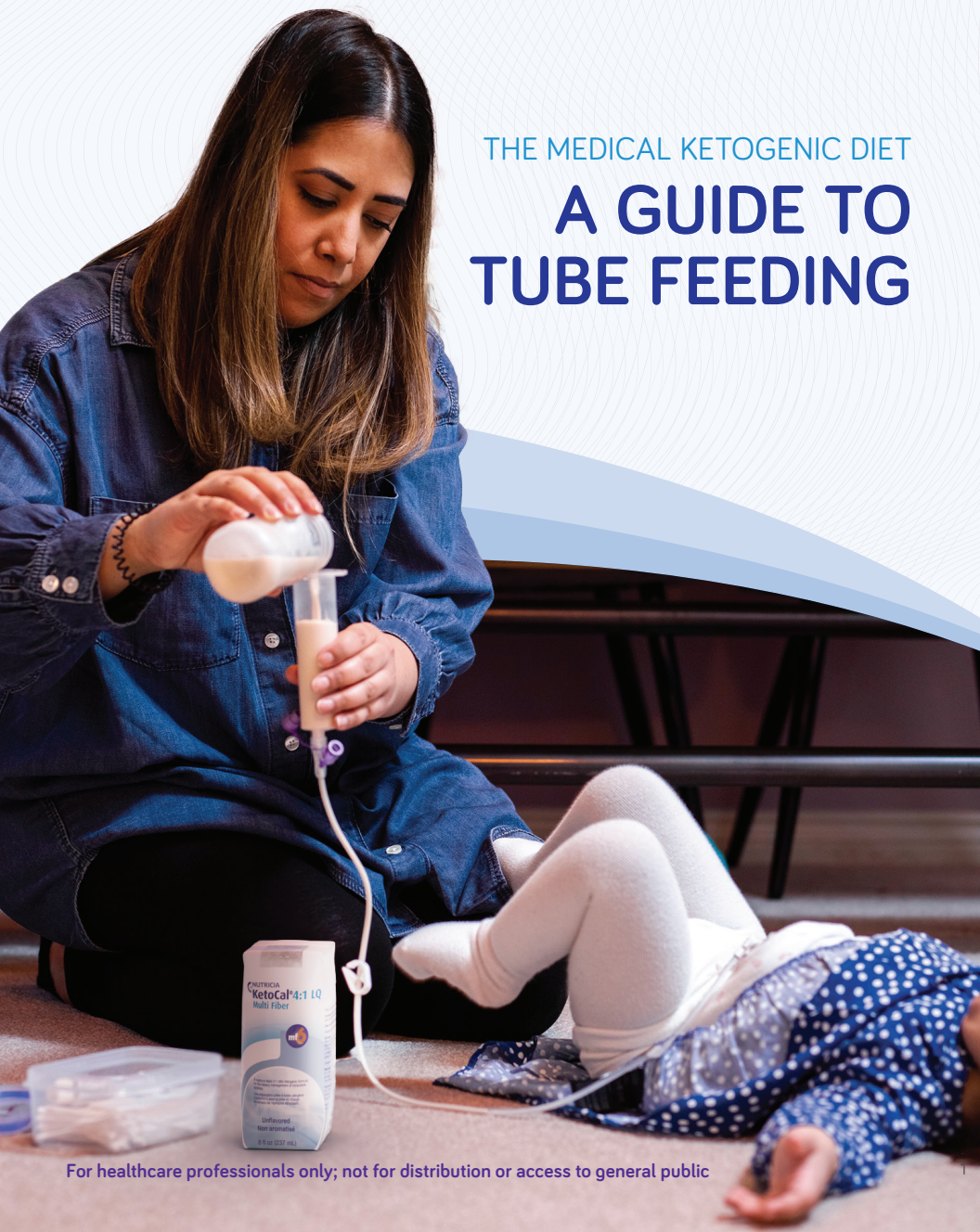


**KETO  
DIETITIAN**

**NUTRICIA  
KetoCal®**

THE MEDICAL KETOGENIC DIET  
**A GUIDE TO  
TUBE FEEDING**



For healthcare professionals only; not for distribution or access to general public

