

# MODIFIED KETOGENIC DIETS FOR CHILDREN AND YOUNG PEOPLE WITH DRUG-RESISTANT EPILEPSY

A reflection of international dietetic practice and  
best practice recommendations for dietitians

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# ABSTRACT

**Introduction:** A global need was identified for a practical, comprehensive tool to guide dietitians internationally working in ketogenic diet therapy (KDT), detailing all aspects of dietetic management. The aim of this project was to develop best practice recommendations for the dietetic management of modified ketogenic diets in the management of epilepsy and neurometabolic conditions.

**Methods:** Expert ketogenic dietitians from six continents were invited to participate as members of either a core working group or advisory group. A systematic literature review was conducted, covering all aspects of dietetic management, from patient selection to diet discontinuation. To complement this, an international survey was distributed to ketogenic dietitians currently delivering modified ketogenic diets, structured around the same key themes.

**Results:** A total of 111 dietitians responded to the survey, representing six continents. For each theme, findings from the literature were presented alongside survey responses. Recommendations were generated where  $\geq 75\%$  consensus was achieved. In areas where this threshold was not met, the most commonly reported practices were presented, acknowledging the variety of international approaches.

**Conclusion:** These are the first international best practice recommendations specifically for ketogenic dietitians and nutrition healthcare professionals supporting children following medically advised modified ketogenic diets. The recommendations are informed by both published evidence and prevailing international dietetic practice, whilst recognizing the variety in clinical delivery.

**Keywords:** modified ketogenic diet; epilepsy; dietetic; guidelines; clinical.

## KEY POINTS

- Modified ketogenic diets are defined as ‘ketogenic diets that include a carbohydrate limit and a fat target, where protein is either unrestricted or guided by general age-based targets, and that do not fit the definition of a classical ketogenic diet or a medium chain triglyceride ketogenic diet’, based on our international survey responses.
- This manuscript outlines the first international best practice recommendations aimed at dietitians managing children and young people with epilepsy referred for treatment with a modified ketogenic diet, as part of a multi-disciplinary team. All aspects of dietetic management are covered, from patient selection to diet discontinuation.

# 1. INTRODUCTION

**Ketogenic diet therapy (KDT) is an umbrella term describing a group of high-fat, low-carbohydrate, moderate protein diets used as a management option for drug-resistant epilepsy.**

The classical ketogenic diet (CKD) is the 'original' form of KDT, described by Wilder in 1921<sup>1</sup>, and is based on a ratio of grams of fat to grams of carbohydrate and protein combined. We adopt the terminology 'classical', coined in 1989<sup>2</sup>, in keeping with the dictionary term meaning 'traditional in style or form' (Cambridge Dictionary), as used in the UK, mainland Europe and further afield; we do, however, acknowledge that the term 'classic' ketogenic diet is also used, particularly in the USA, as has been debated in recent literature<sup>3</sup>. To allow for a higher carbohydrate intake and/or protein without compromising ketosis, Huttenlocher later introduced a variant of KDT incorporating medium chain triglyceride (MCT) fat, with 60% of energy derived from MCTs<sup>4</sup>. A modified version using 30% of calories from MCT was subsequently developed to reduce gastrointestinal side effects<sup>2</sup>.

In 2006, following a case series of six individuals with epilepsy treated with a version of the popular 'Atkins' diet<sup>5</sup>, the 'modified Atkins diet' (MAD) was formally described<sup>6</sup>. MAD typically restricts carbohydrate to 10g/day for the first month, encourages high fat intake, and allows unrestricted protein. More recently, the term 'modified ketogenic diet' (MKD) has appeared in the epilepsy literature, although it was not comprehensively described until 2019<sup>7</sup>. Another variation, the low-glycemic index treatment (LGIT), is a more liberal low-carbohydrate diet that may or may not be ketogenic<sup>8</sup>. LGIT typically permits 40-60g of carbohydrate per day, all with a glycemic index <50, with fat comprising 60-70% and protein 20-30% of total energy intake.

All KDT types except the CKD can come under the umbrella term of 'modified ketogenic diets'; however, terminology remains inconsistent. For example, The Charlie Foundation refers to 'modified keto' as a CKD with ratios lower than 4:1, while Matthew's Friends and much of the clinical literature, align more closely with MAD and MKD definitions. Optimal clinical management recommendations for healthcare professionals managing children with epilepsy on KDT were updated in 2018<sup>9</sup>. While these include guidance relevant to dietitians, they are predominantly clinically focused and do not explore the full spectrum of dietetic practice, such as calculating prescriptions or initiating or discontinuing KDT.

A clear gap was identified for a practical resource tailored to the needs of dietitians delivering KDT. Due to the discrepancy in use of the terms MKD and MAD in recent years, this KDT type was chosen to focus on first, alongside CKD, the most commonly used KDT<sup>10</sup> (see separate resource for CKD recommendations).

We aimed to explore the breadth of international dietetic practice in KDT and develop best practice recommendations informed by the published literature and the most commonly reported approaches in clinical practice.

## 2. MATERIALS AND METHODS

A call for expert volunteers to contribute to the development of 'best practice dietetic recommendations for modified ketogenic diets' was circulated via the Ketogenic Dietitians Research Network (KDRN) and ketogenic dietitians .listserv mailing list.

Sixteen dietitians were selected to form the core working group, each with a minimum of five years' clinical experience in KDT, including the use of MAD or MKD. Where possible, the number of dietitians from each geographical area (USA, Canada, UK and Europe, Central and South America, Middle East and Asia, Africa and Oceania) was aligned proportionally to the number of ketogenic centers in that area, based on listings from The Charlie Foundation, Matthew's Friends and The International League Against Epilepsy. In the case of over-representation of volunteers from one country/continent, selection was based on a short written statement outlining each candidate's experience and capacity to contribute to the project. Due to overwhelming interest from certain regions, an additional 'advisory group' was formed to provide expert review of draft manuscripts. As with the core group, efforts were made to ensure proportional representation by geographical area, relative to the number of ketogenic centres.

### 2.1. Literature Search

A dedicated subgroup of the core working group conducted the literature review. A virtual training session was delivered and the topics and search strategy were standardized and agreed.

Each subgroup member was assigned a specific subtopic, with the aim of collating published evidence related to the dietetic management of MKDs, ranging from initial referral to diet discontinuation. The subtopics included:

- Patient selection
- Pre-diet preparation (dietetic and psychosocial)
- Diet prescription, including macronutrients, fluids, vitamins and minerals, enteral feeding, special dietary requirements, different age groups
- Prescribable ketogenic products
- Diet initiation
- Monitoring, including adverse effects, management of illness, psychosocial impact, adherence and tele-healthcare
- Diet discontinuation

The following core terms were used to search the online PubMed database, last updated on 24/02/2024: (child\* OR infant) AND (ketogenic OR "modified atkins") AND (epilepsy OR seizure\*), followed by additional search terms according to the subtopic (see Table S1 for full search terms). Relevant data were extracted into a structured Excel template capturing the following fields: author, year of publication, article title, study design, age of participants/cohort, type of KDT and details relevant to each subtopic. Findings for each subtopic were then summarised in bullet-point format.

Of 530 articles retrieved from the literature search, 155 studies were included following title/abstract and full-text screening. Of the 155, five articles addressed patient selection, 20 pre-diet preparation, 23 diet prescription, 11 prescribable ketogenic products, 39 diet initiation, 50 diet monitoring and 12 addressed diet discontinuation.

## 2.2. Survey

A subgroup of the core working group was responsible for developing and delivering the survey. A total of 131 multiple choice questions were created, aligned with the same subtopics explored in the literature review. Each question included a free-text or 'other' option to allow respondents to describe alternative practices and capture the diversity of global dietetic approaches. The survey was distributed via KDRN and .listserv using the online platform SmartSurvey™ (SmartSurvey Ltd, Tewkesbury, United Kingdom).

A total of 111 dietitians anonymously completed the survey, with the following proportion geographical representation: Europe (31%), North America (23%), South America (14%), Australia (11%), Southeast Asia (6%), East Asia (5%), Canada (4%), New Zealand (4%), Southern Africa (3%), South Asia (1%) and West Asia (1%).

Survey responses were summarized using descriptive statistics. For questions where participants could 'Select all that apply,' response percentages may exceed 100%. Where questions required a choice between types of KDT (e.g. for specific patient populations), only CKD and MKDs were presented as options, reflecting the specific focus of this project (see separate resource for CKD recommendations). All survey answers are available upon request from the authors.

## 2.3. Writing the 'Best practice recommendations'

Bullet-point summaries from the literature review formed the basis of the main document and were presented alongside the corresponding survey results. To reflect the diversity of international dietetic practice while maintaining clarity and conciseness, survey answers selected by  $\geq 5\%$  of respondents were included. In specific cases, such as reporting on the length of time taken to discontinue KDT, all response options were presented in full. Unless otherwise stated, all percentages reported in the text refer to the proportion of respondents selecting that particular answer in the survey.

A set of core recommendations was developed for each aspect of MKD dietary management.

These were drawn from either:

- published literature (restricted to published consensus recommendations, international guidelines, systematic reviews, meta-analyses or randomized controlled trials), or
- survey responses that reached a consensus threshold of  $\geq 75\%$ . Where this threshold was not achieved in survey responses (for example, with 'Select all that apply' questions), the most commonly selected option(s) were reported and wording carefully chosen to acknowledge the variability in dietetic practice.

The worked examples and meal planning sections were developed based on the clinical experience of the core and advisory working groups to give practical suggestions to readers. The draft manuscript and recommendations were first reviewed by the core working group. Following revisions, the updated manuscript was reviewed by the advisory group. Any points of contention were discussed and resolved via virtual meeting.

## 3. RESULTS: INTERNATIONAL DIETETIC PRACTICE

### 3.1. Defining modified ketogenic diets

MAD was first described as a diet in which carbohydrates are restricted to 10g/day for the first month, fat is 'encouraged' and protein is unrestricted<sup>6</sup>. In contrast, MKDs have been defined in a variety of ways in the literature, including diets that contain approximately 80% fat<sup>11</sup>, or 'in which carbohydrates, protein, and fat are individualized'<sup>12</sup>, or where protein intake is '1 g/kg dosing weight using either actual or adjusted weight using a 25% adjustment factor', with varying amounts of carbohydrate and fat goals<sup>13</sup>. Household measures or weighed portions for fat and carbohydrate foods may be used<sup>7</sup>.

**Survey responses highlighted variation in how MKDs (including MAD) are defined across ketogenic diet centers:**

- 54% of respondents described MKDs as KDT with a defined carbohydrate limit and fat target, while allowing protein freely
- 22% also specified calorie and protein targets
- 35% of respondents reported calculating the diet ratio, though approximately half of these noted that this was used only as a dietetic guide, not a formal prescription.

Table S2 outlines the variety of features of MKDs adopted by international centers.

Based on the most common definitions in the survey, MKDs are here defined as 'ketogenic diets that include a carbohydrate limit and a fat target, where protein is either unrestricted or guided by general age-based targets, and that do not fit the definition of a CKD or an MCT KD'.

### 3.2. Patient selection

The role of the multidisciplinary team (MDT) is paramount in deciding whether to accept an individual to start KDT. Ideally, all potential patients should be evaluated within a tertiary epilepsy specialist center, where medical, dietetic, and psychosocial factors can be jointly considered<sup>14</sup>. Typically, the medical team leads on referral and/or acceptance of patients for consideration of KDT.

All patients referred for KDT should be screened for metabolic contraindications prior to initiation. This includes testing serum acylcarnitine profile and/or urine organic acids or serum amino acids<sup>9</sup>. There is currently no definitive consensus regarding the use of KDT during pregnancy<sup>15</sup>. Adolescent females of child-bearing age should be advised to exercise caution and, where pregnancy is confirmed or planned, the decision to initiate or continue KDT should be based on a careful risk-benefit assessment. From a dietetic perspective, certain factors that may complicate following KDT should also be screened for and considered prior to accepting a referral (Table 1).

**Table 1.** Potential contraindications to ketogenic diet therapy: survey responses

Factor	Agreement rate (% survey respondents)
Medication/treatment non-compliance	63%
Lack of family support	61%
Long-term parenteral nutrition	52%
Difficulties with reading and/or understanding (patient or family, as appropriate)	51%
Severe picky eating	50%
Emesis	47%
Gastrointestinal disorders (gastroparesis, short bowel etc)	46%
Poor oral intake, especially fluids and/or formula	38%



Factor	Agreement rate (% survey respondents)
Bone fragility	28%
Financial difficulties	26%
Gastro-esophageal reflux	23%
Endocrine disorders	22%
Language difficulties (e.g. if their native language is different to that of the clinical team)	21%
History of aspiration pneumonia	16%

Note: none of the above are necessarily absolute contraindications to starting a medical ketogenic diet, but rather factors to consider. The risk-benefit ratio should be considered in each individual.

### 3.2.1. Survey results

Table 1 outlines factors that, according to survey respondents, may complicate following KDT.

MKD was favoured by respondents over CKD in the following scenarios:

- Family preference (80%)
- Oral feeding (67%)
- Age >12 years (56%)
- Limited health or diet literacy in the patient or family (48%)
- Very high carbohydrate intake at baseline (41%)
- Age >2 years (30%)

For individuals with GLUT1DS, 35% of survey respondents preferred either CKD or MKDs, depending on contextual factors such as patient age, family understanding, age at diagnosis, age at diet start, mode of feeding, symptom severity, anticipated diet duration, and patient acceptance of dietary change. CKD was preferred in infants under 1 year of age. Only 6% of respondents favoured MKDs for GLUT1DS regardless of these factors. For individuals with PDHD, 42% of survey respondents preferred CKD, while 31% reported that either CKD or MKDs could be appropriate depending on individual circumstance.

## 3.3. Pre-diet preparation

In addition to medical team responsibilities, such as baseline laboratory assessments, nutrition/dietetic and psychosocial preparation play a crucial role in setting the foundation for successful KDT.

### 3.3.1. Dietetic assessment and preparation

As part of the pre-diet preparation, the dietitian should complete a comprehensive diet history. This may include a 3-day dietary record and/or a detailed account of their usual dietary intake, including feeding method, textures tolerated, food allergies, intolerances and other special dietary requirements. Conducting a diet history not only helps to establish the patient and families commitment to KDT, but also provides invaluable insight into habitual calorie intake, eating behaviours, and personal or cultural preferences<sup>16</sup>.

Any food allergies, intolerances or special dietary requirements should be carefully documented and considered within the KDT prescription. A thorough review of current and previously trialled formulas or foods can help avoid unnecessary dietary restrictions<sup>17</sup>.

The dietitian should also collect baseline anthropometry measurements, including weight and length/height, and where appropriate, mid-upper arm circumference and skinfold thickness. These measurements, along with growth history and laboratory results, such as full blood count, ferritin and vitamin D levels, support the assessment of the patient's nutritional status and requirements to inform the diet prescription<sup>16</sup>. It is also important to determine whether the patient is already or has previously been, under dietetic care.

Survey findings showed that over half of survey respondents recommend that patients make dietary adjustments prior to KDT initiation, for example by reducing simple sugars (59%), trying out high-fat foods (49%) or trying keto foods/recipes (46%).

### 3.3.2. Patient / family education and counselling

Parental education is a critical component of KDT and plays a major role in both diet initiation and long-term adherence. While clinical and nutritional safety form the foundation of the education, discussions should also address the broader implications of following a restrictive medical diet. These conversations help minimize potential financial, developmental and psychological burdens, and can improve family preparedness and reduce the risk of non-adherence<sup>18-21</sup>.

The literature identifies key barriers to KDT adherence, which should be explored during education sessions:

- Time investment required for meal/feed preparation<sup>18, 21</sup>
- Adverse effects of KDT<sup>18</sup>
- Parental anxiety pre-diet<sup>22</sup>
- The cost of KDT-compatible supplements and/or specific foods<sup>23</sup>
- Cultural adaptability of KDT<sup>22</sup>
- Disruption of the home environment<sup>22</sup>
- Poor palatability and restrictiveness of KDT<sup>18</sup>.

To support families effectively, clinicians should assess the family's capabilities (knowledge, skills and ability to make dietary change), their resources (food availability, support from school, etc), and their motivation to start KDT in order to best support adherence. Some centres may be equipped with a social worker or child life specialist who can assist but, often, the dietitian plays a central role in this process. Dietitians must also be aware of the patient/family's culture and religious, and socioeconomic background to ensure that education is delivered sensitively and appropriately<sup>18, 19, 23</sup>.

#### 3.3.2.1. Survey results

Survey findings revealed that 92% of respondents delivered at least one structured education session before starting KDT. Education is provided individually (77%) or via group sessions (5%); the timing of the education varies either before (31%), as part of (23%) or after (28%) the baseline visit.

Education sessions are most often led by the dietitian, but may also involve other members of the multidisciplinary team, including specialist nurses, medical doctors, dietetic assistants/support workers or clinical psychologists. The format of education varies across centres, with sessions delivered face-to-face, virtually, or by telephone, depending on local service models and family preference.

A wide range of topics are covered in these sessions, tailored to the individual patient and family. The most commonly covered topics, according to survey responses, are outlined in Table 2.

