml		



Dietetic management

Goals of dietary management:

Ensure adequate growth and nutritional status; achieve ketosis and reduce seizure activity

The parents expectation of management – reduction in seizures, increased alertness and regain some functional skills

Feed recipe (including 120ml extra volume for priming giving sets)

Proprietary ketogenic 4:1 liquid feed	728g		
Powdered carbohydrate supplement	38g		
50% LCT fat emulsion	99g		
Total feed volume	1120ml (cool boiled water added to make this total volume)		
Daily bolus plan (89% of total feed volume)	4x250ml @ 250ml/hr		
Macronutrients per bolus feed	35g fat	5g protein	9g carbohydrate



Speech and language therapy (SALT) assessment

Shortly after starting the CKD there was a slight improvement in alertness and parents keen to restart oral diet if possible. SALT highlighted that on days when the child is less alert/not managing secretions he should not be offered anything orally. However, on days when the child was more alert and managing secretions he could have a pureed ketogenic diet and sips of water.

Texture modified ketogenic diet

The parents were given 2.5:1 ketogenic recipes however due to limited availability of texture modified ketogenic foods in hospital and lack of a diet chef this proved quite challenging. K.Yo had the required semi solid texture. It was easy to store when used on ad hoc basis; easily adjusted to obtain required ratio by adding a carbohydrate powder.

K.Yo daily recipe

K.Yo	100g (1 pot)
Powdered carbohydrate supplement	2g
Ratio	2.5:1
SALT prescription	15 level teaspoons x3 times per day

Education and training

The CKD was initiated in hospital and the parents were educated on the diet, how to test blood glucose/ketone levels and treat abnormal results. They also received gastrostomy pump training and the milk kitchen staff taught them how to prepare feeds.



Follow up and dietetic management

Patient progression

Within 1 week ketones were up to 3mmol/l and he received the first course of immunoglobulin infusions and ribavirin started shortly after. During weekly dietetic reviews, no seizures were reported, although it was difficult to attribute seizure freedom to the CKD alone.

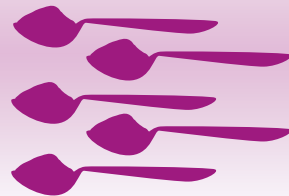
Over the following 2 months in hospital, the child remained on the CKD whilst further investigations and treatment were undertaken, and a social care discharge package was arranged. Ketones reduced to approx 1mmol/l although seizure freedom continued.

Due to the nature of SSPE, there was little improvement in functional skills with variable swallowing capabilities on a daily basis. With the use of K.Yo as a supplementary product this allowed for oral tasters which the patient enjoyed and parents felt involved in food provision.

The patient appeared to really enjoy K.Yo (opened mouth for more) and was able to take the restricted amount prescribed by SALT.



Morning



Afternoon



Evening



Discharge from hospital

The child remained on the ketogenic diet for a further 2 months following discharge, continuing to have K.Yo as an oral supplement alongside his enteral feeding regime. At his 3 month follow-up in the keto clinic, his weight had increased to 23kg (75th centile) and height remained static. After 4 months on the ketogenic diet, the neurological multidisciplinary team agreed to wean him off the diet and monitor any changes to seizure activity. He remained seizure free and subsequently discharged from the dietetic keto team.



Conclusions and key learnings

From a dietetic perspective it is a very practical product to use in the KD, easy to adjust ratio and take out and about with the child. It is ideal for hospital use, especially if ketogenic catering is limited and for those requiring a texture modified diet.



K·Yo is a food for special medical purposes and must be used under medical supervision.
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