# Introduction

The World Health Organization estimates that worldwide, approximately 50 million people have epilepsy.<sup>1</sup> Epilepsy is the 4th most common neurological disorder in the United States<sup>2</sup> and is thought to affect 1 in 100 people in the UK.<sup>3</sup> Up to 65% of individuals with epilepsy will respond to treatment with antiseizure medications.<sup>4</sup> However, up to 35% will develop drug-resistant (also referred to as intractable or refractory) epilepsy and continue to experience uncontrolled seizures.<sup>5</sup> The medical ketogenic diet should be offered to people with epilepsy who have failed 2-3 anti-seizure medications and should be considered as an earlier option in difficult to manage epilepsy.<sup>6</sup> The medical ketogenic diet (KD) is a well-established, tolerated and effective option for children and adolescents with drug-resistant epilepsy.<sup>7-10</sup> There is also growing evidence for the use of the medical KD in adult drug-resistant epilepsy<sup>11-13</sup> with the first adult guidelines published in 2021.<sup>14</sup>

It is not uncommon for those with neurological problems to experience other co-morbid conditions, including swallowing difficulties and an inability to tolerate oral feeds. Consequently, enteral tube feeding is indicated for partial or full nutrition support. A KD can be easily delivered via a tube directly into the stomach (gastric feeding) or jejunum (post-pyloric feeding). Enteral tube feeding via a nasogastric or gastrostomy feeding tube is most common. A multidisciplinary keto team usually includes a neurologist, dietitian and epilepsy nurse, ideally with pharmacy and psychology support too.

However, as awareness and experience with the medical KD grows, there is scope to consider expanding practice into community teams where stable tube-fed older children and adults could be jointly managed by their local team with support as needed from a keto team. We encourage you to start these conversations with your local teams to explore how shared care might help to support better access to access to the ketogenic diet for particularly older adolescents and adults who cannot access pediatric services.

This booklet offers guidance on the initiation, maintenance and discontinuation of the medical ketogenic diet, informed by existing guidelines and recommendations.<sup>6,14,16</sup> The content is built upon opinions and experiences of expert dietitians and neurologists, who kindly gave feedback and practical insights on their best clinical practice. Practices may differ among centers though; please refer to clinic guidelines for tube-feeding.



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# Step 1: Patient Selection

It is important we identify individuals for whom the medical ketogenic diet may be a safe and appropriate management option for their drug-resistant epilepsy. Choosing the appropriate patient to start on the medical ketogenic diet may help increase efficacy. Use the guidelines below to help evaluate patients for inclusion or exclusion of the medical ketogenic diet.

## Indications for the Medical Ketogenic Diet

Refractory epilepsy in children who have failed two or three anti-seizure medications, regardless of age or gender, and particularly in those with symptomatic generalized epilepsies.

Table 1 and 2 are epilepsy syndromes and conditions for which patients may see benefit on the medical ketogenic diet. Table 3 outlines patients who should not be considered for a medical ketogenic diet.

**Table 1. Epilepsy syndromes and conditions listed alphabetically for which KD has been consistently reported as more beneficial (>70%) than the average 50% KD response (defined as >50% seizure reduction)**

Angelman syndrome	Infantile spasms
Complex 1 mitochondrial disorders	Ohtahara syndrome
Dravet syndrome	Pyruvate dehydrogenase deficiency (PDHD)
Epilepsy with myoclonic-atonic seizures (Doose syndrome)	Super-refractory status epilepticus
Glucose transporter protein 1 (Glut-1) deficiency syndrome (Glut1DS)	Tuberous sclerosis complex
Febrile infection-related epilepsy syndrome (FIRES)	
Formula-fed (solely) children	

Adapted from Kossoff et al.<sup>6</sup>

**Table 2. Conditions (listed alphabetically) in which KD has been reported as moderately beneficial (not better than the average ketogenic diet response, or in limited single-center case reports)**