**Table 2.** Topics to cover in initial education sessions for patients/families: survey responses

Topic	Agreement rate (% survey respondents)
Importance of adherence to the diet	94%
Potential adverse effects	93%
Follow-up expectations	86%
Identifying carbohydrates, protein and fat sources	83%
Weighing/measuring of foods and/or formula	83%
Importance of hydration	81%
Other sources of carbohydrates, such as medications	80%
Supplementation	79%
Time commitment needed for ketogenic diets	77%
How to check ketone levels	69%
How to recognize symptoms of hyperketosis and hypoglycemia	68%
Potential impact on quality of life (may be negative or positive)	64%

Topic	Agreement rate (% survey respondents)
Other non-food sources of carbohydrates	60%
Potential social/personal impact of following a restricted diet when around others	59%
How to use a ketone/blood glucose monitor	59%
Developing recipes and using meal calculation tools	56%
Insurance coverage and/or availability of supplies required for monitoring and diet	55%
Plan for sick days	51%
The cost of ketogenic diet-suitable foods	42%
Strategies to manage special occasions	41%
Physical activity with reference to bone health	10%

### 3.4. Diet prescription

Literature review data are outlined in the below sections, according to specific macronutrients.

**88% of survey respondents indicated that the dietitian is responsible for calculating the initial diet prescription. The most commonly reported factors influencing macronutrient targets were:**

- Age (64%)
- Usual diet (44%)
- Epilepsy syndrome (36%)
- Medications (14%)
- Physical activity levels (13%)
- Calorie and protein requirements (6%).

MKD prescriptions are typically calculated using fixed carbohydrate limits and fat targets, with protein either unrestricted or set according to general age-based requirements. See Figure 1 for an example calculation, based on the most commonly used macronutrient targets and prescription strategies reported in the survey.

**Figure 1.** An example calculation for MKD

<b>Step 1</b>	Estimate daily calorie requirements.
<b>Step 2</b>	Calculate the number of grams of fat required to provide 60-80% energy, assuming 9kcal/g.
<b>Step 3</b>	Choose your initial carbohydrate (net or total, as preferred) prescription in grams. Allow for carbohydrate from regular medication, if necessary.
<b>Step 4</b>	You now have your daily allowance of fat and carbohydrate. These can be divided equally into the number of meals and/or snacks, as required. Where possible, fat and carbohydrate intake should be spread evenly throughout the day.
<b>Step 5</b>	Set protein ad libitum, but with age-appropriate portion sizes encouraged.

**Example patient details:** 9-year-old child, 'Jamie'

**Weight = 25 kg. Height = 1.3m (in proportion to weight).** Tracking weight and height centiles. Appropriate growth history.

**Estimated daily intake from food diary:** 1339 kcal/day

**He has 3 meals and 3 snacks per day**

Fat (70% total energy)	$= 70\% \times 1339 \text{ kcal (usual calorie intake)}$ $= 937.3 \text{ kcal}$ $937.3 \text{ kcal} \div 9 \text{ kcals}$ <b>= 104g per day</b>
Carbohydrate	<b>15g total per day</b>
Calculation of daily dietary units	$1340 \div 31 = 43.2 \text{ units daily}$
<b>Fat</b> = number of units x ratio	$43.2 \times 3 = 129.6 \text{ g}$
Protein and carbohydrate = number of units x ratio	$43.2 \times 1 = 43.2 \text{ g}$
Divide the carbs evenly throughout the day	$15 \text{ g} \div 3 \text{ meals and 3 snacks}$
Count snacks as half a meal	$15 \text{ g} \div 9 \text{ (snacks counted as half meals)}$
3 meals and 3 snacks	Per snack = $1.7 \text{ g}$ (round to nearest g) = <b>2g</b> Per meal = $1.7 \text{ g} \times 2 = 3.4 \text{ g}$ (round to nearest g) = <b>3g</b>
Divide the fat evenly throughout the day (70% Fat)	$= 104 \text{ g} \div 9 = 15.6 \text{ g}$ (round to 0.5g) = $15.5 \text{ g}$
Count snacks as half a meal	Per snack = <b>15.5g</b> (approx. 1 tablespoon oil/butter)
3 meals and 3 snacks	Per meal = $15.5 \times 2 = \mathbf{31g}$ (approx. 2 tablespoons oil/butter)

### 3.4.1. Energy

Accurate estimation of energy requirements is important when setting specific macronutrient targets, especially for more structured forms of MKD. In many MKD protocols, energy is not explicitly prescribed to the patient or family<sup>24,25</sup>; instead, carbohydrate limits and fat targets are prioritised, and energy intake is more flexible.

Energy requirements may be estimated using age and gender-specific equations for Estimated Average Requirements (either country-specific or from the World Health Organization<sup>26</sup>). For children with neurological disabilities, standard equations may not reflect true energy needs, which can be influenced by mobility, feeding difficulties, altered metabolism, and disease severity. A detailed food diary, and growth history, should be used alongside predictive equations to guide appropriate energy prescriptions.

**The following percentage of survey respondents adopt the following practices for MKD prescriptions (multiple responses could be selected):**

- 78% consider the patient's current energy intake
- 77% use standard energy equations
- 65% factor in recent growth trends

### 3.4.2. Fat

The original MAD protocol did not prescribe a specific fat target, but fats were 'encouraged'<sup>6</sup>. MKDs have more recently been described as providing '~80% fat'<sup>11</sup>. In the UK version of MKD, fat tends to account for 65–80% estimated energy requirements<sup>7</sup>.

Survey responses reflected this diversity in MKD fat prescription. One-third of respondents prescribed 60–70% of total energy from fat when initiating an MKD, while 23% used 70–80%.

In terms of calculating diet prescriptions, approximately one-third of respondents reported using a sequential method to define macronutrient targets: first estimating overall energy requirements, then setting the carbohydrate limit, followed by determining protein needs, with the remaining energy allocated to fat. This approach reflects the flexible and adaptive nature of MKD prescriptions, particularly when balancing dietary preferences, clinical goals, and patient/family capacity.

### 3.4.3. Protein

The MAD generally does not restrict protein. Published studies describe protein intake as “not restricted”<sup>27,28</sup> or “unlimited”<sup>29</sup>. Similarly, in the UK version of the MKD, protein is often not formally prescribed, although when targets are set, they typically account for 20–25% of total energy intake<sup>7</sup>.

Survey respondents demonstrated a range of approaches to protein prescription. Approximately 39% of respondents reported that they do not prescribe a specific number of grams of protein in the initial diet plan. Instead, protein intake is left flexible or guided by food choices. Around 30% of respondents provide guidance based on minimum daily requirements, without specifying precise targets. A smaller proportion (16%) set a maximum protein intake, typically ensuring it does not exceed 2 grams per kilogram of body weight. A few respondents (5%) reported using a target range based on goal BMI, most commonly prescribing between 1.0–1.2 g/kg/day.

### 3.4.4. Carbohydrate

In KDT, the term ‘net carbohydrates’ is frequently used, but definitions vary internationally. In clinical practice, net carbohydrates are most commonly defined as the total carbohydrate content minus fiber, and in some cases, minus some or all sugar alcohols, which have minimal digestible carbohydrate and glycaemic effect (Table 3).

**Table 3.** Definitions of ‘net carbs’ used in ketogenic diet therapy: survey responses

Definition of ‘net carbs’	Agreement rate (% survey respondents)
Total carbs minus fiber	40%
Total carbs minus fiber and all sugar alcohols	9%
Total carbs minus fiber and 50% sugar alcohols, except erythritol which is 10% of carbs	7%
Total carbs minus fiber and 50% sugar alcohols, except erythritol which is 10% of carbs, and minus 10% monk fruit or allulose	5%

The relevance of this distinction depends heavily on national food labelling regulations. In countries such as the United States and Canada, fibre and sugar alcohols are included in the total carbohydrate count on nutrition labels. In contrast, food labelling regulations in the United Kingdom, Europe, and Australia exclude fiber from the total carbohydrate content, and therefore the term “net carbohydrate” is less commonly used.

For clarity and consistency, all references to carbohydrate within this document refer to net carbohydrates, as defined by the prescribing clinician or local practice.

In MKDs, carbohydrates are generally prescribed as a fixed number of grams per day, rather than as a proportion of total energy. In the MAD literature, this allowance often begins at 10-15g, traditionally including sugar alcohols but excluding fiber<sup>28-30</sup>. In the UK version of MKD, initial carbohydrate prescriptions tend to fall between 15-30g per day, or roughly 5-20% estimated total energy requirements<sup>7</sup>.

According to survey data, 72% of respondents reported specifying the daily carbohydrate allowance in their MKD prescriptions, typically adjusting for the patient’s age. In contrast, 24% of respondents do not factor in age when determining the carbohydrate limit, and only 7% do not set a specific carbohydrate target in initial MKD prescriptions.

Table 4 presents the most common carbohydrate allowances used in MKD prescriptions across different age groups, with most dietitians using consistent values for both total and net carbohydrates. A more detailed breakdown of alternative allowances and respondent preferences can be found in Table S3.

**Table 4.** Carbohydrate allowances used in initial prescriptions for modified ketogenic diets: survey responses

Age group	Carbohydrate allowances most commonly used in initial MKD prescriptions	
	Total (g)	Net (g)
<2 years	10	10
2-5 years	10	10 or 15
6-11 years	15	15 or 20
12-18 years	15	20

### 3.4.5. Carbohydrate – other sources

For patients receiving modified texture diets (across any type of KDT), 60% of survey respondents reported using low-carbohydrate thickeners, such as gum-based thickeners. 26% count starch-based thickeners within the daily carbohydrate allowance, while 26% only count thickeners when clinically indicated – for example, if ketones are sub-optimal. A small proportion (5%) reported never counting either gum- or starch-based thickeners in the prescription.

Medications and supplements can contain carbohydrates, particularly oral solutions, suspension, and chewable tablets, which may contribute significantly to the total carbohydrate intake. If not accounted for, this can impair ketosis or require further restriction of dietary carbohydrate.

Clinical approaches to managing carbohydrate from medications vary:

- engage with the pharmacy team to review and change medications to low-carbohydrate versions (typically tablets or capsules instead of oral solutions or chewable tablets) before initiating KDT
- include the carbohydrate from medication as part of the KDT prescription (the diet plan may require re-calculation if the dosages are significantly altered)
- do not count the carbohydrate from medication and continue with the usual diet prescription, particularly if doses are small or carbohydrate is unavoidable

Survey data were not collected on which of these strategies are most commonly adopted in practice.

### 3.4.6. Fluid

Historically, no restrictions for fluid restrictions were set for MKDs<sup>27</sup>. Maintaining adequate hydration is essential for preventing constipation, supporting metabolic processes, and reducing the risk of nephrolithiasis, particularly in patients taking carbonic anhydrase inhibitors, such as topiramate or zonisamide.

Survey data reflected broad agreement with current recommendations. Ninety-three percent (93%) of respondents reported prescribing fluids to meet 100% of estimated fluid requirements in MKD protocols. Fluid needs may be determined using country-specific age- and weight-based equations, or by continuing the patient's pre-KDT fluid intake if clinically appropriate. The method of calculation varies between centres, depending on local protocol and clinician preference.

### 3.4.7. Micronutrient supplementation

The restricted nature of KDT significantly alters the intake of vitamins, trace minerals, and electrolytes compared to a well-planned traditional diet<sup>31,32</sup>. Micronutrient deficiencies are most commonly reported in individuals following CKDs<sup>33-36</sup>. Documented deficiencies include thiamine, folate, pantothenic acid, calcium, phosphorus, iron, vitamin D, Vitamin C, selenium, ferritin, and magnesium, as well as carnitine (a conditionally essential amino acid, not a micronutrient). Several case reports of scurvy have been published in individuals on CKD who were not receiving adequate vitamin C supplementation<sup>36,37</sup>. Selenium deficiency has also been reported in children on CKD<sup>33</sup>, and has been associated with impaired myocardial function<sup>38</sup>. One study found selenium levels declined after 6 and 12 months on CKD, prompting recommendations for close monitoring<sup>34</sup>, although it remains unclear whether selenium supplementation beyond standard multivitamin is necessary<sup>9</sup>. It is generally accepted that the more restrictive the ketogenic diet, the greater the risk of micronutrient deficiencies. This risk applies not only to CKDs but also to MKDs, which still impose significant limits on food variety and intake.

To prevent micronutrient deficiencies, optimal clinical management recommendations are to provide a complete carbohydrate-free multivitamin and mineral supplement for individuals on KDT. This should include, at a minimum, selenium, calcium and vitamin D<sup>9</sup>.

If a carbohydrate-free formulation is not available or tolerated, the carbohydrate content of an alternative supplement should be included in the overall dietary prescription. Supplementation should be aligned with age-specific recommended daily intakes, taking into account the individual's dietary intake and any contributions from commercial ketogenic products or formula feeds.

In addition to preventing deficiencies, some micronutrients may play a role in mitigating the adverse effects of KDT. Particular attention should be given to calcium and vitamin D, as individuals on KDT can be at increased risk of acidosis and impaired bone health, including reduced bone mineral density and osteoporosis<sup>39</sup>.

#### **3.4.7.1. Survey results**

In clinical practice, 90% of respondents reported routinely prescribing multivitamin/mineral supplements for MKDs, or doing so as indicated based on dietary intake. The most commonly used additional supplements were carnitine (if deficient, 42%), calcium (43%), and vitamin D (27%). A small number of practitioners (5%) noted that micronutrient supplementation for MKDs was managed by the medical team rather than the dietitian. Potassium citrate was prescribed prophylactically by 14%, in response to hypercalciuria by 13%, and sodium bicarbonate in cases of acidosis by 16%.

### **3.5. Special dietary requirements**

With appropriate planning and professional support, most special dietary requirements can be accommodated within KDT. This includes dietary restrictions related to food allergies, intolerances, cultural or religious practices, and personal preferences such as vegetarianism or veganism.

When adapting a ketogenic diet to meet these needs, particular attention should be given to micronutrient adequacy, as food substitutions may reduce the variety or nutrient density of the diet. Vitamin and mineral supplementation should be reviewed and adjusted accordingly to prevent deficiencies.

It is important to obtain a detailed history of not only the patient's dietary requirements, but also any allergies or restrictions within the household, as these may effect food preparation, safety, and adherence to the prescribed diet.

Families may benefit from a tailored list of ingredient substitutions that are suitable for their dietary needs—for example, dairy-free, egg-free, or vegan alternatives. A summary of commonly used ketogenic ingredients and suggested substitutions is provided in Table S4.

#### **3.5.1. Survey results**

Survey responses confirmed that MKDs are generally preferred over CKDs when accommodating plant-based dietary preferences. Approximately 48% of respondents reported preferring MKDs for individuals following a vegan diet, and 66% indicated a preference for MKDs for those who are vegetarian. This preference reflects the greater flexibility offered by MKDs in food choices, macronutrient distribution, and ingredient substitution.

To support the success of vegetarian or vegan KDT, respondents reported using a range of strategies. The most common was the incorporation of MCT-enriched products, used by 60% of respondents. Commercial ketogenic formulas and protein powders were each reported by 36% of respondents as useful tools. Additionally, 27% allowed a more liberal carbohydrate allowance, and 22% allowed greater flexibility in protein targets, to accommodate plant-based sources that may contain both protein and carbohydrates.

Several practitioners also commented that when working with vegan families, they advised prioritising 'pure' fat sources—such as oils—over processed plant-based fat alternatives (e.g., vegan spreads or creams), which may contain added carbohydrates or protein and could reduce the diet's ketogenic potential.

For patients requiring allergen-safe ketogenic diets, similar strategies were reported. Use of MCT oils or MCT-containing products was the most common approach, used by 51% of respondents. Commercial ketogenic formulas were used by 44%, while 19% relied on protein powders. Where needed, 13% allowed a more liberal carbohydrate limit, and 14% adjusted protein targets to support adequacy and tolerability in the context of food allergies or intolerances.



### 3.6. Meal planning

Translating a ketogenic diet prescription into a practical and sustainable meal plan is a crucial component of dietary implementation. While formats may vary between centres, meal plans are most commonly provided as macronutrient targets for each meal or snack, enabling families to structure their food intake around the prescribed fat, protein, and carbohydrate allowances. Sample meal plans and recipe examples are provided in Tables S5, demonstrating typical approaches for MKD prescriptions. The fat content naturally present in high-protein foods is included in the fat allowance —although this practice may differ between centres.

For MKDs, families may benefit from structured guidance on how to 'build a meal' within their macronutrient targets.

A common approach involves selecting a protein source, adding a measured portion of vegetables or fruit in line with the carbohydrate prescription, and then incorporating a source of fat to meet the fat target. This framework offers a practical and flexible way for families to assemble meals without requiring full calculation for every ingredient.

Many centers provide choice or exchange lists to further support meal planning. These may include either weighed options or household measurements, depending on local practice. The number of grams of carbohydrate or fat assigned to each 'choice' may vary between centers. Examples of such lists are included in Tables S6 and S7.

In addition, some centers provide families with a list of 'free foods'—items that contain negligible amounts of carbohydrate and may be consumed without being included in the diet prescription. These may include very low-carbohydrate vegetables (e.g. mushrooms), small amounts of fruit (e.g. lemon), sugar-free drinks (e.g. squash, cordial, carbonated beverages), and flavorings such as herbs and spices. The criteria for defining free foods differ between centers and should be clearly explained during the education process.

### 3.7. Enteral nutrition

Enteral nutrition is a common and effective method for delivering KDT, particularly for individuals who are unable to meet their nutritional needs orally. CKD are most frequently used in this context<sup>8</sup>, and can be administered via nasogastric, gastrostomy, or jejunostomy tubes. Although MKDs can also be delivered via enteral nutrition - either wholly or in part - their structure and principles are generally more applicable to oral or blended food-based feeding approaches. When used enterally, MKDs may require additional planning and monitoring to maintain dietary balance and ensure therapeutic efficacy.

