

# Versatility in the use of K.Yo for oral and enteral tube feeding of an adolescent with drug resistant epilepsy

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## Patient Details & Medical History

**Age:**  
13

**Gender:**



**Diagnosis:**

Tuberous sclerosis complex and epilepsy

**Relevant family/social history:**

Lives with mum, dad and older sister

### Other Diagnosis:

Autistic spectrum disorder, polycystic kidney disease, hypertension, hyperlipidaemia (pre-ketogenic diet), IBS

### Relevant Medical History

- Complex medical needs as above - started ketogenic diet (KD) aged 7 years and has responded very well.
- Pre ketogenic diet was having multiple tonic clonic seizures, sometimes daily, now goes long periods (currently 14 months) without any, having what parents describe as 'small' seizures a few times a week, but these are more manageable and have less impact on both his and the family's overall quality of life.
- Parents are delighted with his response to KD and are very engaged and keen for him to continue.

**Medications:** Polypharmacy due to complex medical situation.

- Amlodipine, Atenolol, Oxybutynin, Trimethoprim, Clobazam, Vigabatrin (recently weaned off successfully), Midazolam (previously given around once a month, none needed in last 14 months), Aripiprazole, Lorazepam (for challenging behaviour), Simvastatin.



## Dietetic Assessment

### Nutritional History

- KD commenced August 2015 - initially fully oral, but following a period of acute behavioural food refusal and NG feeding, a PEG was fitted in 2018.
- 3:1 classical oral diet (approx. 3 meals per day 250-300kcal each and 2 snacks of 200-300kcal each).
- Uses 1 pot of K.Yo daily as a meal or snack - easy to incorporate as his oral diet is in a 3:1 ratio.
- 4:1 tube feed (2 x 175 ml feeds daytime and 400ml overnight - flexible depending on oral intake - approx. 550-750ml per day).
- Incorporates some MCT to aid ketosis (to tolerance).
- Overall intake:
  - Average 2300kcal
  - 27-39g protein from feed and K.Yo (+ variable protein from other oral intake)

### Anthropometry:

**Height:** Approx. 75th centile.

**Weight history:** 50th-75th centile whilst on his ketogenic diet however, in April 2021:

- Weight 56kg just under 91st centile - generally very active but has been isolating for long periods over the last year due to the COVID-19 pandemic leading to lower activity levels, although these are increasing as covid restrictions are lifting.
- Height 160.2 cm just under 75th centile.

### Biochemistry

- Regular blood tests undertaken as part of his overall medical management as well as ketogenic diet monitoring.
- Blood ketones are generally in the lower 3mmol/l region in the mornings and between 4.5-5.5mmol/l in the evenings.
- Mum reports a very strong correlation between lower ketones and increasing seizures. If kept above 5mmol/l he will be seizure free. This is difficult to maintain due to tolerance issues associated with the high levels of fat needed - MCT is used to help boost ketones.









### Overall aim/goal

Optimise ketosis whilst meeting nutritional requirements and personal needs.

Nutritional Requirements	
Energy (EAR)	2410kcal/d
Protein (RNI)	42.1g/d
Minimum safe protein	0.9g/kg = 50.4g/d
Fluid requirements	2200ml/d (100 x 10=1000ml, 50 x 10 = 500ml, 20 x 36 = 720ml)

### Enteral Tube feeding instructions for K.Yo

Advice on using K.Yo as an enteral tube feed were provided to Mum for times when her son was unable to or unwilling to eat and drink orally:

-  1 Pour a minimum of **120 ml of water\*** into a feeding container or jug.
-  2 Add **1 pot of K.Yo\***
-  3 Stir until evenly mixed in the water.
-  4 Suitable for bolus feeding via **gravity, syringe** and **feeding pump**.
-  5 Use **within 4 hours**.
-  6 Flush with a **minimum of 10 ml of water** after feeding.

### Monitoring

Seen in keto clinic every 6 months with routine blood tests and regular telephone/email reviews between Mum and the dietitian in between to monitor weight, ketosis and overall compliance.

## Follow-up: 4 ways of using K.Yo

1. Patient usually has 1 pot of K.Yo a day - he really loves it and generally takes it well orally. There are times when he is off his food if unwell, or struggling with IBS symptoms and he may take more K.Yo orally at these times in place of other food.
2. Really useful if he has a planned/unplanned hospital admission. Hospital catering struggles to meet his needs at short notice, and if Mum has not had the opportunity to prepare meals ahead it's a convenient option to bring in. Mum cooks and prepares most meals and snacks for her son at the time, rather than in advance.
3. Having the flexibility of using K.Yo via a PEG enables Mum to be confident that even if he is unwell she only needs to take a certain amount of his feed and K.Yo with her if away from home or if he is off his food. He rarely refuses his K.Yo as he loves the taste, but it helps Mum relax to know there is an alternative if he won't take it orally, that she can give it via his PEG - meaning she's not needing to take extra feed 'just in case'.
4. A reassuring back up option at respite as he may be more prone to food refusal there, which causes anxiety amongst the staff caring for him, as they appreciate the importance of complying with his diet - so it's great for them to be able to give the K.Yo via PEG in that situation where they haven't easily got another option if he's refusing a meal/snack with them.

## Conclusions & Key Learnings

- Patient loves his K.Yo orally and it forms a daily part of his KD.
- Provides the flexibility of giving K.Yo via a PEG if required to ensure overall intake can stay the same at times when unable or unwilling to take it orally.
- When away from home a set amount of feed and K.Yo can be taken knowing he can take the K.Yo orally or via the PEG, rather than just relying on the feed in these situations.
- Helps to normalise mealtimes and snacks for the patient - still having his K.Yo even if he's unable to take it orally - which the dietitian believes he will find reassuring - as he enjoys it so much.



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All information correct at the time of print

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