Adenylosuccinate lyase deficiency	Lafora body disease
CDKL5 encephalopathy	Landau-Kleffner syndrome
Childhood absence epilepsy	Lennox-Gastaut syndrome
Cortical malformations	Phosphofructokinase deficiency
Epileptic encephalopathy with continuous spike-and-wave during sleep	Rett syndrome
Glycogenesis type V	Subacute sclerosing panencephalitis (SSPE)
Juvenile myoclonic epilepsy	

Adapted from Kossoff et al.<sup>6</sup>

**Table 3: Contraindications to the use of ketogenic diet**

### Absolute

Carnitine deficiency (primary)  
 Carnitine palmitoyltransferase (CPT) I or II deficiency  
 Carnitine translocase deficiency  
 $\beta$ -oxidation defects  
 Medium-chain acyl dehydrogenase deficiency (MCAD)  
 Long-chain acyl dehydrogenase deficiency (LCAD)  
 Short-chain acyl dehydrogenase deficiency (SCAD)  
 Long-chain 3-hydroxyacyl-CoA deficiency  
 Medium-chain 3-hydroxyacyl-CoA deficiency  
 Pyruvate carboxylase deficiency  
 Porphyrria

### Relative

Poor weight gain  
 Inability to maintain adequate nutrition  
 Surgical focus identified by neuroimaging and video-EEG monitoring  
 Propofol concurrent use (risk of propofol infusion syndrome may be higher)  
 Parent or caregiver noncompliance

Adapted from Kossoff et al.<sup>6</sup>

## Enteral tube feeding

A ketogenic enteral feed can be used for:

- Existing enterally fed individuals who are starting a KD.
- Individuals already established on KD who later require supplementary or full enteral feeding.

### Indicated for patients at nutritional risk or malnourished who:

Cannot meet their nutritional requirements orally and have a functioning gastrointestinal tract such as:

- Inadequate or unsafe intake due to co-morbid conditions, including gastrointestinal and respiratory problems, spasticity, quadriplegia, dystonia and impaired cognition
- Faltering growth
- Poor compliance to oral diet
- Behavioral feeding difficulties unresolved by usual strategies

The classical KD is the preferred high fat option as enteral feeds including KetoCal<sup>®</sup> 2.5:1, 3:1 and 4:1 can be used. These are high fat, low carbohydrate, nutritionally complete enteral feeds available in a range of powdered or liquid formula to offer flexibility for dietitians calculating individualized KD prescriptions for children or adults undertaking medical KD.

### Contraindications for enteral tube feeding:

- Severe malabsorption
- Intestinal obstruction or ileus
- Intestinal ischemia
- High output fistula
- Severe shock
- Severe intestinal hemorrhage





## Step 2: Pre-diet assessment and counseling

It is vitally important to explore the family's or individual's expectations of the medical ketogenic diet, together with the baseline seizure types, frequency and duration. Explore the outcomes which are important to them; what with the baseline seizure types, frequency and duration.

Consider the existing support in place for the family or individual and how this might be optimized if possible.

### Recommendations for baseline assessment for ketogenic diet

#### Classification of epilepsy

- Description of seizures: types, frequency and duration
- Epilepsy syndrome
- Impact of epilepsy or other co-morbid conditions, e.g. developmental delay

#### Establish management goals

- Reduction in seizure frequency or severity
- Improvement in quality of life
- Improvement in associated symptoms; including but not limited to sleep, fatigue, behavior, cognition, alertness and concentration
- Optimal nutritional status, growth and development in children

#### Resources and peer support

- Provide written resources to support the family or individuals in their choice to start on the medical KD
- Provide links to appropriate, reliable and peer-reviewed online resources like recipes, videos and meal planners, as appropriate, if food is still able to be consumed orally
- Connect patients/caregivers with established local and international charities
- Consider connecting families and individuals starting a medical KD through group education sessions or social sessions like coffee mornings and keto cooking sessions (if appropriate)