### 3.8. Parenteral nutrition

Parenteral nutrition (PN) may be indicated in clinical situations where enteral feeding is not possible and bowel rest is required – such as gastrointestinal complications or severe illness<sup>40</sup>. Unlike MKDs, which are often structured around flexible macronutrient targets or food-based prescriptions, KPN requires precise macronutrient calculations. Each macronutrient component must be prescribed to ensure safe intravenous delivery and therapeutic efficacy<sup>41</sup>.

### 3.9. Prescribable ketogenic products

Prescribable ketogenic products are commonly used to support the diet. These products may be used alongside oral food intake to increase daily fat consumption, modify the type of fat used, and improve intake of protein, vitamins, and minerals<sup>29</sup>. They can be particularly useful in managing complex prescriptions or supporting dietary variety.

In addition to prescribable items, a range of non-prescribable products—such as low-carbohydrate baking mixes, cereals, and snacks—may also be suitable for individuals following KDT. The choice of product should be individualised and based on factors including the patient's age, energy requirements, ketogenic ratio, presence of food allergies or intolerances, and any needs for plant-based or texture-modified diets.

All prescribable and specialty food products used in KDT should be counted within the diet prescription, and their use should be monitored and moderated to maintain dietary balance and therapeutic efficacy.



### 3.9.1. Survey results

According to survey responses, 84% of dietitians offer commercial ketogenic formulas to orally fed patients on KDT, although these are not always used routinely. The availability, prescribing process, and formulation of these products vary between countries and healthcare systems. An outline of commonly used prescribable ketogenic products is provided in Table S8. The availability, composition, and prescribing processes for these products vary by country.

Medium-chain triglyceride (MCT) products are widely used as part of KDT protocols, with 87% of survey respondents reporting their inclusion. Most respondents (78%) reported prescribing or increasing MCTs in millilitre volumes, adjusting according to clinical goals and tolerance.

When asked about the regulation of keto-specialty food products, 69% of respondents stated they only restrict these items if they are found to negatively affect ketosis or seizure control. A small proportion (7%) reported limiting such products during the first month of treatment, while 6% reported always applying limitations, depending on the individual patient.

## 3.10. Diet initiation

### 3.10.1. Modified ketogenic diets

There are limited published data detailing specific protocols for the initiation of MKDs. In clinical practice, particularly within the UK, MKDs are typically initiated in an outpatient setting. The introduction of the diet is usually gradual, most commonly over a period of seven days or less<sup>6</sup>. This approach allows for close monitoring of tolerance and adherence while minimising disruption to family life. Unlike CKDs, MKD initiation rarely involves hospital admission or a formal fasting period.

#### 3.10.1.1. Survey results

Survey responses revealed a variety of approaches to initiating MKDs. One third of practitioners reported starting with the most liberal macronutrient targets possible and only increasing dietary strictness if needed to improve efficacy. In contrast, 18% of respondents begin with more restrictive macronutrient goals and gradually liberalise the diet as tolerated. For the remaining 40%, the approach depends on individual patient needs, highlighting the importance of flexibility and personalisation in MKD initiation.

The majority of centres (89%) do not use a fasting protocol when initiating MKDs. Among the small number who do, fasting typically lasts between 8–12 hours (7% of centres), with a smaller proportion (6%) reporting fasting durations longer than 18 hours.

Regarding the practical method of initiation, 47% of respondents reported beginning the MKD at full calorie targets (where calorie goals are set), with macronutrient goals either introduced immediately or advanced gradually. Similarly, 49% of centres reported introducing the diet one meal at a time.

Time taken to reach the target prescription varied between services. Approximately one third (35%) of respondents reported that patients typically reach their full MKD prescription within 3–4 weeks. Others indicated more rapid initiation, with 26% reaching targets in 1–2 weeks, and 17% within less than one week.

Examples of MKD initiation approaches are provided in Table S9.

## 3.11. Home monitoring

### 3.11.1. Ketones

Monitoring ketone levels at home can be a useful marker to assess whether the dietary prescription is sufficient to induce and maintain therapeutic ketosis. It may also guide any necessary dietary adjustments. However, it is important to note that individuals following MKDs may exhibit lower ketone levels than those on CKDs<sup>42</sup>.

Ketones can be measured via urine (detecting acetoacetate) or blood (detecting beta-hydroxybutyrate, BHB). Urine testing is less invasive and more widely accessible but tends to be less accurate, as results may be affected by hydration status and do not reflect real-time ketone levels<sup>43</sup>. Nevertheless, urine ketone testing remains a practical option for home monitoring and, when used, should be performed several times per week<sup>9</sup>. Blood ketone testing provides a more accurate reflection of current metabolic state and can be performed both in clinical settings and at home using glucose meters compatible with ketone strips. BHB levels have been shown to correlate more closely with seizure control than urine ketones<sup>44,45</sup>. Urine ketone levels of 3–4+ (approximately 8–16 mmol/L) typically correspond to blood ketone levels of around 2 mmol/L. Blood ketone concentrations exceeding 3 mmol/L, and in some cases 4 mmol/L, may be most effective for seizure reduction, although the literature remains inconclusive<sup>44,46,47</sup>. In infants, routine blood ketone monitoring is recommended to identify potential excess ketosis and mitigate risks in this vulnerable population<sup>48</sup>.

#### 3.11.1.1. Survey results

For MKD initiation, over half of respondents (57%) recommend that ketone monitoring should begin with the first MKD meal, whereas 30% advise waiting until the full diet prescription is reached. Just over half (52%) advise testing ketones twice daily during initiation, while one third (33%) recommend once-daily monitoring. Guidance on when to reduce or discontinue ketone testing varies: 53% suggest stopping or reducing once levels are stable, 19% after treatment goals are met, 10% after three months on the diet, and 6% within four weeks. However, 16% of respondents advise continuing ketone monitoring indefinitely.

In addition to routine monitoring, 89% of respondents recommend checking ketones in the event of symptoms of hyperketosis. Other commonly cited indications include loss of seizure control (88%), signs of illness (66%), and before or after physical activity (14%).

Target ketone ranges vary across practices and are often individualised. However, it is common for clinicians to aim for blood BHB levels between 2–6 mmol/L and urinary acetoacetate levels between 8–16 mmol/L (personal communication with study authors).

### 3.11.2. Glucose

Due to the low carbohydrate content of KDT, there is a recognised risk of hypoglycaemia, particularly during the initiation phase or during episodes of illness. While this is a known concern, published reports suggest that hypoglycaemia is rare, with most cases occurring in infants receiving CKD<sup>49–52</sup>. Nonetheless, careful monitoring during initiation—especially in younger or medically complex children—is recommended to identify and manage any episodes of low blood glucose promptly.

#### 3.11.2.1. Survey results

Survey responses highlighted that, for initiation of MKDs, glucose monitoring is less common compared to initiation of CKD. Only 35% of respondents recommend twice-daily checks at initiation of MKDs, 15% suggest once-daily checks, and 32% do not routinely monitor glucose at all. The remainder tailor their recommendations to the individual patient, often depending on the child's age or presence of symptoms suggestive of hypoglycaemia. Among those who do recommend monitoring, most discontinue checks once glucose levels are stable (26%), while others stop when ketone levels stabilise (7%), when the full prescription is achieved (6%), or after a fixed duration such as two weeks (6%).

Definitions of hypoglycaemia varied between centres. The most commonly cited thresholds were <3.0 mmol/L (23%) or <2.5 mmol/L (19%), while other respondents used thresholds of <50 mg/dL (18%) or <40 mg/dL (11%).

In the event of hypoglycaemia, most practitioners recommend rapid intervention. Three-quarters (77%) advise a specific volume of sugar-sweetened beverage, 41% recommend a defined quantity of carbohydrate in grams, 33% use a commercial carbohydrate modular product, and 31% report use of intravenous dextrose. From survey comments, the most commonly suggested oral or enteral intervention was 3–5 grams of carbohydrate, often provided as 30–50 ml of fruit juice.

### 3.12. Follow-up

Optimal clinical management guidelines recommend that children aged over one year should receive a clinical review, including laboratory monitoring, at one month after initiation, followed by reviews at 3, 6, 9, and 12 months<sup>9</sup>. After the first year, follow-up visits typically occur every six months. Between visits, regular communication with the dietetic team—via telephone or email—is strongly encouraged to monitor progress and address issues promptly. For infants under one year of age, more frequent and intensive follow-up is advised due to their rapid developmental changes and heightened nutritional vulnerability<sup>9</sup>.

Each follow-up appointment should involve a multidisciplinary assessment of clinical and nutritional status. This includes review of serum and urine biochemistry, evaluation of growth parameters (height, weight, BMI, and head circumference in infants), and assessment of adherence to the diet. Nutritional status should be assessed in the context of growth velocity and ideal weight for stature, with consideration of whether the current KDT prescription remains appropriate. Supplementation with vitamins and minerals should also be reviewed and adjusted if necessary.

Nutritional assessments at follow up should include (adapted from optimal clinical management recommendations<sup>9</sup>):

- Height, weight, ideal weight for stature, growth velocity, BMI when appropriate
- Head circumference in infants
- Review appropriateness of KDT prescription
- Review vitamin and mineral supplementation
- Assess compliance to KDT
- Adjust KDT if necessary to improve compliance, seizure control and/or nutritional status

Psychosocial factors identified during pre-diet preparation—such as family support, cultural considerations, and educational needs—should also be revisited during follow-up, as these may impact long-term adherence and outcomes.

If non-adherence is identified or suspected, a number of strategies can be considered to improve engagement and dietary success. These include practical interventions such as teaching kitchens or cooking demonstrations<sup>18,53</sup>, use of ketogenic applications or calculators<sup>21,54,55</sup>, trial of alternative dietary regimens such as LGIT<sup>54,56,57</sup>, and leveraging digital communication tools (e.g. email, WhatsApp) to maintain regular contact and reinforce support between visits<sup>58</sup>.

#### 3.12.1. Survey results

Survey responses indicate broad alignment with optimal clinical management recommendations for follow-up practices. The majority of practitioners (88%) monitor gastrointestinal health and non-seizure benefits—including cognition and quality of life (72%)—as part of routine follow-up. Satiety is also reviewed by two-thirds of respondents (66%), reflecting an emphasis on the holistic impact of the ketogenic diet beyond seizure control.

In assessing adherence to KDT, ketone levels are the most widely used indicator, with 93% of respondents relying on blood or urinary ketones to gauge dietary compliance. Verbal discussions during clinic appointments or phone calls are also common (91%), with food diaries used by 62% of practitioners. A smaller proportion (12%) make use of formal questionnaires to support their assessment.

Medication weaning decisions vary between centres but are most commonly considered when seizure control is achieved (69%). A third of respondents (33%) indicated that they also consider tapering medication if there is a risk of adverse interactions between antiepileptic drugs and KDT. Timelines for initiating medication reduction vary: 29% consider weaning after three months on diet, 13% after six months, and 10% as early as six weeks, depending on clinical response and practitioner judgement.

### 3.12.2. Telehealthcare

Telehealthcare has become an increasingly valuable tool in the maintenance of ketogenic diet therapy (KDT), particularly following its expanded use during the COVID-19 pandemic<sup>58-60</sup>. While not universally appropriate, it can offer enhanced flexibility and accessibility for families, especially those living at a distance from specialist centres. However, careful consideration should be given to both the advantages and disadvantages of telehealth (outlined in Table S10) when determining its suitability for individual patients and at specific stages of their treatment journey.

There are no changes to the recommended frequency or content of clinical reviews when delivered via telehealth. With appropriate planning, a tailored approach, and support from an experienced multidisciplinary team, KDT can also be successfully initiated remotely for selected patients and families<sup>58-60</sup>. This flexibility supports continuity of care and broadens access to ketogenic services, while maintaining clinical safety and effectiveness.

#### 3.12.2.1. Survey results

In clinical practice, telehealthcare is commonly used to support ketogenic diet therapy (KDT), particularly for patients and families who live far from the clinical centre. Over half of survey respondents (62%) reported using telehealth for this reason, while others (23%) indicated it was used as an adjunct for patients requiring additional support. A third of practitioners (32%) use video consultations for all patients, while 39% reported using them specifically for monitoring or review appointments between face-to-face visits. Additionally, 37% offer video appointments on an as-needed basis, and 14% use video for all clinic appointments except for rare instances when in-person assessment is necessary. Thirteen percent conduct one face-to-face consultation per year, with all other appointments held remotely.

In addition to video appointments, other forms of remote communication were widely adopted. Telephone contact was the most commonly used (93%), followed by email (80%). Some teams used messaging through electronic medical charts, online personal health records or apps (14%), while others reported providing support via patient support groups (13%), educational videos (13%), newsletters (6%), or messaging services such as WhatsApp (11%).

## 3.13. Fine-tuning the diet prescription

Fine-tuning of the ketogenic dietary prescription is an important part of clinical care, allowing practitioners to optimise therapeutic ketosis, improve treatment efficacy, and minimise adverse effects. While often associated with the initial trial or adjustment period, fine-tuning can be required at any stage during treatment. Adjustments may include changes to macronutrient ratios, energy intake, fluid targets, or supplement use, and are typically informed by clinical response, ketone levels, side effects, and patient or family feedback. Evidence from Selter et al. demonstrated that fine-tuning led to improved seizure control in 18% of patients already responding to the classical ketogenic diet, with 3% achieving seizure freedom following adjustments<sup>61</sup>.

### 3.13.1. Survey results

According to our survey, changes to the KDT prescription are most commonly made by the dietitian (69%), or jointly with the wider ketogenic team (20%). In a smaller number of cases (7%), adjustments are led by the medical doctor. The primary driver for fine-tuning the prescription is seizure control, cited by 85% of respondents. This is followed by ketone levels (63%) and achieving a specific macronutrient ratio or prescription (74%). Survey comments also highlighted the importance of factors such as dietary adherence, acceptability and tolerance, glucose levels, growth, behaviour, and changes in weight. Most practitioners (88%) reported that they consider liberalising the dietary prescription as the patient gets older. This is usually based on clinical diagnosis and progression, the stability of ketosis, duration on the diet, and adherence over time.

#### **3.13.1.1. Fat**

Adjustments to fat intake within a KDT prescription are primarily driven by the need to optimise ketosis, manage side effects, and improve seizure control. The majority (84%) of survey respondents reported that fat content is modified based on ketone levels, gastrointestinal side effects (84%), and seizure control (84%). Other influencing factors include the presence of hyperlipidaemia (reported by 72% respondents), weight change (56%), and the need to improve dietary adherence (54%). To a lesser extent, changes in blood glucose levels (25%) and linear growth (25%) may also guide fat prescription adjustments.

MCTs are commonly used to support fine-tuning of KDT, as their metabolism yields more ketones per gram than LCTs, owing to their rapid absorption and hepatic conversion. Ninety-five percent of practitioners reported using MCT as part of this process, most frequently when ketone levels are suboptimal or inconsistent (96%), or when further restriction of carbohydrate is poorly tolerated (48%). Based on survey comments, MCT is typically prescribed up to 60% of total calories in MKDs, depending on individual tolerance and clinical judgement. Introduction is often gradual due to the risk of gastrointestinal side effects, including abdominal discomfort, loose stools, nausea, and vomiting<sup>62</sup>.

#### **3.13.1.2. Carbohydrate**

Carbohydrate intake is often adjusted during KDT to improve efficacy, metabolic control, and diet tolerability. According to our survey, the most common reason for modifying carbohydrate prescription is to address suboptimal ketone levels, cited by 82% of respondents. Adjustments may also be made when seizure control or other treatment goals are not being met (78% respondents), or to support better blood glucose regulation (69%). Improving adherence to the diet is another key driver (62%), as is the need to mitigate adverse effects such as gastrointestinal discomfort or poor appetite (59%). In some cases, carbohydrate is adjusted in response to weight changes (56%) or concerns about linear growth (25%). When fine-tuning carbohydrate intake, it is important to account for non-nutritive sources that may influence ketone production. Ingredients such as sugar alcohols—commonly found in low-carbohydrate or 'keto' food products, drinks, and some liquid medications—can impact ketosis and should be included in dietary assessments.

#### **3.13.1.3. Protein**

Protein prescriptions in KDT are adjusted based on a range of clinical indicators and patient needs. Survey results show that the most common reason for modifying protein intake is to support linear growth, cited by 62% of respondents for MKD. Suboptimal ketone levels are also a factor (54% respondents), as are laboratory markers such as low serum urea or abnormal amino acid profiles (49%). Adjustments may also be made to improve dietary adherence (49%), respond to lack of efficacy in terms of seizure control or other clinical goals (44%), or address weight changes (42%). Less commonly, adverse effects (27%) and blood glucose levels (23%) influence the decision to amend protein targets.

### **3.14. Adverse effects**

Potential adverse effects associated with KDT are detailed in published optimal clinical management recommendations<sup>9</sup>. Gastrointestinal symptoms are the most frequently reported side effects during the early stages of treatment and are typically short-lived or manageable through dietary modifications and, if necessary, medical intervention. Over the longer term, more serious complications can arise, including hyperlipidaemia, renal calculi, reduced bone mineral density, hypercalciuria, growth concerns, cardiac abnormalities, and in rare cases, pancreatitis<sup>9,63</sup>. These adverse effects require careful monitoring and multidisciplinary management. While medical oversight is essential, adjustments to the ketogenic diet can play a role in mitigating some of these risks. A range of potential dietary strategies for addressing persistent symptoms and adverse effects is summarised in Table 5.