## Nutritional assessment

- Assess baseline measurements. Plot on growth chart for children 18 years of age and younger
  - Plot on growth chart: weight, length or head circumference for age, weight-for-length, body mass index and growth history
  - Adults: weight, height, BMI, weight history
- Review gastrointestinal symptoms, including frequency of bowel movements, existing reflux, constipation or diarrhea and associated management strategies
- Consider the presence of food allergies
- Assess the nutritional profile of the existing tube feeding regimen and the need for additional vitamin and mineral supplementation in the calculated KD prescription
- Consider the type of feeding tube in place and location. Is enteral feeding likely to be required for a short period or long term?
- Ensure pre-KD laboratory values and urinalysis have been arranged and reviewed according to local protocol or international recommendations.<sup>6,14,16</sup>

## Step 3: Calculation, introduction and fine-tuning of the KD

### The classical ketogenic diet (CKD)

The classical KD (CKD) is often the preferred option for enterally fed individuals. The KetoCal® range of nutritionally complete formulas (Figure 1) is available for use in a range of KD ratios and preparations. KetoCal can be used as a base feed in the volume required to reach the individual's protein requirements. Additional long chain fat or medium chain fat (MCT oil or Liquigen®) can be added as needed to meet the fat prescription; and carbohydrate (Polycal™), if required, to meet the carbohydrate needs.

### Proud to provide a broad range of products to help make the medical ketogenic diet easier



**Figure 1: Nutricia KetoCal and Modulars Product Range**

Product	Characteristics
 KetoCal® 2.5:1 LQ	A nutritionally complete ready-to-feed ketogenic formula in a 2.5:1 ratio (fat:carbohydrate + protein) designed as a sole source or supplemental nutrition for individuals 8 years of age and older. A medical food.
 KetoCal® 3:1	A nutritionally complete, powdered ketogenic formula in a 3:1 ratio (fat:carbohydrate + protein) designed as a sole source of nutrition for young children or as a supplementary feed for individuals 1 year of age and older. A medical food.
 KetoCal® 4:1	A nutritionally complete, vanilla flavored, powdered ketogenic formula in a 4:1 ratio (fat:carbohydrate + protein) designed as a sole source or supplemental nutrition for individuals 1 year of age and older. A medical food.
 KetoCal® 4:1 LQ	A nutritionally complete, ready-to-feed ketogenic formula in a 4:1 ratio (fat:carbohydrate+protein) designed as a sole source or supplemental nutrition for individuals one year of age and older.* Available in unflavored, vanilla and chocolate. A medical food.
 Liquigen®	An emulsified MCT oil. A creamy, palatable alternative to traditional MCT oil. Mixes easily with other liquids. Unflavored for oral or enteral use. A medical food.
 Complete Amino Acid Mix	An unflavored, powdered mixture of essential and non-essential amino acids. Indicated for conditions in which a nutritionally complete feed is not suitable or a modular approach is required. A medical food.
 Phlexy-Vits®	A concentrated, powdered vitamin, mineral and trace element preparation designed to help meet the micronutrient requirements of older children (11 years and older) and adults. A medical food.
 Polycal™	A powdered, concentrated source of energy based on maltodextrin. A medical food.

For detailed product information, please visit [MyKetoCal.com](http://MyKetoCal.com).

All products are medical foods and must be used under medical supervision.

\* KetoCal 4:1 LQ chocolate designed for individuals 3 years of age and older

A ketogenic ratio outlines the proportion of fat in the diet compared to carbohydrate (CHO) plus protein combined. Table 4 summarizes the macronutrient proportions and percentages energy for each ratio. Typically, the diet is started at a low ratio, slowly increasing until adequate ketosis is achieved.

**Table 4: Ratio system used to calculate the classical KD**

Diet ratio	Macronutrient Proportions (g)		Percentage of dietary energy from macronutrients (%)	
	Fat (g)	Pro & CHO combined (g)	Fat (%)	Pro & CHO combined (%)
1:1	1	1	69	31
1.5:1	1.5	1	77	33
2:1	2	1	82	18
2.5:1	2.5	1	85	25
3:1	3	1	87	13
3.5:1	3.5	1	89	11
4:1	4	1	90	10

### Calculating a classical ketogenic diet prescription

Here we share an example case study to guide your calculations and decisions but remember that this is for guidance only. You may need to adjust further for your individual patient. Remember to review the companion KetoCal Case Study Tube Feeding booklet for additional examples including in adults.

**Meet Jay, a 7-year-old boy weighing 17.8kg, who is fully enterally fed via a gastrostomy.**

Current enteral feeding regimen provides: 1200kcal per day via 4 x 200ml bolus feeds of a 1.5kcal/ml feed. He is going to transition to a classical KD. Parents hope this will reduce his daily seizures and improve his alertness and interactions with his sister and wider family.

**Aim: 1200 kcal and 18g protein (1 g/kg bodyweight)**

#### Calculating a classical ketogenic diet prescription using the dietary unit method

A dietary unit is calculated from the calorie content of each macronutrient in the target diet ratio based on protein and carbohydrate, each providing 4kcal/g and fat 9kcal/g.

**1:1 ratio**

Each dietary unit =1g of fat and 1g of protein and carbohydrate  
Energy content of each dietary unit = (1 x 9kcal) + (1 x 4kcal) = **13kcal**

**2:1 ratio**

Each dietary unit =2g of fat and 1g of protein plus carbohydrate.  
Energy content of each dietary unit = (2 x 9kcal) + (1 x 4kcal) = **22kcal**

**3:1 ratio**

Each dietary unit =3g of fat and 1g of protein plus carbohydrate.  
Energy content of each dietary unit = (3 x 9kcal) + (1 x 4kcal) = **31kcal**

**4:1 ratio**

Each dietary unit =4g of fat and 1g of protein plus carbohydrate.  
Energy content of each dietary unit = (4 x 9kcal) + (1 x 4kcal) = **40kcal**

## Calculating Jay's CKD prescription

Our initial target ratio is 2:1, and this will be introduced gradually by mixing KetoCal with Jay's existing feed. We will assess ketosis and increase the ratio gradually thereafter if needed. This is an efficient way of starting a CKD for the dietitian rather than calculating an individual ketogenic feed recipe at 1:1 ratio and increasing in increments of 0.5:1 ratio. For the family, the ketogenic feed recipe is a combination of just 2 ingredients, and they welcome it being introduced gradually over a week.

### 2:1 ratio

22kcal per dietary unit  
 Dietary units = 1200/22= 54.5 diet units per day  
 Fat = 54.5 x 2 = 109g  
 Pro + CHO = 54.5 x 1 = 54.5g

Pro = 18g  
 CHO = 54.5-18 = 36.5g  
**2:1 classical KD = 109g fat, 18g Pro, 36.5g CHO**

### Ketogenic feed recipe

Product	Fat (g)	Pro (g)	CHO (g)
680 ml KetoCal 4:1 LQ	100.6	21.0	4.2
130 ml of standard formula	8.8	7.7	20.8
<b>Total</b>	<b>109.4 g</b>	<b>28.7 g</b>	<b>25 g</b>
<b>109 g fat/ 53.7 g pro + CHO combined = 2:1 ratio</b>			

This recipe provides more protein and less CHO than originally calculated but still equates to a 2:1 ratio of fat to protein + CHO.

- Mix KetoCal 4:1 LQ with the standard formula and shake well

### Introduction of CKD

For Jay, we introduced the 2:1 ratio ketogenic feed gradually by alternating this with his standard formula.

**Day 1-3:** 2 x 200ml 2:1 ketogenic feed and 2 x 200ml standard formula

**Day 4-6:** 3 x 200ml 2:1 ketogenic feed and 1 x 200 ml standard formula

**Day 7 onwards:** 4 x 200ml 2:1 ketogenic feed

### Jay reached optimal ketosis at a 3.5:1 ratio

35.5kcal per dietary unit  
 Dietary units = 1200/35.5= 33.8 diet units per day  
 Fat = 33.8 x 3.5 = 118.3g  
 Pro + CHO = 33.8 x 1 = 33.8g

Pro = 18g  
 CHO = 33.8-18 = 15.8g  
**3.5:1 classical KD = 118.3g fat, 18g Pro, 15.8g CHO**

For demonstration purposes, we calculated his diet with KetoCal 4:1 powder.