**Table 5.** Dietary adjustments for individuals on ketogenic diet therapy with specific symptoms / adverse effects

Symptom	Considerations	Strategies (% of survey respondents who selected each strategy)
High ketone levels and/or acidosis	<ul style="list-style-type: none"> <li>Is calorie intake sufficient / weight gain appropriate?</li> <li>Any recent weight loss?</li> <li>Any missed meals or feeds?</li> <li>Any delay in meals or feeds?</li> <li>Any recent changes in ingredient brands used?</li> <li>Any recent changes in medication?</li> <li>Any signs of illness?</li> <li>Evaluate fluid intake/dehydration</li> <li>Evaluate which fat sources are being used</li> </ul>	<ul style="list-style-type: none"> <li>Increase carbohydrate intake (80%)</li> <li>Reduce fat intake (73%)</li> <li>Increase fluid intake (54%)</li> <li>Start bicarbonate (38%)</li> </ul>
Low ketones	<ul style="list-style-type: none"> <li>Is calorie intake too high / is there rapid weight gain?</li> <li>Is protein intake excessive?</li> <li>Check adherence to diet prescription</li> <li>Check if there are any recent change in products or ingredient brands</li> <li>Any signs of illness?</li> <li>Any recent changes in medication?</li> <li>Any changes in family situation / routine / travel?</li> <li>Any pattern as to which time of day ketones are lower/higher?</li> <li>Any change to bowel habits? Constipation can slow digestion and impact ketosis.</li> </ul>	n/a (not asked in survey)
Recurrent hypoglycemia	<ul style="list-style-type: none"> <li>Check adherence to diet prescription</li> <li>Check for any changes in activity levels</li> <li>Check for patterns of hypoglycemia</li> <li>Evaluate frequency of meals/snacks</li> <li>Check for level of ketosis</li> <li>Check energy intake and growth</li> <li>Evaluate feed dilution, where applicable</li> </ul>	<ul style="list-style-type: none"> <li>Increase carbohydrate intake (86%)</li> <li>Increase daily calories (58%)</li> <li>Decrease fat intake (28%)</li> <li>Provide a specified amount of sugar-sweetened beverage or commercial carbohydrate modular component every time hypoglycemia occurs (20%)</li> <li>Increase protein intake (18%)</li> </ul>

Symptom	Considerations	Strategies (% of survey respondents who selected each strategy)
Diarrhea	<ul style="list-style-type: none"> <li>Any new medications recently started, in particular antibiotics? If so, could this be linked?</li> <li>Any new foods/ingredients/fat sources introduced recently?</li> <li>Consider feeding rate (enteral feeders)</li> <li>Check adherence to diet prescription</li> <li>Check food portion or feed volume</li> <li>Check for history of constipation, as could be overflow diarrhea</li> <li>Evaluate signs of steatorrhea</li> <li>Consider bacterial overgrowth as a potential differential</li> </ul>	<ul style="list-style-type: none"> <li>Reduce MCT (86%)</li> <li>Supplementation with probiotics (60%)</li> <li>Increase fluid intake (57%)</li> <li>Reduce fat intake (41%)</li> <li>Lower diet ratio / liberalize diet prescription (39%)</li> <li>Decrease fiber from food (33%)</li> <li>Supplementation with modular fiber (29%)</li> <li>Increase fiber from food (26%)</li> </ul>
Vomiting	<ul style="list-style-type: none"> <li>Check for excess ketosis or hypoglycemia</li> <li>Any new foods/ingredients introduced recently?</li> <li>Consider feeding amount and rate (enteral feeders)</li> <li>Check adherence to diet prescription</li> <li>Check food portion or feed volume</li> <li>Consider reflux and/or constipation</li> </ul>	<ul style="list-style-type: none"> <li>Lower diet ratio / liberalize diet prescription (76%)</li> <li>Reduce fat intake (56%).</li> <li>Oral rehydration solution mixed with water (44%)</li> <li>Increase fluid intake (34%)</li> <li>Provide electrolyte solution (33%)</li> <li>Suggest periods of fasting (18%)</li> <li>Other (27%), for example, consider constipation or reflux, look at timings and volume of meals, trial a peptide formula if applicable.</li> </ul>
Constipation	<ul style="list-style-type: none"> <li>Check fluid intake</li> <li>Check fiber intake</li> <li>Evaluate usual bowel habits</li> <li>Consider recommending smaller meals</li> <li>Chronic constipation should be discussed with the medical team to consider treatment options</li> </ul>	<ul style="list-style-type: none"> <li>Increase fluid intake (96%)</li> <li>Advise on fiber-rich food sources (80%)</li> <li>Add MCT (58%)</li> <li>Supplementation with modular fiber (49%)</li> <li>Supplementation with probiotics (40%)</li> <li>Supplementation with magnesium citrate (23%)</li> <li>Offer prune juice (8%) [consider amount required without impacting ketone/glucose levels or seizure control]</li> </ul>
Reflux	<ul style="list-style-type: none"> <li>Evaluate pattern of symptoms</li> <li>Check food portion or feed volume</li> <li>Consider enteral feeding pattern or rate</li> <li>Consider types of fat</li> <li>Consider constipation</li> <li>Is reflux optimally medically managed, if applicable?</li> </ul>	<ul style="list-style-type: none"> <li>Sit upright when eating/feeding (91%)</li> <li>Smaller meals / feeds (91%)</li> <li>Reduce fat intake (53%)</li> <li>Lower diet ratio / liberalize diet prescription (47%)</li> <li>Consider introduction of a thickener (34%)</li> <li>Ginger tea (11%)</li> <li>Decrease calories (9%)</li> </ul>



Symptom	Considerations	Strategies (% of survey respondents who selected each strategy)
<b>Hyperlipidemia</b>	<ul style="list-style-type: none"> <li>Were laboratory measures taken in a fasted state?</li> <li>Dietary assessment to identify current fat sources</li> <li>Check carnitine levels</li> <li>Consider that, in many cases, lipid values will stabilize or normalize without intervention within approximately 12 months</li> <li>In cases of persistent hyperlipidemia, referral to the metabolic team may be required for genetic testing and/or further investigation</li> </ul>	<ul style="list-style-type: none"> <li>Advise on alternative fat sources (94%)</li> <li>Add MCT (60%)</li> <li>Lower diet ratio or liberalize diet prescription (46%)</li> <li>Other (19%), for example, encourage food sources of soluble fiber, add plant stanols</li> <li>Stop KDT (6%)</li> </ul>
<b>Hypercalcemia or hypercalciuria</b>	<ul style="list-style-type: none"> <li>Assess fluid intake (increased hydration is recommended for individuals with hypercalcemia, with calcitonin as the next therapeutic option<sup>76</sup>)</li> <li>Assess calcium intake</li> <li>Review level of ketosis</li> <li>Consider Citrate supplementation</li> <li>Consider contributing factors, including carbonic anhydrase inhibitors</li> <li>Consider referral for medical support, if persistent</li> </ul>	<ul style="list-style-type: none"> <li>Increase fluid intake (63% re. hypercalcemia / 70% re. hypercalciuria)</li> <li>Refer to renal specialty (50% / 51%)</li> <li>Lower supplement dose (49% / 40%)</li> <li>Add a citrate (38% / 48%)</li> <li>Lower diet ratio or liberalize diet prescription (37% / 40%)</li> </ul>

### 3.15. Management of illness

During episodes of intercurrent illness, dietary adjustment may be necessary to maintain ketosis and reduce the risk of seizure recurrence. In such cases, a ketogenic 'milkshake' tailored to the individual's prescription can be used as a temporary meal replacement, and may be diluted if poorly tolerated<sup>64</sup>. Close monitoring of both blood glucose and ketone levels is advised, as the risk of hyperketosis or hypoglycaemia is heightened during illness, particularly if dietary intake is reduced<sup>64</sup>.

As with any unwell child, medical advice should be sought if there are concerns or the illness persists, to ensure appropriate treatment is provided. Ideally, medications—including antibiotics—should be in low-carbohydrate formulations. However, if no suitable alternative is available, the medication should not be withheld; treating the underlying illness must take priority. If long-term treatment with carbohydrate-containing medication is required and ketosis is affected, the dietary prescription may need to be temporarily adjusted.

Maintaining hydration is also a priority. Sugar-free fluids should be encouraged, and if needed, rehydration solutions can be used in diluted form to avoid exceeding the individual's carbohydrate allowance. These may help prevent hyperketosis and/or acidosis, particularly in children who are unable to tolerate full meals. If vomiting or diarrhoea occurs, a temporary reduction in fat intake—particularly MCT—may be necessary. This can be achieved by adjusting the diet prescription or offering half-sized meals or feeds.

If the child is nil by mouth for over 12 hours, such as in preparation for surgery, it is advisable to check whether the anaesthetic team has access to a ketogenic protocol<sup>65</sup>. During this time, ketone and blood glucose levels should be monitored more frequently (every 4 hours is recommended) to reduce the risk of hypoglycaemia or excessive ketosis.



The diet should be reintroduced as soon as the child is able to tolerate food again. If intravenous fluids are required, non-dextrose-containing solutions should be used, unless dextrose is necessary to manage acute hypoglycaemia or hyperketosis<sup>64</sup>. Studies have shown that children on KDT undergoing general anaesthesia with carbohydrate-free intravenous fluids maintained stable glucose levels; however, some experienced metabolic acidosis<sup>65</sup>. As such, serum pH or bicarbonate levels should be monitored during prolonged procedures. If oral or enteral feeding must be withheld for more than 48 hours, PN may be considered<sup>41,66</sup>.

### 3.15.1. Survey results

In the event of illness, survey respondents reported several common strategies to support patients while maintaining dietary goals. The overwhelming majority (93%) prioritise maintaining adequate fluid intake during illness. Many also reported adapting meal formats to improve tolerability: 78% offer smaller meals or feeds, and 57% recommend the use of oral rehydration solutions to support hydration and electrolyte balance. Just over half of respondents (51%) use ketogenic meal replacement shakes, tailored to the individual's diet prescription, as a temporary alternative when full meals are not tolerated. A smaller proportion (21%) reported offering meals or feeds without added fats, i.e. not fully within the ketogenic diet prescription, to help manage intake during periods of gastrointestinal upset or reduced appetite.

## 3.16. Diet discontinuation

### 3.16.1. When to consider discontinuing KDT?

The decision to discontinue KDT should be made on an individual basis, involving shared discussion between the child (where appropriate), their parents or carers, the dietitian, and the neurologist. As a medical therapy, KDT carries the risk of adverse effects and should not be continued if treatment goals are not being achieved. Evidence suggests that 75% of children who will respond to KDT do so within the first 14 days<sup>67</sup>, though some may take longer (up to two months or more) to show benefit. Optimal clinical management recommendations advise discontinuing the diet after approximately three months if there has been no reduction in seizures or other therapeutic benefits<sup>9</sup>. In such cases, particularly for patients on MKD, a transition to CKD may be considered to assess whether a stricter regimen may yield improvement<sup>68</sup>.

For individuals who do respond well—typically defined as achieving a seizure reduction of 50% or more—discontinuation is often considered after around two years of treatment<sup>9</sup>. However, there is no defined maximum duration for KDT<sup>9</sup> and long-term use has been documented for up to 20 years in individuals experiencing significant seizure control with minimal side effects<sup>69,70</sup>. In certain cases, longer treatment durations may be appropriate. For example, children with epileptiform discharges on EEG, focal abnormalities on MRI, or a diagnosis of tuberous sclerosis may benefit from extended therapy due to a higher risk of seizure recurrence<sup>71</sup>. Additionally, for individuals with GLUT1 deficiency syndrome (GLUT1-DS), it is recommended that the diet be continued at least until puberty<sup>9</sup> or into adulthood<sup>72</sup>. In those with pyruvate dehydrogenase deficiency (PDHD), extended use beyond two years may also be appropriate depending on response and tolerability<sup>9</sup>.

### 3.16.2. How to discontinue KDT?

Discontinuation of KDT should be carefully planned and individualised based on patient response, clinical condition, and the duration of therapy. A retrospective review suggested that a gradual weaning period of 4–6 weeks is both feasible and well tolerated in most cases<sup>73</sup>.

Once ketone levels fall—typically defined as <1 mmol/L (<20 mg/dL) or <0.5 mmol/L (<5 mg/dL)—the transition back to the child's usual diet can be accelerated<sup>48,71,74</sup>. If seizure control deteriorates during discontinuation, many patients can regain seizure stability through dietary or anti-seizure medication adjustments<sup>71,73</sup>. In such cases, practitioners may opt to pause the weaning process for 3–7 days, reassess clinical response, and then resume at a slower pace. Alternatively, returning temporarily to the previous, better-tolerated dietary prescription before resuming the wean may be helpful.

In all cases, medical input is recommended if seizure frequency increases.

According to optimal clinical management recommendations, micronutrient supplementation should be continued until KDT is fully discontinued<sup>9</sup>.

### 3.16.2.1. Survey results

Survey responses indicate that the length of time taken to discontinue ketogenic diet therapy (KDT) is highly individualised and influenced by several patient-specific factors. The most common determinant was the clinical response to the diet, including seizure control and achievement of other therapeutic goals, cited by 91% of respondents. Seventy-five percent noted that the total duration on KDT influenced the weaning timeline, while 67% reported that patient or family preference played a role. Additional factors included any adverse effects experienced while on the diet (65%), level of ketosis achieved (55%), type of ketogenic diet used (43%), mode of feeding (33%), and the patient's age (with 16% taking longer to wean younger patients, although 5% reported the opposite). A smaller proportion (14%) also considered the epilepsy syndrome when planning discontinuation.

A variety of approaches were described for discontinuing MKDs. Over half of survey respondents (51%) reported that they increase carbohydrate intake and decrease fat intake simultaneously in a stepwise fashion. Another 37% increased carbohydrate first, and only 6% decreased fat first. One common approach when using food choice or exchange lists was to reduce fat choices by one or two per day and increase carbohydrate choices by 1 g per meal or snack every 1–7 days. For patients on MKD for a short period with no observed benefit, changes may be made more quickly (e.g., every 1–2 days), or MKD meals and snacks may be gradually replaced with standard meals over a number of days. Table 6 summarises the reported duration for weaning off MKDs, which tended to be longer for patients who had followed the diet for at least two years, and was frequently individualised.

**Table 6.** Length of time to wean off modified ketogenic diets: survey responses

Individuals following an MKD for approximately 3 months with no/minimal response	Agreement rate (% survey respondents)	Individuals following an MKD for at least 2 years with good response	Agreement rate (% survey respondents)
<1 week	20%	<1 week	2%
1-2 weeks	38%	1-2 weeks	5%
3-4 weeks	16%	3-4 weeks	23%
1-2 months	5%	1-2 months	18%
3-4 months	0%	3-4 months	5%
Very individualized	22%	4-6 months	2%
		>6 months	3%
		Very individualized	41%

Table S11 outlines worked examples of how to discontinue MKDs, presenting two distinct approaches: one that gradually adjusts the daily carbohydrate and fat intake, and another that replaces individual MKD meals with typical or higher-carbohydrate meals over time. For both methods, two scenarios are illustrated: (1) for patients who have been on MKD for a short time or have shown no clinical response, and (2) for those who have followed the diet longer and/or demonstrated a good response in seizure control.

During the weaning process, over half of survey respondents (64%) continue to monitor ketone levels, while 23% do not. The remainder either leave the decision to families or monitor only until ketosis is no longer present. Regarding vitamin and mineral supplementation, 87% of respondents reported stopping supplementation at the end of the weaning process, whereas 5% only stopped once ketosis was lost. It is important to note that some form of supplementation may still be required for reasons unrelated to the ketogenic diet itself, such as concurrent medications or baseline nutritional status, and ongoing monitoring should be determined by local clinical practice, the healthcare system, and the responsibilities of the individual service or centre.

### **3.16.3. Dietary advice after discontinuing KDT**

Following a successful period on KDT, some families may be hesitant to reintroduce carbohydrates (particularly processed or refined sources) due to concerns about seizure recurrence or other negative effects. This is an important consideration when supporting families in transitioning back to a more typical dietary pattern.

Survey findings reflect a wide range of professional approaches. One third of respondents recommend avoiding processed and refined sugars altogether when returning to a standard diet. Others take a more gradual approach: 21% advise slowly reintroducing simple carbohydrates, while 14% support gradual reintroduction of processed and refined sugars specifically. A smaller proportion (9%) advise avoiding simple carbohydrates entirely. Notably, 14% of respondents do not provide specific guidance on carbohydrate reintroduction, underscoring the variation in practice and the importance of tailoring advice to individual patient and family needs.

### **3.16.4. Follow-up post diet discontinuation**

Post-diet discontinuation follow-up practices vary between services and are often influenced by local resources and patient needs. According to survey data, 34% of respondents discharge orally fed patients from their service once they are fully weaned off the KDT. Others continue to provide follow-up support for a period after discontinuation: 18% discharge patients more than four weeks after weaning is complete, 14% after two to four weeks, and 13% within one to two weeks.

Decisions regarding continued follow-up are typically guided by individual clinical considerations, such as concerns about nutritional status or growth. In many cases, ongoing support may transition to general or community dietetic services, where available, to ensure continuity of care. This highlights the need for effective handover and clear communication between specialist ketogenic teams and broader healthcare services.

## 4. RESULTS: DIETETIC PRACTICE CORE RECOMMENDATIONS

Table 7 outlines the core recommendations for MKDs, based on published evidence or survey consensus ( $\geq 75\%$  agreement rate).

**Table 7.** Core recommendations for modified ketogenic diets

Aspect of dietary management	Source
<b>Definition of modified ketogenic diets type</b>	
<ul style="list-style-type: none"> <li>MKD encompasses all ketogenic diets that do not fit the definition of a CKD or a Medium Chain Triglyceride (MCT) KD.</li> </ul>	L1
<ul style="list-style-type: none"> <li>MKD is most commonly defined as ketogenic diets that have a carbohydrate limit and a fat target, whereas protein is allowed freely or has a more general age-specific target.</li> </ul>	S; L1
<b>Patient selection (dietary factors)</b>	
<ul style="list-style-type: none"> <li>MKD is preferred over CKD in the case of patient/family preference, for orally fed patients, and those aged over 12 years.</li> </ul>	S
<ul style="list-style-type: none"> <li>MKD may be preferred over CKD for vegetarian and vegan diets, but this is patient dependent.</li> </ul>	S
<b>Pre-diet preparation</b>	
<ul style="list-style-type: none"> <li>Patients may benefit from pre-diet dietary adjustments before starting KDT, for example, by reducing simple sugars, trying out high-fat foods or ketogenic recipes.</li> </ul>	S
<ul style="list-style-type: none"> <li>At least one education session is required, following agreement from the patient/family and the multidisciplinary healthcare team that KDT will be started.</li> </ul>	S
<ul style="list-style-type: none"> <li>At a minimum, education session should include the following topics:               <ul style="list-style-type: none"> <li>Importance of adherence to the diet</li> <li>Potential adverse effects</li> <li>Follow up expectations</li> <li>Identifying carbohydrates, protein, and fat sources</li> <li>Weighing/measuring of foods and/or formula</li> <li>Importance of hydration</li> <li>Identify other sources of carbohydrate, such as medications</li> <li>Supplements</li> <li>Time commitment needed</li> </ul> </li> </ul>	
<b>Diet prescription (energy, fat, protein, carbohydrate, fluid)</b>	
<ul style="list-style-type: none"> <li>Although calorie prescriptions are typically not given for MKDs, if energy requirements are calculated, they are based on standardized energy equations, current feeding regimen and growth trends.</li> </ul>	S; L1
<ul style="list-style-type: none"> <li>Protein is not routinely prescribed in MKDs, but care should be taken to ensure minimum daily requirements are met.</li> </ul>	S; L1
<ul style="list-style-type: none"> <li>Fat targets are most commonly 60-80% total energy. Alternatively, the fat target may be set as any remaining calories after calculating carbohydrate and protein goals.</li> </ul>	S; L1
<ul style="list-style-type: none"> <li>When setting carbohydrate goals for MKDs, the amount is commonly set based on the age of the patient. Carbohydrate allowances mostly range between 10 – 20 grams per day (total or net carbohydrate can be used).</li> </ul>	S; L1
<ul style="list-style-type: none"> <li>Fat and carbohydrate should be spread evenly throughout the day.</li> </ul>	S; L1

Aspect of dietary management	Source
<ul style="list-style-type: none"> <li>For modified texture diets, low-carbohydrate options, such as gum-based thickeners, may be used.</li> <li>Fluid requirements should not be restricted.</li> <li>The ketogenic dietitian is typically responsible for advising on micronutrient supplementation, commonly a complete multivitamin and mineral supplement, plus additional supplements as required, such as carnitine (if low), calcium, and vitamin D.</li> </ul>	<p>S</p> <p>S; L1</p> <p>S; L1</p>
<b>Prescribable ketogenic products</b>	
<ul style="list-style-type: none"> <li>MCT oil and MCT-based products can be used as part of CKD and MKDs and the amount should be increased incrementally.</li> <li>Commercial ketogenic formulas can be offered to orally fed patients on MKDs.</li> <li>Consider limiting keto specialty food products if they seem to negatively impact ketosis or seizure control.</li> </ul>	<p>S</p> <p>S</p> <p>S</p>
<b>Diet initiation</b>	
<ul style="list-style-type: none"> <li>MKD tend to be started at full calories and advanced either by adding in one MKD meal at a time at target macronutrient goals, or by advancing per macronutrient goal, with the aim of reaching the target prescription typically between 1-4 weeks.</li> <li>Ketones should be monitored (once or twice daily) during the initiation phase, until ketone levels and the diet prescription are as stable as possible.</li> </ul>	<p>S; L1</p> <p>S; L1</p>
<b>Follow-up, monitoring and fine-tuning</b>	
<ul style="list-style-type: none"> <li>Offer in-person clinic visits, or virtual clinic visits (where appropriate) at a minimum of 1, 3, 6 and 12 months post diet start, then 6-monthly.</li> <li>Provide additional follow-up phone calls and/or emails as needed.</li> <li>At follow-up appointments, anthropometrics, the nutritional adequacy of the diet prescription, diet adherence and any non-seizure benefits from KDT should be reviewed.</li> <li>Adherence is measured by monitoring ketone levels and through discussions with patients/families.</li> <li>Additional ketone checks may be done in the case of symptomatic hyperketosis, loss of seizure efficacy or during illness.</li> <li>Consider use of MCT to promote higher levels of ketosis, if other changes to the diet prescription do not result in seizure improvement or if further restrictions in carbohydrate intake is not tolerated or possible.</li> <li>The diet prescription may be liberalized as patients get older, if needed.</li> </ul>	<p>L1</p> <p>L1</p> <p>L1</p> <p>S; L1</p> <p>S</p> <p>S</p> <p>S</p>
<b>Intercurrent illness</b>	
<ul style="list-style-type: none"> <li>In case of constipation, increasing fluid intake and advise on fiber-rich food sources are considered.</li> <li>For the treatment of acute hypoglycemia, a specified amount of a sugar-sweetened beverage, such as juice, or a specific amount of carbohydrate (grams) is recommended.</li> <li>In case of recurrent hypoglycemia, increasing carbohydrate intake in diet prescription is considered by dietitians is recommended.</li> <li>In case of illness, prioritize fluid intake, in some cases with an oral rehydration solution, and temporarily offer snack portions in place of full calorie meals.</li> <li>In case of hyperlipidemia, changing dietary fat sources is considered.</li> </ul>	<p>S; L1</p> <p>S</p> <p>S</p> <p>S</p> <p>S; L1</p>

Aspect of dietary management	Source
<b>Diet discontinuation</b>	
<ul style="list-style-type: none"> <li>There is no maximum amount of time that KDT can be followed but, if effective, diet discontinuation can be considered after approximately 2 years.</li> </ul>	S; L2
<ul style="list-style-type: none"> <li>If on diet for a short period of time (&lt;3 months) with no/minimal response, KDT is most commonly weaned over 1-4 weeks.</li> </ul>	S
<ul style="list-style-type: none"> <li>If on diet for a longer period of time (&gt;2 years) with good response, the length of time over which KDT is discontinued is most commonly individualized to each patient, but is generally longer than those on diet for short periods of time.</li> </ul>	S
<ul style="list-style-type: none"> <li>When discontinuing MKDs, the most common method is to increase carbohydrate and decrease fat in a stepwise fashion. For example, increase carbohydrate by 1 g per meal/snack and reduce fat by one or two 'choices' every 1-7 days.</li> </ul>	S; L1
<ul style="list-style-type: none"> <li>Continue monitoring ketones whilst discontinuing KDT, but once ketone levels are minimal, the speed of transition back to the patient's usual diet can be increased.</li> </ul>	S
<ul style="list-style-type: none"> <li>Vitamin/mineral supplementation should be continued until the end of the diet discontinuation process.</li> </ul>	S
<ul style="list-style-type: none"> <li>Patients may be advised to avoid processed and refined sugars when they return to their usual diet, in line with general healthy eating guidelines, or to gradually re-introduce simple carbohydrates.</li> </ul>	S
<b>S = survey consensus (≥75% agreement); L1 = published consensus recommendations or international guidelines; L2 = published surveys, systematic reviews, meta-analyses, or randomised controlled trials</b>	

## 5. DISCUSSION

These recommendations represent the first international best practice guidance for the dietetic management of children and young people with epilepsy following MKDs. They are grounded in a combination of published evidence and the most commonly reported dietetic practices, while also acknowledging and valuing the diversity of approaches used across different countries and healthcare systems.

The document is intended as a practical resource for ketogenic dietitians and nutrition professionals involved in the care of children and adolescents receiving medically advised MKDs for epilepsy management. While the recommendations seek to support greater consistency and quality in dietetic care worldwide, they are not prescriptive or mandatory, and clinical judgement remains essential. Local policy, patient preference, and resource availability should all be considered when applying these recommendations in practice.

Evidence to support dietetic management of KDT remains limited, particularly for MKDs. The recommendations therefore reflect the best available evidence at the time of writing, alongside expert opinion and international survey data. As with all survey-based research, certain limitations must be acknowledged. These include the potential for sampling and response bias, and a relatively restricted set of response options. While we achieved a substantial number of respondents globally, the survey was designed to capture individual practice, which may not always represent centre-wide protocols. In cases where multiple dietitians from a single centre contributed, there is a possibility of overrepresentation of certain practices. However, this also reflects the reality that dietetic practice can vary between professionals even within the same institution.

## 6. CONCLUSION

Despite the limitations discussed, these recommendations are highly relevant to practicing dietitians and offer a valuable resource for supporting children and young people on MKDs. By promoting consistency in practice, they aim to enhance patient and family experience, support adherence to dietary therapy, and potentially improve clinical outcomes. Future research should prioritise the perspectives of service users and seek to evaluate the clinical impact of differing dietetic approaches, in order to further strengthen the evidence base and optimise care.

## ABBREVIATIONS

The following abbreviations are used in this manuscript:

Term	Definition
BKD	Blended ketogenic diet
BMI	Body mass index
CKD	Classical ketogenic diet
IV	Intravenous
LGIT	Low glycemic index treatment
KDRN	Ketogenic Dietitians Research Network
KDT	Ketogenic diet therapy
MAD	Modified Atkins diet
MCT	Medium chain triglyceride
MKD	Modified ketogenic diet



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# SUPPLEMENTARY MATERIAL

**Table S1.** Search terms

Search topic	Search terms	Date of last search
Patient selection	(child* OR infant) AND (ketogenic OR "modified atkins") AND Epilepsy[MeSH Terms] AND (patient selection [MeSH Terms] OR Nutrition Assessment[MeSH Terms] OR contraindications[MeSH terms] OR "indication*")	14/02/2024
Patient selection (diet types)	(child* OR infant) AND (ketogenic OR "modified atkins") AND Epilepsy[MeSH Terms] AND (diet selection [MeSH Terms] OR Nutrition Assessment[MeSH Terms] OR contraindications[MeSH terms] OR "indication*")	22/02/2024
Diet prescription	(child* OR infant) AND (ketogenic OR "modified atkins") AND Epilepsy[MeSH Terms] AND ("diet prescription" OR "grams" OR "percentage energy" OR macronutrient* OR micronutrient* OR "ratio*")	12/02/2024
Mode of feeding	("child*" OR "infant") AND ("ketogenic" OR "modified atkins") AND Epilepsy[MeSH Terms] AND ("enteral" OR "tube" OR "blended" or "gastrostomy")	24/01/2024
Adolescents and ketogenic diets	(ketogenic OR "modified atkins") AND Epilepsy[MeSH Terms] AND (Infant[MeSH Terms] OR Child[MeSH Terms] OR Adolescent[MeSH Terms]) AND (social OR adapt*)	22/02/2024
Differences in practice with patients of different age group	(ketogenic OR "modified atkins") AND Epilepsy[MeSH Terms] AND (Infant[MeSH Terms] OR Child[MeSH Terms] OR Adolescent[MeSH Terms]) AND (Dietary Supplements[MeSH Terms] OR Infant Formula[MeSH Terms] OR prescrib*)	22/02/2024
Monitoring	(child* OR infant) AND (ketogenic OR "modified atkins") AND Epilepsy[MeSH Terms] AND ("monitoring" or "blood test" or "Monitoring, Ambulatory" or "lab*" or "blood work" or "adverse effects" [Subheading] or "side effects")	25/01/2024
Adherence	(child* OR infant) AND (ketogenic OR "modified atkins") AND Epilepsy[MeSH Terms] AND (psycho* OR social OR Treatment Adherence and Compliance[MeSH Terms] OR Patient Compliance[MeSH Terms])	13/02/2024
Telemedicine	(child* OR infant) AND (ketogenic OR "modified atkins") AND Epilepsy[MeSH Terms] AND ( telemedicine* OR COVID-19 OR "virtual" OR "remote*" or "telehealth*")	25/01/2024

**Table S2:** Components of modified ketogenic diets (% agreement rate from survey respondents)

<b>'Components' of modified ketogenic diets</b>	<b>Agreement rate (survey respondents)*</b>
Specify carbohydrate limit and fat target, with protein allowed freely	54%
Give all macro and kcal goals, including fat, carb and protein targets	22%
Specify NET carbs only; calories and protein are free	19%
I calculate the ratio of the diet, but only as a guide for myself	18%
I calculate the diet using a ratio, but it is administered via household measurements and/or food exchanges	17%
Specify TOTAL carbs only; calories and protein are free	14%
Based on fat/protein/carb percentages	11%
Other**	9%
Ketogenic diet with a 2:1 or 1:1 ratio weighed on a gram scale	6%
I don't use MAD or MKD	6%
Advise on a 50% total carb reduction	3%

\* Respondents were able to select more than one answer.

\*\* 'Other' comments:

1. Specify net carbohydrate, protein goal and fat goal.
2. We give kcal, fat and carb goals.
3. I give target macro ranges because most patients use a tracking app, but I tell patients that sticking to the carb limit is most important, they need to meet at least their minimum protein needs (OK to go over the provided range), and use fat as a tool to promote satiety and ketosis. People with a higher BMI may be able to eat less fat and use body stores. I tell patients to aim for at least 2 added fats per meal and at least one added fat per snack. Though I provide ranges, I'm flexible and teach patients how to think through building meals.
4. MAD = net carb restriction; MKD = ratio below 3:1 and measuring on gram scale.
5. I also encourage fat and protein with every meal and snack.
6. We do different variations according to what suits the patient. We tend to give max carbs, min fat and a protein range. And will liberalize it from there if needed.
7. I give minimum fat and maximum carbs in g and protein as a range in g. I give kcal as a range.
8. Specify net carb goal. Provide fat and protein targets.
9. I sometimes have to give protein goals.
10. Like option 3 (limit CHO by grams, guide on rough portions of fat per meal to avoid hunger) but advise moderation/caution with protein - based on their normal intake -and eat a portion at each meal. We don't talk about any macro being free. Explain balance ...all macros influence ketosis.

**Table S3:** Carbohydrate allowances in initial modified ketogenic diet prescription for different age ranges (% agreement rate from survey respondents)

	5g net	5g total	10g net	10g total	15g net	15g total	20g net	20g total	50% BC*	5% EFC**	10% EFC**	15% EFC**	N/A***
<2 yrs	2%	3%	9%	10%	5%	1%	7%	6%	2%	3%	5%	3%	21%
2-5 yrs	0%	1%	9%	13%	9%	5%	7%	5%	2%	1%	6%	5%	16%
6-11 yrs	0%	0%	6%	6%	13%	8%	13%	4%	4%	2%	4%	6%	13%
12-18yrs	0%	0%	0%	1%	9%	12%	20%	11%	4%	4%	5%	5%	9%

\* Baseline carb

\*\* Energy from carb

\*\*\* Not Applicable



**Table S4:** List of commonly used ingredients and suggested alternatives for individuals with special dietary requirements

Ingredient	Substitute					
	Dairy	Egg	Soy	Peanuts	Tree Nuts	Wheat/Gluten
Oil	✓	✓	✓	✓	✓	✓
Cream (Dairy)	Soy cream	✓	Dairy cream	✓	✓	✓
Egg	✓	<u>Raising agents</u> Baking soda Baking powder “No egg” substitute  <u>Protein Source</u> Pea protein Meat	✓	✓	✓	✓
Butter & Shortening	Olive oil butter Almond butter Coconut butter/ shortening Vegan butter, Avocado	Olive oil butter Almond butter Coconut butter/ shortening Vegan butter, Avocado	Dairy Butter Almond butter Vegan butter, Avocado	Olive oil butter Almond butter Coconut butter/ shortening Vegan butter, Avocado	Olive oil butter Vegan butter, Avocado	Olive oil butter Almond butter Coconut butter/ shortening Vegan butter, Avocado
Flour, Standard	Watch out for some Gluten free flour that contains dairy	Almond flour Soy Flour Walnut flour Standard flour	Almond flour Walnut flour Standard flour	Almond flour Soy Flour Gluten Free flour Walnut flour Standard flour	Standard flour Soy Flour Gluten Free flour	Almond flour Soy Flour Gluten Free flour Walnut flour
Generic Protein Powder	Pea protein	Skimmed milk powder Protifar™	Skimmed milk powder Protifar™	✓	✓	✓
Generic Fat	Oil, dairy free butter/ margarine	Oil, butter, avocado	Oil, butter, avocado	Oil, butter, avocado	Oil, butter, avocado	Oil, butter, avocado
Formula / milk	Plant based keto products Rice milk Almond milk Soy milk	✓	Rice milk Almond milk Dairy milk	✓	✓	✓
Cheese	Soy cheese Vegan cheese	✓	Dairy cheese	✓	✓	✓
Almond Flour	✓	✓	✓	✓	✓	✓
Yoghurt	Soy yoghurt	✓	Dairy yoghurt	✓	✓	✓
Avocado	✓	✓	✓	✓	✓	✓
Berries	✓	✓	✓	✓	✓	✓
Cocoa Powder	✓	✓	✓	✓	✓	✓
Cream Cheese	Soy cream cheese	✓	✓	✓	✓	✓

**Table S5:** Example modified ketogenic diet daily meal plan

9 year old child, Weight = 20 kg  
Estimated dietary intake = 1339 kcal/day  
3 meals and 2-3 snacks per day

*Gram measurements are rounded to 1 decimal place,  
as well as exact measurements*

**Meal Option #1 (Breakfast)**

**- Muesli with Yoghurt**

	<b>Fat (g)</b>	<b>Carbohydrate (g)</b> excluding fibre
3-4 tablespoons or ¼ cup (loosely packed) (31g) Brazil nuts (roughly 5-6 nuts)	21 (21.2)	0 (0.1)
½ teaspoon (4g) Pumpkin seeds (shelled)	21 (21.2)	0 (0.4)
~1 teaspoon (2g) Desiccated coconut (fine or medium texture)	1 (1.3)	0 (0.1)
¼ teaspoon (1g) Cinnamon spice, ground	0 (0.03)	0 (0.3)
1 teaspoon (2g) Rolled oats (loosely packed)	0 (0.1)	1 (1.2)
1 teaspoon (5g) Coconut oil	5 (4.9)	0 (0)
½ cup (120g) Low-carb yoghurt (1% carb)	2 (1.7)	1 (0.96)
<b>Total</b>	<b>31 (30.9)</b>	<b>3 (3.06)</b>

Directions:

Roughly chop Brazil nuts.