### 3.5:1 ratio recipe

Product	Fat (g)	Pro (g)	CHO (g)
172 g KetoCal 4:1 Powder (mixed to a final volume of 800mL)	119.0	24.8	5.0
4 g Polycal Powder	-	-	3.8
<b>Total</b>	<b>119.0 g</b>	<b>24.8 g</b>	<b>8.8 g</b>
<b>Total Energy</b>	<b>1206 kcal/day</b>		

### KetoCal 4:1 Powder can be mixed in various dilutions, for example:

**45 kcal/fl oz:** 21.3 g powder, plus 79 mL water for a final volume of 100 mL.

**30 kcal/fl oz:** 14.2 g powder, plus 86 mL water for a final volume of 100 mL.

Water must be at a temperature of 113-122°F (45-50°C).

## Transition to ketogenic diet for those already enterally fed

KetoCal enteral feeds may be introduced in several different ways. The choice of which will largely depend on the earlier assessment of the individual and their expected tolerance of a change in enteral feed.

### 1) Introducing full ketogenic feeds at a reduced ratio (adapted from Neal, 2012)

- Calculate a recipe for each ratio and introduce as per Table 5 (below) over 6-18 days.
- If adequate ketosis is reached at a lower ratio, then remain there rather than continuing to increase.
- This is labor-intensive for the dietitian, and parents have a different recipe to manage for each increase.

**Table 5: Phased transition to KD by introducing KetoCal at a reduced ratio**

Phase	Duration	Ketogenic feed 100% of energy
1	1-3 days	1:1
2	1-3 days	1.5:1
3	1-3 days	2:1
4	1-3 days	2.5:1
5	1-3 days	3:1
6	1-3 days	3.5:1
7	1-3 days	4:1



### 2) Introducing KetoCal as a percentage of existing feeds

This method is useful if you have concerns regarding the individuals' ability to tolerate a change in enteral feed:

- Calculate a low ratio recipe (e.g. 1:1 or 1.5:1) using KetoCal.
- Slowly introduce this as per Table 6 (below); gradually decreasing existing feed and increasing low ratio KetoCal.
- Once tolerance to low ratio KetoCal is established, increase the ratio as per table 5 above.

**Table 6: Phased transition to KD by introducing KetoCal as a percentage of existing feed**

Phase	Duration	Existing Feed	Ketogenic Feed
1	1-3 days	75% of energy	25% of energy
2	1-3 days	50% of energy	50% of energy
3	1-3 days	25% of energy	75% of energy
4	1-3 days		100% of energy

These timelines are for guidance only. They can be adjusted to a shorter or longer duration depending on formula tolerance and local protocols.

## Transition to enteral feeding for individuals already established on oral KD

This situation may arise if the individual is unwell and requires a short period of enteral feeding or oral intake or swallow may have deteriorated to the point where longer term supplementary or full enteral feeding is indicated:

- Establish if full or supplementary enteral tube feeding is indicated.
- Aim to match the current KD ratio or similar % energy contribution from fat, protein and carbohydrate.
- Calculate an appropriate recipe using KetoCal.
- If a higher MCT content of feeds is desired, MCT oil can easily be added to KetoCal. Since Liquigen is an MCT oil emulsion, it mixes easily with KetoCal.

## KetoCal® as a supplementary feed

### Mixed oral and tube feeding

The KetoCal range is very versatile and can be used as outlined earlier for children and adults who are fully enterally fed. However, it can also be used as a supplementary or top-up feed in a variety of situations. For example, an individual might be enjoying tastes of oral food, and these should continue alongside KetoCal. KetoCal can also be consumed orally and top-up feeds given if the full volume is not taken orally.