Fry nuts, pumpkin seeds, desiccated coconut, cinnamon, oats and half the coconut oil in a frying pan on a medium heat for approximately 5 minutes. Allow to cool.

Melt the second half of the coconut oil in a small ramekin in the microwave for approx 20-30 seconds.

Stir melted coconut oil into yoghurt.

Serve muesli with yoghurt mixture.

[Source of nutritional composition: New Zealand Food Composition Database (NZFCD). Values may vary between countries]

**Meal Option #2 (Breakfast)**

**- Sour Milk with Myungu (Gourd)**

	<b>Fat (g)</b>	<b>Carbohydrate (g)</b> excluding fibre
12g Myungyu, cooked	0 (0.03)	1 (0.6)
50g Sour milk (fermented milk)	2 (1.5)	2 (2.4)
26g Vegetable oil	26 (26)	0 (0)
22g Avocado, Zambian	3 (3.4)	0 (0.4)
<b>Total</b>	<b>31 (30.9)</b>	<b>3 (3.4)</b>

Directions:

Mash the avocado, then add the gourd flesh and mix.

Add sour milk to the mixture. Add the oil and stir until evenly mixed.

[Source of nutritional composition: Zambian food composition table, version 4. Values may vary between countries]

<b>Meal Option #3 (Breakfast)</b> <b>- Scrambled Eggs, Bacon and Blueberries</b>	<b>Fat (g)</b>	<b>Carbohydrate (g)</b> excluding fibre
2 Medium slices bacon (42g)	12 (11.8)	0 (0.21)
1 Small egg (45g)	4 (3.6)	0 (0.4)
1 tablespoon (15g) Fresh cream (37–40% fat)	6g (5.5)	0 (0.4)
2 teaspoons (10g) Olive oil	10 (9.9)	0 (0)
¼ cup (16.5g) Blueberries (frozen)	0 (0.04)	2 (1.9)
<b>Total</b>	<b>31 (30.8)</b>	<b>3 (2.9)</b>

Directions:

Whisk egg and cream.

Heat pan with oil. Fry the egg mixture, slowly swirling it around the pan.

Grill or fry the bacon.

Serve scrambled eggs with bacon. Serve blueberries on the side.

[Source of nutritional composition: New Zealand Food Composition Database (NZFCD). Values may vary between countries]

<b>Meal Option #4 (Lunch or Dinner)</b> <b>- Bacon &amp; Cheese Wrap</b>	<b>Fat (g)</b>	<b>Carbohydrate (g)</b> excluding fibre
1 (30g) Low-carbohydrate wrap (4% carbs)	3 (3.3)	2 (1.9)
1 tablespoon (15g) Mayonnaise	12 (11.8)	0 (0.2)
¼ cup (30g) Cheddar cheese, grated	11 (10.6)	0 (0.2)
3 slices (20g) Ham, thinly sliced	0 (0.42)	0 (0.2)
1 tablespoon (2g) Carrot, raw, grated	0 (0)	0 (0.1)
<b>Total</b>	<b>31 (31.1)</b>	<b>3 (2.9)</b>

Directions:

Spread mayo over the wrap. Sprinkle cheese and carrot over the wrap and lay the ham over the top. Roll up wrap.

[Source of nutritional composition: New Zealand Food Composition Database (NZFCD). Values may vary between countries]

<b>Meal Option #5 (Lunch or Dinner)</b> <b>- Avocado Salad</b>	<b>Fat (g)</b>	<b>Carbohydrate (g)</b> excluding fibre
1 small (or ½ to ⅔ medium) (116g) Avocado Fuerte variety, flesh (NB: 100g California avocado has 1.52g carbs in 100g) *check your country's food database*	26 (25.5)	1 (0.7)
1 tablespoon (15g) Celery, chopped	0 (0.03)	0 (0.2)
2 teaspoons (10g) Cream cheese, softened	4 (3.6)	1 (0.5)
2 tablespoon (25g) Cucumber, diced	0 (0.04)	0 (0.4)
2-3 (10g) or 1 tablespoon Olives, in brine, sliced	1 (1.1)	0 (0.3)
2-3 (25g) Ham, thinly sliced (or 2 tablespoons Ham, diced)	1 (0.5)	0 (0.3)
2 tablespoons (22g) Cherry tomatoes, chopped	0 (0.1)	1 (0.7)
<b>Total</b>	<b>31 (30.9)</b>	<b>3 (3.1)</b>

Directions:

Dice the avocado, celery, cucumber, tomatoes and ham into even pieces. Cut olives in half.

Mix all with the cream cheese to create a salad.

[Source of nutritional composition: New Zealand Food Composition Database (NZFCD). Values may vary between countries]

**Meal Option #6 (Lunch or Dinner)**  
**– Moroccan Chicken**

	<b>Fat (g)</b>	<b>Carbohydrate (g)</b> excluding fibre
8-10 each (1kg) Chicken thighs, boneless	44 (43.6)	0 (0)
¾ cup (200g) Olive oil	199 (199.2)	0 (0.4)
2 teaspoons (10g) Garlic, crushed	0 (0.06)	1 (0.9)
2 teaspoons (10g) Paprika	1 (0.7)	2 (1.7)
1 teaspoon (4g) Cumin, ground, powder	1 (0.9)	1 (1.4)
½ teaspoon (2g) Coriander ground, powder	1 (0.5)	0 (0.4)
½ teaspoon (2g) Ginger ground, powder	0 (0.07)	1 (1.3)
1 teaspoon (2.5g) Turmeric, ground, powder	0 (0.3)	1 (1.1)
1 teaspoon (2.5g) Cinnamon, ground, powder	0 (0.08)	1 (0.6)
1 can (400g) Tomatoes, diced	0 (0.4)	13 (13.2)
¼ cup (30g) Chickpeas, tinned	0 (0.07)	3 (3.1)
<b>Total for 8 servings (batch)</b>	<b>246 (257.9)</b>	<b>24 (24.1)</b>
<b>Total for each serving</b>	<b>31 (32.2)</b>	<b>3 (3)</b>

**Directions:**

Mix all ingredients except chicken together in a small bowl to make a marinade.

Place chicken inside a zip-lock bag. Add marinade to the bag, press the air out and seal shut.

Rub marinade into the chicken until evenly coated.

Put the marinated chicken in the fridge for a few hours or overnight (optional).

Preheat oven to 180°C (350 °F).

Fry a few pieces of chicken at a time until lightly browned, then transfer to a baking dish.

Add tinned tomatoes and chickpeas.

Cover and bake for 45 mins or until soft.

Suggestion: Serve with low/no carb rice or noodles.

[Source of nutritional composition: New Zealand Food Composition Database (NZFCD). Values may vary between countries]

**Meal Option #7 (Lunch or Dinner)**  
**- Sole Mediterranean**

	<b>Fat (g)</b>	<b>Carbohydrate (g)</b> excluding fibre
8 small or 4-5 medium Fillets (850g) sole, fresh	10 (10.2)	0 (0)
1 teaspoon (5g) Salt	0 (0)	0 (0)
1 teaspoon (5g) Pepper	0 (0)	0 (0)
2 teaspoon (4g) Cumin seeds, ground	1 (0.9)	1 (1.4)
1 teaspoon (4g) Garlic powder	0 (0.03)	3 (2.8)
3-4 each (15g) Garlic cloves, thinly sliced	0 (0.1)	1 (1.3)
2 each Shallots or 2 tablespoons (20g) Shallots, thinly sliced	0 (0.02)	2 (1.7)
½ cup (110g) Butter	117 (116.9)	1 (1.1)
½ cup (120g) Olive oil	120 (119.5)	0 (0)
1 tablespoon (20g) Lime juice	0 (0.04)	0 (0.2)
2 tablespoons (10g) Capers	0 (0.05)	0 (0.2)
8 (240g) Low-carbohydrate wraps (4% carbs)	26 (26.4)	16 (15.6)
Lemon slices and green onion, cut lengthways, for garnish		
<b>Total for 8 servings (batch)</b>	<b>274 (274.1)</b>	<b>24 (24.3)</b>
<b>Total for each serving</b>	<b>34 (34.3)</b>	<b>3 (3)</b>

Directions:

In a small bowl, whisk together lime juice, olive oil and melted butter with a dash of seasoned salt.

Stir in the shallots, garlic and capers.

In a separate small bowl, mix together the seasoned salt, pepper, cumin and garlic powder. Spice fish fillets on both sides.

Place the fish fillets on a large lightly oiled baking pan or dish.

Cover with the buttery lime mixture.

Arrange the green onion and lemon slices on top (for flavour, not counted in the recipe).

Bake in oven at 190°C (375 °F) for 10-15 minutes.

Suggestion: Serve with a low carb wrap.

[Source of nutritional composition: New Zealand Food Composition Database (NZFCD). Values may vary between countries]

**Meal Option #8 (Lunch or Dinner)**  
**– “Brazilian Feijoada”**

	<b>Fat (g)</b>	<b>Carbohydrate (g)</b> excluding fibre
¼ cup or 2 tablespoons (50g) Black turtle beans, raw	1 (0.6)	19 (18.5)
2 cups shredded/diced (300g) Jerk beef (roughly 10–12 slices, deli-style)	48	9
1¼ cups of chopped Pork rib meat (without bone) (300g) (about 2–3 ribs)	79	0
1¼ cups of diced Pork loin (300g) (roughly 1–2 pork loin chops)	33	0
1⅓ cups diced or sliced (200g) Calabrese sausage	60	3
1⅓ cups diced or sliced (200g) Paio sausage (half an average sausage)	46	2 (1.7)
½ cup (100g) chopped or diced Pork	62 (61.5)	2 (1.6)
1 cup diced (200g) Bacon (approx. 7 rashers)	129	1 (0.9)
For seasoning:		
1 cup chopped (150g) Onion, approximately 2 medium onions	0 (0.2)	11 (10.7)
1 tablespoon minced (15g) Garlic (2.5 cloves)	0	3 (3.4)
2 Bay leaves	0	0
3 tablespoons (45ml) Olive oil	45	0
Black pepper	0	0
Pinch fresh parsley	0	0
<b>Total for 16 servings (batch)</b>	<b>502</b>	<b>49</b>
<b>Total for each serving</b>	<b>31</b>	<b>3</b>

Directions:

Cook the black beans with the bay leaf in water until tender. Set aside.

In a small pan, brown the bacon, then add the de-salted meats. Once browned, add the sausages (calabrese and paio) and cook until all are nicely browned.

Add the cooked beans and their liquid to the pot with the meats. Simmer on a low heat for about 30 minutes.

Add hot water if needed.

Heat the olive oil in a small skillet, then sauté the garlic and onion until golden. Add this to the feijoada, adjusting salt and pepper to taste.

Before serving, add freshly chopped herbs on top. Serve with konjac rice if desired.

[Source of nutritional composition: Tabela Brasileira de Composição de Alimentos (TBCA). Universidade de São Paulo (USP). Food Research Center (FoRC). Version 7.2. São Paulo, 2023. Values may vary between countries]

<b>Meal Option #9 (Lunch or Dinner)</b> <b>- Stir Fry Konjac Noodles with Fried Egg and Capsicum</b>	<b>Fat (g)</b>	<b>Carbohydrate (g)</b> excluding fibre
2.5ml Maggi Liquid Seasoning	0 (0)	0 (0.2)
1/3 teaspoon (1g) Sesame seeds	1 (0.5)	0 (0.2)
100g Konjac noodles (~1/2 packet)	0 (0)	0 (0)
1/4 cup (28g) chopped Pepper, capsicum, yellow, raw or 1/4 to 1/3 capsicum	0 (0.1)	1 (1.2)
1/4 cup (28g) chopped Pepper, capsicum, red, raw or 1/4 capsicum	0 (0.1)	1 (1.3)
1/2 (30g) Egg, whole, raw	2 (2.4)	0 (0.3)
1 1/2 tablespoon (20g) Vegetable Oil	20 (19.8)	0 (0.16)
1/2 tablespoon (8g) Sesame Oil	8 (7.9)	0 (0)
<b>Total</b>	<b>31 (30.8)</b>	<b>3 (3.2)</b>

Directions:

Drain the konjac noodles.

Beat the raw egg. Heat the pan with 5g vegetable oil. Fry the egg. Cut the fried egg into strips.

Use the same pan, heat the remaining 15g vegetable oil. Add onion and fry until golden and fragrant.

Add peppers, drained konjac noodles and soy sauce and stir fry.

Finally, add the egg strips. Cook and stir fry for a couple more minutes.

Top with sesame seeds and sesame oil.

[Source of nutritional composition: New Zealand Food Composition Database (NZFCD). Values may vary between countries]

<b>Meal Option #10 (Lunch or Dinner)</b> <b>- Fisashi</b>	<b>Fat (g)</b>	<b>Carbohydrate (g)</b> excluding fibre
11g Chibwabwa (Pumpkin leaves)	0 (0)	1 (0.77)
15g Groundnuts	7 (6.75)	3 (2.55)
24g Vegetable Oil	24 (24)	0 (0)
<b>Total</b>	<b>31 (30.75)</b>	<b>4 (3.32)</b>

Directions:

Peel, dice and wash pumpkin leaves. Leave to boil for 5 minutes and add chopped tomatoes.

Stir periodically for 10 minutes.

Add salt and groundnuts and leave to simmer until the groundnuts are completely submerged.

Cook for another 5 minutes, whilst stirring continuously.

[Source of nutritional composition: Zambian food composition table, version 4. Values may vary between countries]

<b>Snack Option #1</b> <b>- Strawberry "Ice Cream"</b>	<b>Fat (g)</b>	<b>Carbohydrate (g)</b> excluding fibre
8-10 medium (100g) Strawberries (frozen)	0 (0.4)	6 (5.5)
1/2 cup (95g) Double or heavy cream (45-48% fat)	46 (45.6)	3 (2.5)
2 tablespoons (28g) 50% fat emulsion or 1 tablespoon (16g) vegetable oil	16 (16)	0 (0)
<b>Total for 4 servings (batch)</b>	<b>62 (62)</b>	<b>9 (8)</b>
<b>Total for each serving</b>	<b>15.5 (15.5)</b>	<b>2 (2)</b>

Directions:

Add all ingredients to a food processor/blender and whizz to combine.

You may need to scrape down the sides a few times between blasts. Add sweetener to taste.

Serve immediately for it to resemble soft-serve ice cream.

[Source of nutritional composition: New Zealand Food Composition Database (NZFCD). Values may vary between countries]

**Snack Option #2**  
**- Bliss Balls or Fat Bombs**

	<b>Fat (g)</b>	<b>Carbohydrate (g)</b> excluding fibre
1 tablespoon or 10-12 whole (15g) Almonds, roasted salted	8 (7.9)	1 (1.1)
1 teaspoon (7.5g) Sugar free dark chocolate (chopped)	2 (2.4)	2 (2.0)
1 tablespoon (15g) Cream cheese (softened)	6 (5.6)	1 (0.8)
¼ cup (23.5g) Walnuts (4-5 whole walnuts)	15 (15.1)	0 (0)
<b>Total for 2 servings (batch)</b>	<b>31 (31)</b>	<b>4 (3.9)</b>
<b>Total for each serving</b>	<b>15.5 (15.5)</b>	<b>2 (2)</b>

Directions:

Roast almonds and walnuts in the oven until slightly brown, then crush them.

Mix the nuts together with all other ingredients.

Roll the mixture into balls and freeze for 20 mins before eating.

If left frozen for later, take ball(s) out of the freezer 10 mins before serving.

[Source of nutritional composition: New Zealand Food Composition Database (NZFCD). Values may vary between countries]

**Snack Option #3**  
**- Chocolate Mousse**

	<b>Fat (g)</b>	<b>Carbohydrate (g)</b> excluding fibre
½ cup mashed or ½ medium (120g) Avocado	26 (26.4)	1 (0.7)
1 tablespoon (10g) Cocoa powder	2 (2.2)	1 (0.9)
1 pottle or ½ cup (150g) Low-carb yoghurt (1% carb)	2 (2.1)	1 (1.2)
2 tablespoons (50g) Stevia/ Nativia or 14.5g fibre maple syrup	0	1 (1.1)
<b>Total for 2 servings (batch)</b>	<b>30 (30.7)</b>	<b>4 (3.9)</b>
<b>Total for each serving</b>	<b>15 (15.4)</b>	<b>2 (2)</b>

Directions:

Using a food processor, blend avocado, cocoa powder and sweetener until smooth.

Add yoghurt. Blend again until thick and creamy.

Divide mixture into 2 bowls or mugs. Serve immediately.

Suggestion: Use frozen avocado for a thicker consistency.

[Source of nutritional composition: New Zealand Food Composition Database (NZFCD). Values may vary between countries]



**Snack Option #4****– Keto Cheese Bread (Brazilian Pão de queijo)**

	<b>Fat (g)</b>	<b>Carbohydrate (g)</b> excluding fibre
1 cup (100g) Almond flour	50 (49.9)	9 (9)
1 ½ cups (150g) Parmesan cheese, grated	55 (55.1)	7 (7.2)
1 Egg, whole (50g)	5 (4.5)	1 (1.1)
2 tablespoons (30g) Melted butter	22 (22.3)	0 (0.2)
¼ cup (60g) Cream cheese	13 (13.4)	1 (1.2)
½ teaspoon (5g) Baking powder	0 (0)	2 (2.2)
Salt to taste (optional)	0 (0)	0 (0)
Black pepper (optional)	0 (0)	0 (0)
Garlic powder (optional)	0 (0)	0 (0)
<b>Total for 10 servings (batch)</b>	<b>145 (145.2)</b>	<b>20 (20.9)</b>
<b>Total for each serving</b>	<b>15 (14.5)</b>	<b>2 (2.1)</b>

Directions:

Preheat oven to 180°C (350°F).

Grease a baking tray or line with parchment paper.

In a large bowl, combine the almond flour, baking powder, salt, black pepper and garlic powder (if using).

Add the egg, melted butter, cream cheese and grated Parmesan cheese to the dry ingredients. Combine to make a smooth dough.

Grease your hands and shape the dough into small balls, about 25-30 g each (roughly the size of a walnut). Place the balls on the prepared baking tray, leaving some space between them.

Place in the oven and bake for 10-15 minutes, or until the cheese breads are golden brown and firm to the touch.

Leave to cool for a few minutes before serving.

[Source of nutritional composition: Tabela Brasileira de Composição de Alimentos (TBCA). Universidade de São Paulo (USP).

Food Research Center (FoRC). Version 7.2. São Paulo, 2023. Values may vary between countries]

**Table S6:** 5g fat (long-chain triglyceride) choices for Modified ketogenic diets

Item	Weight (g) to provide 5g of fat	Household measurement to provide 5g fat*
Butter	6	1 teaspoon
Oil	5	1 teaspoon
Mayonnaise	7	1.5 teaspoon
Double cream	10	2 teaspoons
Avocado	33	2 tablespoons of mashed, or ¼ a medium avocado

\* Rough approximations

**Table S7:** 1g carbohydrate choices for Modified ketogenic diets

Item	Weight (g) to provide 1g carbohydrate	Household measurement to provide 1g carbohydrate*
Apple, raw	8	One medium slice
Asparagus	30	2-3 medium spears
Blueberries, raw	7	4-5 medium-sized blueberries
Broccoli, raw	31	½ cup of small florets
Cauliflower, raw	23	2-3 small florets
Celeriac, raw	43	⅓ cup of diced celeriac
Courgette, raw	56	½ cup of chopped or sliced courgette
Fennel, raw	50	1 cup of sliced fennel
Garlic, raw	6	2-3 medium garlic cloves
Green leafy vegetables	40-50	1 cup spinach, argula, or 2 cups lettuce
Onion, raw	13	2 tablespoons of finely chopped onion
Peaches, raw	13	1-2 slices
Raspberries, raw	22	8-10 raspberries (medium-sized)
Strawberries, raw	16	3-4 medium
Tomatoes, raw	32	2-3 cherry tomatoes or ¼ of a medium tomato
Tomatoes, tinned	26	2 tablespoons of drained, chopped tinned tomatoes
Tomatoes, puree	8	less than 1 tablespoon

Ref: Matthew's Friends choice lists

\* Rough approximations

**Table S8:** List of ketogenic prescribable products

Product	Company	Description	Indications*
<b>Nutritionally complete</b>			
Ketocal 4:1 powder	Nutricia	Powdered feed enriched with multi-fibre and LCPs available in vanilla and unflavoured varieties. The standard feed concentration is 14.3%	Suitable as a sole source of nutrition, in children aged 1-10 years or as a supplement for those over 10 years and adults.
Ketocal 4:1 LQ	Nutricia	Ready to use fibre enriched liquid feed available in vanilla and unflavoured varieties	Suitable as a sole source of nutrition in children aged 1–10 years or as a supplement for those over 10 years and adults
Ketocal 3:1 powder	Nutricia	Powdered feed, fibre-free, enriched with LCPs, unflavoured. The standard feed concentration is 9.5%	Suitable as a sole source of nutrition in infants from birth to 3 years or as a supplement in those over 3 years (UK version).
Ketocal 2.5:1 LQ	Nutricia	Ready to use multi-fibre enriched liquid feed with 21% of total energy from MCT. Available in vanilla flavour	Suitable as a sole source of nutrition in children aged 8 years to adults or as a supplement
Ketovie 4:1	Cortex Health / Ajinomoto Cambrooke Inc	Ready to use fibre, carnitine and citrate enriched liquid feed with 25% of total energy from MCT. Available in unflavoured, vanilla or chocolate flavour	Suitable as a sole source of nutrition in children from 1 year of age
Ketovie Peptide 4:1	Cortex Health / Ajinomoto Cambrooke Inc	Extensively hydrolyzed whey protein. Ready to use fibre, carnitine and citrate enriched liquid feed with 15% of total energy from MCT	Suitable as a sole source of nutrition in children from 1 year of age
Ketovie 4:1 Plant-Based Protein	Cortex Health / Ajinomoto Cambrooke Inc	Pea protein Ready to use fibre, carnitine and citrate enriched liquid feed with 25% of total energy from MCT	Milk and soy allergies. Suitable as a sole source of nutrition in children from 1 year of age
Ketovie 3:1	Cortex Health / Ajinomoto Cambrooke Inc	Ready to use partially hydrolyzed whey protein with 20% of total energy from MCT. Enriched with prebiotic fibre and carnitine	Suitable as a sole source of nutrition in children from 1 year of age
K.Flo 4:1	Nestle Health Science/VitaFlo	Ready to use fibre-enriched liquid feed available in vanilla	Suitable from 3 years of age onwards
Ketonia	Namyang Dairy Products Co., Ltd.	Ready to use liquid formula for oral or enteral use in infants and young children	Suitable from birth
K.Yo	Nestle Health Science/VitaFlo	Ready to eat semi-solid food	Suitable from 3 years of age onwards. Suitable as a sole source of nutrition up to 10 years of age
Ketobiota 2.5:1	Dr Schaer/Kanso	Powdered, texture can be adapted (e.g. liquid or yogurt) with 73% of total energy from MCT. Enriched with 11 vitamins	Suitable from 3 years of age onwards

Product	Company	Description	Indications*
KetoEpi 2:1	Dr Schaer/Kanso	Ready to use liquid formula with 65% of total energy from MCT, allergen-free	Suitable from 3 years of age onwards Suitable as a sole source of nutrition
KetVit	Dr Schaer/Kanso	Ready to eat creamy food, with 44% MCT. Enriched with minerals, vitamins and fiber Ketogenic ratio 5.7:1	Suitable from 3 years of age
MCTfiber	Dr Schaer/Kanso	Powder, 60% MCT and ketogenic ratio 7.2:1. Added with soluble fiber	Suitable from 3 years of age
DelimCT creams (champignons, tomatoes, classical)	Dr Schaer/Kanso	Ready to use, enriched with MCT (ranging from 85% to 95% of total energy)	Suitable from 3 years of age
MCT Margarine 83%	Dr Schaer/Kanso	Ready to eat, with 83% MCT fat of the total fat content. Enriched with omega-3 + omega-6, vitamins A, D, E, folate, vitamin B12	Suitable from 1 years of age Maximum temperature 180°
DelimCT Cacaobar	Dr Schaer/Kanso	Ready to eat, with 33% of total energy from MCT, enriched in fiber. Ketogenic ratio 5.2:1	Suitable from 3 years of age
KetoClassic 3:1 Bisk	Ketocare foods	3:1 ratio high fat, high fibre food	Suitable from 3 years of age
KetoClassic 3:1 breakfast Porridge	Ketocare foods	3:1 ratio, high fat, high fibre, ready prepared meal	Suitable from 3 years of age
KetoClassic 3:1 breakfast Muesli	Ketocare foods	3:1 ratio, high fat, high fibre, ready prepared meal	Suitable from 3 years of age
KetoClassic 3:1 meal Savoury	Ketocare foods	3:1 ratio, high fat, high fibre solid meal	Suitable from 3 years of age
KetoClassic 3:1 meal Chicken	Ketocare foods	3:1 ratio, high fat, ready prepared meal	Suitable from 3 years of age
KetoClassic 3:1 meal Bolognese	Ketocare foods	3:1 ratio, high fat, ready prepared meal	Suitable from 3 years of age
<b>Carbohydrate free formula</b>			
RCF	Abbott	Liquid feed very low in carbohydrate, soy protein	Milk allergy Suitable from birth
Carb free mix	Nutricia	Powdered feed very low in carbohydrate	Suitable for infants and children
<b>Fat modules</b>			
Liquigen	Nutricia	Ready to use 50% MCT emulsion	Suitable for children and adults
MCT oil	Nutricia	Liquid containing only a mixture of MCT	Suitable for children and adults
MCT oil (77% and 100%)	Dr Schaer/Kanso	Liquid containing only a mixture of MCT	Suitable from birth MCT 100% must be used raw
Calogen	Nutricia	50% LCT fat emulsion	Use with caution in children under 6 years of age
K.Quik	Nestle Health Science/Vitafo	Ready to use 20% emulsion of MCT	Suitable from 3 years of age

Product	Company	Description	Indications*
<b>Protein modules</b>			
Protifar	Nutricia	Powdered milk based high protein supplement	Not suitable for children under 3 years of age
Complete Amino Acid Mix	Nutricia	Powdered mix of essential and non-essential amino acids	Suitable from birth
Beneprotein	Nestle Health Science	Powdered milk based high protein supplement	Suitable from birth
MCT Procal	Nestle Health Science/Vitafo	Neutral tasting protein powder supplement high in MCT	Suitable from 3 years of age
ProSource TF	Nutrinovo	Liquid high protein milk-free (beef collagen derivative) supplement for tube feeding	Suitable from 3 years of age
<b>Carbohydrate modules</b>			
Polycal/Polyjoule	Nutricia	Powdered unflavoured carbohydrate supplement	Suitable from 1 year of age
Super Soluble Maxijul	Nutricia	Powdered neutral flavoured carbohydrate energy source	Suitable from birth
Vitajoule	Nestle Health Science/Vitafo	Powdered unflavoured carbohydrate supplement	Suitable from birth
<b>Other</b>			
Keto Peptide	Functional Formularies	Whole foods-based formula (2.43:1 ratio). Includes peptide proteins	No specific indications given

LCP, long chain polyunsaturated fatty acids; MCT, medium chain triglycerides; LCT, long chain triglycerides

\* Indications may vary between countries

**Table S9:** Example initiation schedule for a modified ketogenic diet

**Patient details:** 9 year old child, 'Jamie.'

**MKD prescription:**

- **104g/day FAT (31g/meal and 15.5g/snack)**
- **15g/day CARBOHYDRATE (3g/meal and 2g/snack)**
- 3 meals and 3-4 snacks per day

**Option 1: advance by macronutrient prescription**

Full calories, no fasting period

Week 1 Start with 40% energy from fat and 50g carb/day [starting amounts can be agreed with the individual/family]

**Fat:**  $40\% \times 1339 \text{ kcal} = 535.6 \text{ kcal} \div 9\text{kcal} = \mathbf{59.5 \text{ g fat per day}}$   
(6.5g/snack and 13g/meal)

**Carbohydrate:** 50g/day (6-7g/snack and 10g/meal)

Protein food/portions remain as before (or age-appropriate portions)

Week 2 50% energy from fat and 30g carb/day

**Fat:**  $50\% \times 1339 \text{ kcal} = 669.5 \text{ kcal} \div 9\text{kcal} = \mathbf{74.4\text{g fat per day}}$   
(8g/snack and 16.5g/meal)

**Carbohydrate:** 30g/day (2g/snack and 8g/meal)

Protein food/portions remain as before (or age-appropriate portions)

Week 3 60% energy from fat and 20g carb/day

**Fat:**  $60\% \times 1339 \text{ kcal} = 803.4 \text{ kcal} \div 9\text{kcal} = \mathbf{89.3\text{g fat per day}}$   
(10g/snack and 20g/meal)

**Carbohydrate:** 20g/day (1-2g/snack and 5g/meal)

Protein food/portions remain as before (or age-appropriate portions)

Week 4 70% energy from fat and 10g carb/day

**Fat:**  $70\% \times 1339 \text{ kcal} = 937.3 \text{ kcal} \div 9\text{kcal} = \mathbf{104\text{g fat per day}}$   
(15.5g/snack and 31g/meal)

**Carbohydrate:** 10g/day (1g/snack and 2g/meal)

Protein food/portions remain as before (or age-appropriate portions)

**Patient details:** 9 year old child, 'Jamie.'

**MKD prescription:**

- 104g/day FAT (31g/meal and 15.5g/snack)
- 15g/day CARBOHYDRATE (3g/meal and 2g/snack)
- 3 meals and 3-4 snacks per day

**Option 2: add in one ketogenic meal at a time**

Week 1: MKD Lunch	Breakfast: as usual Morning snack: as usual <b>Lunch: MKD (31g Fat (6 choices), 3g Carb (3 choices))</b> Afternoon Snack: as usual Dinner: as usual Bedtime snack: as usual
Week 2: MKD Breakfast + lunch	<b>Breakfast: MKD (31g Fat (6 choices), 3g Carb (3 choices))</b> Morning snack: as usual <b>Lunch: MKD (31g Fat (6 choices), 3g Carb (3 choices))</b> Afternoon Snack: as usual Dinner: as usual Bedtime snack: as usual
Week 3: MKD Breakfast + lunch + dinner	<b>Breakfast: MKD (31g Fat (6 choices), 3g Carb (3 choices))</b> Morning snack: as usual <b>Lunch: MKD (31g Fat (6 choices), 3g Carb (3 choices))</b> Afternoon Snack: as usual <b>Dinner: MKD (31g Fat (6 choices), 3g Carb (3 choices))</b> Bedtime snack: as usual
Week 4: MKD for all meals and snacks	<b>Breakfast: MKD (31g Fat (6 choices), 3g Carb (3 choices))</b> <b>Morning snack: MKD (15.5g Fat (3 choices), 2g Carb (2 choice))</b> <b>Lunch: MKD (31g Fat (6 choices), 2g Carb (2 choices))</b> <b>Afternoon Snack: MKD (15.5g Fat (3 choices), 2g Carb (2 choice))</b> <b>Dinner: MKD (31g Fat (6 choices), 3g Carb (3 choices))</b> <b>Supper: MKD (15.5g Fat (3 choices), 2g Carb (2 choice))</b>



**Table S10:** Advantages and disadvantages of the use of telemedicine for ketogenic diet therapy

Advantages	Disadvantages
Reduces travel time, so particularly beneficial for patients/families who have to travel long distances, potentially with nursing needs such as suction difficulties or mechanical ventilation, and/or behavioral disorders or mobility issues <sup>1</sup> Environmental benefit of reducing travel <sup>2</sup>	May not be appropriate for young infants, clinically unstable patients, those at high risk of hypoglycemia or metabolic issues, families without access to technology, and those unable to access emergency medical care if necessary <sup>3</sup>
Can reduce waiting lists <sup>1</sup>	Inconsistency with anthropometric measurements and difficulties in getting clinical information/results (labs and other routine assessments) <sup>1,3</sup>
May reduce patient / family stress <sup>2</sup>	Detailed discussions may seem less personal when done by video call - particularly pertinent when discussing diet discontinuation, or lack of response to treatment <sup>1,3</sup>
Multiple family members and caregivers may be able to join the education sessions <sup>3</sup>	Technological aspects, such as difficulties with connecting online, can be a limiting factor <sup>1</sup>
Allows the team to see the patient in their own house (potentially including the kitchen) <sup>2</sup>	
Electronic communication may be appealing for adolescents <sup>4</sup>	

**References:**

- <sup>1</sup> Armeno M, Caballero E, Verini A, *et al.* Telemedicine- versus outpatient-based initiation and management of ketogenic diet therapy in children with drug-resistant epilepsy during the COVID-19 pandemic. *Seizure*. 2022, **98** 37-43.
- <sup>2</sup> Bara VB, Schoeler N, Carroll JH, *et al.* Patient and carer perspectives on the use of video consultations in the management of the ketogenic diet for epilepsy. *Epilepsy Behav*. 2023, **145** 109280.
- <sup>3</sup> Kossoff EH, Turner Z, Adams J, *et al.* Ketogenic diet therapy provision in the COVID-19 pandemic: Dual-center experience and recommendations. *Epilepsy Behav*. 2020, **111** 107181.
- <sup>4</sup> Cervenka MC, Henry BJ, Felton EA, *et al.* Establishing an Adult Epilepsy Diet Center: Experience, efficacy and challenges. *Epilepsy Behav*. 2016, **58** 61-8.