### KetoCal and blended diet

The number of individuals and families using a blended diet continues to grow, although practice varies in different countries. Typically, this involves blending everyday foods with liquid to be given via an enteral feeding tube. There are many general toolkits available (although not specific to the medical KD) that may help support families with blended diets. KetoCal can be used to supplement a blended diet and ensure the prescribed ratio is achieved.

Unique Blenderized Recipes -  
A Mixture of real food &  
KetoCal Formula



### Benefits of enteral tube feeding with KetoCal

- Well tolerated
- Nutritionally complete
- Easy to prepare
- Consistency in ketogenic ratio
- Easy to administer to already enterally-fed children
- Tube feeding offers better compliance than oral diets
- Simple for dietitians to calculate and prescribe
- Can be given as a supplement to oral ketogenic food
- Helps simplify meal preparation for families and caregivers

## Fine-tuning the medical ketogenic diet

Frequent monitoring is essential. Fine-tuning the medical KD supports the individual to achieve optimal benefit. This is achieved by altering individual macronutrients' ratio or % energy contribution. If ketones are lower than ideal and seizures or other symptoms are ongoing, the strategies in Table 7 (below) may help to optimize ketosis.

### Before adjusting the KD prescription

- Check for hidden carbohydrate in medications or oral intake (if any)
- Recheck KD and recipe calculations
- Check adherence to the provided KD prescription. In particular, the recipe, home preparation and volume delivered
- Consider checking blood carnitine levels as supplementation may be required if deficient
- Check if ideal weight/age and height was used in original calculations especially if gaining or losing weight unexpectedly

**Table 7: Fine-tuning the diet**

Issue	Action
Excessive weight gain	This can negatively impact ketosis, so reduce energy by 5-10% until weight stabilizes
Ketones too low	Increase the ratio by 0.2-0.5:1 by increasing total fat and decreasing carbohydrate and/or protein
	Replace 5% of energy as MCT fat, reassess and increase further as needed
Ketones too high	Decrease the ratio by 0.2-0.5:1 increasing protein and/or carbohydrate and lowering total fat.
	Decrease % energy from MCT fat if using and replace with LCT fat
	Consider if total energy should increase

## Step 4: Monitoring ketones, glucose and nutrition-related side effects

Ketosis is usually monitored at home. Twice daily initially, dropping in frequency if able as the individual stabilizes on the medical KD. Urinary ketones measure acetoacetate, and blood testing (via a finger prick device and meter) measures serum  $\beta$ -hydroxybutyrate. Seizure control is often the primary outcome, and optimal ketone levels can vary for individuals. Some can achieve good seizure control with relatively low ketone levels, others may need to be closer to the top of the target range to see the same benefit.

At initiation, there is some risk of hypoglycemia, so many centers monitor blood glucose in the early weeks of diet commencing, especially in younger children.

**Table 8: Glucose and ketone measurements**

Parameter	Target
Blood glucose	2.5-6.5 mmol/l
Blood ketones	2-5 mmol/l
Urine ketones	8-16 mmol/l

Refer to local protocols for managing excessive ketosis or low blood glucose and ensure the individual or family have appropriate advice on handling this at home.

Most side effects of the ketogenic diet are relatively mild and easily managed.<sup>6,13</sup> They typically do not prevent patients from continuing on the ketogenic diet.

**Table 9: Management of nutrition-related side effects<sup>6,13</sup>**

Symptoms	Action
Constipation	<ul style="list-style-type: none"> <li>• Increase fiber content without increasing net carbohydrates</li> <li>• Check total fluid intake and increase by 20-30%</li> <li>• Consider carbohydrate-free laxatives</li> </ul>
Reflux	<ul style="list-style-type: none"> <li>• Consider starting anti-reflux medication if indicated</li> <li>• Consider a thickener with the lowest carbohydrate content and account for this in the calculation of KD prescription</li> <li>• Ensure anti-reflux medication is carbohydrate-free</li> <li>• Position patient in an upright position for tube feeding</li> </ul>
Weight loss	Increase energy by 5-10% until desired weight gain is achieved
Weight gain	Decrease energy by 5-10% until weight stabilizes
Excessive ketosis	Lower ratio until desired ketosis is achieved by adding Polycal. If MCT oil or Liquigen are used, then reduce this fat source to lower the ratio. If hyperketotic on a very low ratio, consider mixing KetoCal with standard formula to lower the ratio
Vomiting and or diarrhea without fever	<ul style="list-style-type: none"> <li>• If bolus feeding, reduce the volume and give smaller, more frequent feeds</li> <li>• If gravity feeding, try to slow the rate of delivery</li> <li>• If pump feeding, slow the rate for bolus feeds or switch to continuous feeds</li> </ul>
Vomiting and/ or diarrhea with fever (seek medical support)	<ul style="list-style-type: none"> <li>• Dilute the KetoCal enteral feed with 50% water, max 24-48 hrs</li> <li>• In gastroenteritis or prolonged intolerance to feed: consider oral rehydration solution for 24-48 hours, individually calculating the required dose volume. In addition to: <ul style="list-style-type: none"> <li>- Carbohydrate-free fluid/water</li> <li>- Compensate for each vomiting/diarrhea episode with 10mL oral rehydration solution/kg bodyweight</li> <li>- Consider development of individual emergency protocol</li> <li>- Check ketone/glucose levels frequently to check for hyperketosis/hypoglycemia</li> </ul> </li> </ul>

Approaches to management may differ from clinic to clinic based on clinical experience. These are guidelines only.

## Step 5: Evaluation of the medical ketogenic diet

The ketogenic diet should be provided for a minimum of a three-month trial period to assess response and clinical outcomes. Explore the individual's or family's expectations about the KD prior to starting the diet. Together, agree appropriate outcomes to be assessed at baseline and then monitor the clinical outcomes. Check in monthly thereafter about how the KD is meeting the family's expectations.

**My Keto Diary** is a useful resource for parents to use during the first 3 months of the ketogenic diet journey to help them track their child's experience while trialling the diet.

[Nutricialearningcenter.com/en/neurology/patient-resource-content](https://nutricialearningcenter.com/en/neurology/patient-resource-content)

The CORE-KDT study (Core Outcomes in Refractory childhood Epilepsy treated with Ketogenic Diet Therapy<sup>17</sup>) was undertaken to develop a core outcome set for childhood epilepsy managed with the medical KD. This study was motivated by the necessity to identify both seizure and non-seizure related outcomes of importance and seek and incorporate parents' views on priority outcomes for the first time. The CORE outcome set will inform future clinical trials, but the findings will also support the selection and reporting of outcomes in clinical practice via routine data collection, audit or service evaluation.



### Select outcomes identified by the CORE-KD study to monitor and report regularly<sup>18</sup>

- Seizure frequency and severity
- Tolerance to and adherence with KD
- Adverse effects of KD
- Ketone levels
- Parents, carers' or individuals' confidence with KD
- Quality of life for the individual on KD
- Alertness, concentration and behavior
- Unplanned hospital admission
- Status epilepticus and use of rescue medications
- Anti-seizure medication use

## Step 6: Ketogenic diet discontinuation

If clinical outcomes are improving during the trial period of the medical KD and the team and family/individual are in agreement, then the medical KD should continue. Monitor as per local policy or relevant international recommendations.<sup>6,14-16</sup>

### Consideration should be given to discontinue the ketogenic diet

- After three months (if unsuccessful)
- After two years (if successful)
- Based on individual diagnosis or circumstances. Longer diet durations are necessary for GLUT-1 and PDHD; lifelong if possible. Duration may also be based on individual response.

### How to wean the medical KD

- A gradual wean over 2-3 months is recommended when the diet is successful. If the diet is unsuccessful, it can be weaned over 4-6 weeks.
- Reduce ratio weekly as tolerated by 0.25-0.5:1 by adding glucose or mixing KetoCal with standard enteral feeding formula.
- Rate of decrease should be based on tolerance and seizure frequency.
- If a trial of KD has proven unsuccessful then wean from the diet over 4-6 weeks.

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