**Table S11:** Worked examples of how to discontinue a modified ketogenic diet

## SCENARIO 1

'Jamie' has been on diet for approximately 3 months and is discontinuing due to no effect on seizures.

MKD prescription:

**104g/day FAT (31g/meal and 15.5g/snack)**

**10g/day CARBOHYDRATE (3g/meal and 2g/snack)**

3 meals and 3 snacks per day

## ONE WEEK DISCONTINUATION PROTOCOL

Option 1: advance by macronutrient prescription	
Day 1	<p><b>65% fat and 30g carbohydrate</b></p> <p><b>Fat:</b> <math>65\% \times 1339 \text{ kcal} = 870.4 \text{ kcal} \div 9\text{kcal} = 96.7\text{g fat per day (23g/meal and 9g/snack)}</math>  <b>Carbohydrate:</b> <b>30 g/day (7g/meal and 3g/snack)</b></p> <p>Protein food/portions remain as before (or age-appropriate portions)</p>
Day 2	<p><b>60% fat and 40g carbohydrate</b></p> <p><b>Fat:</b> <math>60\% \times 1339 \text{ kcal} = 803.4 \text{ kcal} \div 9\text{kcal} = 89.3\text{g fat per day (22g/meal and 7g/snack)}</math>  <b>Carbohydrate:</b> <b>40 g/day (9g/meal and 4g/snack)</b></p> <p>Protein food/portions remain as before (or age-appropriate portions)</p>
Day 3	<p><b>55% fat and 50 g carbohydrate</b></p> <p><b>Fat:</b> <math>55\% \times 1339 \text{ kcal} = 736.5 \text{ kcal} \div 9\text{kcal} = 81.8\text{g fat per day (22g/meal and 5g/snack)}</math>  <b>Carbohydrate:</b> <b>50 g/day (13g/meal and 7g/snack)</b></p> <p>Protein food/portions remain as before (or age-appropriate portions)</p>
Day 4	<p><b>50% fat and 60g carbohydrate</b></p> <p><b>Fat:</b> <math>50\% \times 1339 \text{ kcal} = 669.5 \text{ kcal} \div 9\text{kcal} = 74.4\text{g fat per day (20g/meal and 4g/snack)}</math>  <b>Carbohydrate:</b> <b>60 g/day (13g/meal and 7g/snack)</b></p> <p>Protein food/portions remain as before (or age-appropriate portions)</p>
Day 5	<p><b>45% fat and 80 g carbohydrate</b></p> <p><math>45\% \times 1339 \text{ kcal} = 602.6 \text{ kcal} \div 9\text{kcal} = 67\text{g fat per day (19g/meal and 3g/snack)}</math>  <b>Carbohydrate:</b> <b>80 g/day (18g/meal and 9g/snack)</b></p> <p>Protein food/portions remain as before (or age-appropriate portions)</p>
Day 6	<p><b>5% fat and 100g carbohydrate</b></p> <p><math>45\% \times 1339 \text{ kcal} = 602.6 \text{ kcal} \div 9\text{kcal} = 67\text{g fat per day (19g/meal and 3g/snack)}</math>  <b>Carbohydrate:</b> <b>100 g/day (22g/meal and 11g/snack)</b></p> <p>Protein food/portions remain as before (or age-appropriate portions)</p>
Day 7	<p><b>Usual diet</b></p>

## SCENARIO 1

'Jamie' has been on diet for approximately 3 months and is discontinuing due to no effect on seizures.

MKD prescription:

**104g/day FAT (31g/meal and 15.5g/snack)**

**10g/day CARBOHYDRATE (3g/meal and 2g/snack)**

3 meals and 3 snacks per day

### ONE WEEK DISCONTINUATION PROTOCOL

Option 2: wean off one MKD meal at a time	
Day 1	Breakfast: MKD Morning snack: MKD <b>Lunch: no restrictions / usual (pre-MKD) meal</b> Afternoon snack: MKD Dinner: MKD Bedtime snack: MKD
Day 2	Breakfast: MKD Morning snack: MKD <b>Lunch: no restrictions / usual (pre-MKD) meal</b> Afternoon snack: MKD Dinner: MKD <b>Bedtime snack: no restrictions / usual (pre-MKD) meal</b>
Day 3	<b>Breakfast: no restrictions / usual (pre-MKD) meal</b> Morning snack: MKD <b>Lunch: no restrictions / usual (pre-MKD) meal</b> Afternoon snack: MKD Dinner: MKD <b>Bedtime snack: no restrictions / usual (pre-MKD) meal</b>
Day 4	<b>Breakfast: no restrictions / usual (pre-MKD) meal</b> Morning snack: MKD <b>Lunch: no restrictions / usual (pre-MKD) meal</b> Afternoon snack: MKD <b>Dinner: no restrictions / usual (pre-MKD) meal</b> <b>Bedtime snack: no restrictions / usual (pre-MKD) meal</b>
Day 5	<b>Breakfast: no restrictions / usual (pre-MKD) meal</b> <b>Morning snack: no restrictions / usual (pre-MKD) snack</b> <b>Lunch: no restrictions / usual (pre-MKD) meal</b> Afternoon Snack: MKD <b>Dinner: no restrictions / usual (pre-MKD) meal</b> <b>Bedtime snack: no restrictions / usual (pre-MKD) meal</b>
Days 6-7	<b>All meals / snacks – no restrictions / usual (pre-MKD) diet</b>

## SCENARIO 2

'Jamie' has been on diet, with good response, for more than 2 years.  
He is discontinuing the diet as he has been on it for over 2 years.

MKD prescription:

**104g/day FAT (31g/meal and 15.5g/snack)**

**15g/day CARBOHYDRATE (3g/meal and 2g/snack)**

3 meals and 3 snacks per day

### FOUR WEEK DISCONTINUATION PROTOCOL

#### Option 1: advance by macronutrient prescription\*

Week 1	<b>65% fat and 20g carbohydrate</b>  Fat: $65\% \times 1339 \text{ kcal} = 870.4 \text{ kcal} \div 9\text{kcal} = 96.7\text{g fat per day (23g/meal and 9g/snack)}$ Carbohydrate: <b>20 g/day (4g/meal and 2g/snack)</b>  Protein food/portions remain as before (or age-appropriate portions)
Week 2	<b>55% fat and 25g carbohydrate</b>  Fat: $55\% \times 1339 \text{ kcal} = 736.5 \text{ kcal} \div 9\text{kcal} = 81.8\text{g fat per day (22g/meal and 5g/snack)}$ Carbohydrate: <b>25 g/day (3g/meal and 5g/snack)</b>  Protein food/portions remain as before (or age-appropriate portions)
Week 3	<b>45% fat and 30g carbohydrate</b>  $45\% \times 1339 \text{ kcal} = 602.6 \text{ kcal} \div 9\text{kcal} = 67\text{g fat per day (19g/meal and 3g/snack)}$ Carbohydrate: <b>30 g/day (7g/meal and 3g/snack)</b>  Protein food/portions remain as before (or age-appropriate portions)
Week 4	<b>35% fat and 40g of carbohydrate</b>  $35\% \times 1339 \text{ kcal} = 602.6 \text{ kcal} \div 9\text{kcal} = 52\text{g fat per day (14g/meal and 3g/snack)}$ Carbohydrate: <b>40 g/day (9g/meal and 4g/snack)</b>  Protein food/portions remain as before (or age-appropriate portions)
Week 5	<b>35% fat and 50g of carbohydrate</b>  $35\% \times 1339 \text{ kcal} = 602.6 \text{ kcal} \div 9\text{kcal} = 52\text{g fat per day (14g/meal and 3g/snack)}$ Carbohydrate: <b>50 g/day (11g/meal and 5.5g/snack)</b>  Protein food/portions remain as before (or age-appropriate portions)
Week 6	<b>35% fat and 60g of carbohydrate</b>  $35\% \times 1339 \text{ kcal} = 602.6 \text{ kcal} \div 9\text{kcal} = 52\text{g fat per day (14g/meal and 3g/snack)}$ Carbohydrate: <b>60 g/day (13g/meal and 7g/snack)</b>  Protein food/portions remain as before (or age-appropriate portions)

\* This discontinuation protocol is based on the re-introduction of 20 g carbohydrates per week and 10% decrease in fat per week.  
This is an example only – the amount of carbohydrate and fat that is changed per unit of time is to be decided by the dietitian and will partly depend on the initial MKD prescription

## SCENARIO 2

'Jamie' has been on diet, with good response, for more than 2 years.  
He is discontinuing the diet as he has been on it for over 2 years.

MKD prescription:

**104g/day FAT (31g/meal and 15.5g/snack)**

**15g/day CARBOHYDRATE (3g/meal and 2g/snack)**

3 meals and 3 snacks per day

### FOUR WEEK DISCONTINUATION PROTOCOL

Week 7	<b>35% fat and 70g of carbohydrate</b>  $35\% \times 1339 \text{ kcal} = 602.6 \text{ kcal} \div 9\text{kcal} = \textbf{52g fat per day (14g/meal and 3g/snack)}$ <b>Carbohydrate: 70 g/day (15.5g/meal and 8g/snack)</b>  Protein food/portions remain as before (or age-appropriate portions)
Week 8	<b>35% fat and 80g of carbohydrate</b>  $35\% \times 1339 \text{ kcal} = 602.6 \text{ kcal} \div 9\text{kcal} = \textbf{52g fat per day (14g/meal and 3g/snack)}$ <b>Carbohydrate: 80 g/day (18g/meal and 9g/snack)</b>  Protein food/portions remain as before (or age-appropriate portions)
Week 9	<b>Usual diet</b>

### Option 2: wean off one MKD meal at a time

Week 1	Breakfast: MKD Morning snack: MKD <b>Lunch: no restrictions / usual (pre-MKD) meal</b> Afternoon snack: MKD Dinner: MKD Bedtime snack: MKD
Week 2	Breakfast: MKD Morning snack: MKD <b>Lunch: no restrictions / usual (pre-MKD) meal</b> Afternoon snack: MKD Dinner: MKD <b>Bedtime snack: no restrictions / usual (pre-MKD) meal</b>
Week 3	<b>Breakfast: no restrictions / usual (pre-MKD) meal</b> Morning snack: MKD <b>Lunch: no restrictions / usual (pre-MKD) meal</b> Afternoon snack: MKD Dinner: MKD <b>Bedtime snack: no restrictions / usual (pre-MKD) meal</b>
Week 4	<b>Breakfast: no restrictions / usual (pre-MKD) meal</b> Morning snack: MKD <b>Lunch: no restrictions / usual (pre-MKD) meal</b> Afternoon snack: MKD <b>Dinner: no restrictions / usual (pre-MKD) meal</b> <b>Bedtime snack: no restrictions / usual (pre-MKD) meal</b>
Week 5	<b>All meals / snacks – no restrictions / usual (pre-MKD) diet</b>

## Example modified ketogenic diet recipes using KetoCal provided by Nutricia

### Cinnamon and blueberry breakfast cereal

Recipe serves: 5

	Fat (g)	Carbohydrate (g) excluding fibre
30 g KetoCal 3:1 Powder	20.58	2.16
2 g butter, salted	1.64	0.01
25 g almonds, flaked and ground	13.95	1.73
37 g blueberries	0.07	3.37
2 g cinnamon, ground	0.02	–
10 g water	–	–
<b>Total entire recipe</b>	<b>23.06</b>	<b>3.38</b>

Directions:

Preheat oven to 170°C/gas mark 3.

In a bowl, mix all ingredients (except water) together until a crumbly texture.

Add water and mix into a ball.

Gently roll small amounts of mixture with fingers into balls.

Place on oven tray and bake for 8-10 mins.

Divide baked balls into 5 separate portions.

Store in an airtight container.

### Cheese and tomato pizza

Recipe serves: 1

	Fat (g)	Carbohydrate (g) excluding fibre
15 g KetoCal 3:1 Powder	10.29	1.08
4 g olive oil	3.64	–
28 g chopped mushrooms	0.06	0.08
12 g chopped green pepper	0.04	0.31
5 g spring onion, white part only	–	0.42
1 g tomato puree	–	0.13
1 g garlic puree	0.34	0.17
33 g canned chopped tomatoes	0.03	1.25
1 g curry powder	0.11	0.26
20 g spinach leaves	0.12	0.04
5 g water	–	–
<b>Total entire recipe</b>	<b>14.63</b>	<b>3.74</b>

Directions:

Preheat oven to 170°C/gas mark 3.

Mix KetoCal 3:1 Powder with olive oil, egg and water in a bowl.

Spread mixture onto a lightly greased baking sheet in a 6" circle.

Mash tomato with tomato puree and garlic puree.

Spread mixture on top of pizza base.

Sprinkle on the cheese and add a pinch of herbs.

Cook for 15 mins or until golden.

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**PLEASE NOTE:** Nutritional analysis is based on recipes from MyKetoPlanner. Please check individual food labels for exact composition.

## Mushroom and spinach curry

Recipe serves: 1

	Fat (g)	Carbohydrate (g) excluding fibre
15 g KetoCal 3:1 Powder	10.29	1.08
4 g olive oil	3.64	–
28 g chopped mushrooms	0.06	0.08
12 g chopped green pepper	0.04	0.31
5 g spring onion, white part only	–	0.42
1 g tomato puree	–	0.13
1 g garlic puree	0.34	0.17
33 g canned chopped tomatoes	0.03	1.25
1 g curry powder	0.11	0.26
20 g spinach leaves	0.12	0.04
5 g water	–	–
<b>Total entire recipe</b>	<b>14.63</b>	<b>3.74</b>

Directions:

Heat oil in a pan

Add mushrooms, pepper, spring onion, tomato puree, garlic puree and cook on a medium heat for 5 mins.

Add chopped tomatoes, curry powder and spinach, cook a further 5 mins on low heat.

Mix the KetoCal 3:1 Powder with water to form a paste, then add to the curry sauce and serve.

## Spiced nuts

	Fat (g)	Carbohydrate (g) excluding fibre
10 g KetoCal 4:1 Powder (unflavoured)	6.92	0.29
100 g nuts, mixed	49.1	11.6
10 g egg	0.9	–
25 g olive oil	22.75	–
Pinch of salt, pepper, smoked paprika and ground cumin		
<b>Total entire recipe</b>	<b>79.67</b>	<b>11.89</b>

Directions:

Add the nuts to a bowl pour over the egg white and olive oil and stir to coat.

Line a baking sheet with the baking paper and pour on the nuts making sure you spread so it's one even layer.

Put the KetoCal 4:1 Powder in a small bowl and add in a pinch of salt, pepper, smoked paprika, and ground cumin.

Sprinkle this mixture over the nuts.

Bake at 170°C for 10 minutes, remove from the oven and turn the nuts around with a spoon or fish slice, bake for another 10 minutes.

Allow to cool on the tray, once completely cooled store in a jar or air-tight container.

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## Bagels

Recipe serves: 2

	Fat (g)	Carbohydrate (g) excluding fibre
10 g KetoCal 4:1 Powder (unflavoured)	6.92	0.29
70 g almonds. flaked and ground	39.06	4.83
40 g Alpro Greek style plain yogurt	13.2	1.04
10 g carbohydrate free baking powder	–	–
pinch of salt and pepper	–	–
sea-salt. nigella seeds. mixed seeds. chopped nuts. sesame seeds to decorate as desired	1.74	0.03
<b>Total entire recipe</b>	<b>60.92</b>	<b>6.19</b>

Directions:

In bowl whisk the almond flour, KetoCal 4:1 Powder, baking powder, and salt to combine.

Add the yogurt and mix until you have a soft smooth dough.

Divide into 2 and roll in-between your hands place onto a lined baking sheet press down to slightly flatten, to make the hole use the handle of a wooden spoon or finger press into the middle of the bagel make the hole about 1/2, brush with water and sprinkle with (sea-salt, nigella seeds, mixed seeds, chopped nuts, sesame seeds).

Bake at 170°C for 12/15 minutes until golden brown, allow to cool on the tray.

Store in an airtight container until needed.

Great toasted for breakfast or fill or a lunch box on the go, wrap and freeze (good idea to cut them in half before freezing so can add them straight to a toaster for a quick breakfast or snack).

## Pancakes

Recipe serves: 3

	Fat (g)	Carbohydrate (g) excluding fibre
26 g KetoCal 3:1 Powder	17.84	1.87
2 g butter. salted	1.64	–
26 g egg	2.34	–
4 g water	–	–
9 g milk. skimmed	0.03	0.43
15 g raspberries	0.04	0.69
1 g oil spray	0.54	–
<b>Total entire recipe</b>	<b>22.43</b>	<b>2.99</b>

Directions:

Melt butter, stir in egg and milk then mix well.

Mix KetoCal 3:1 Powder and water into the mixture.

Add spray oil to a frying pan and warm on medium heat.

Cook until golden brown.

Serve with raspberries.

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### Strawberry ice cream

Recipe serves: 5

	Fat (g)	Carbohydrate (g) excluding fibre
40 g KetoCal 3:1 Powder	27.44	2.88
75 g strawberries	0.38	4.58
300 g water	–	–
10 g single cream	1.91	0.22
0 g vanilla extract. carbohydrate free	–	–
0 g liquid sweetener	–	–
<b>Total entire recipe</b>	<b>29.73</b>	<b>7.68</b>

Directions:

Chop strawberries into small pieces.

Mix together KetoCal 3:1 Powder, strawberries, water, cream, 4 drops of vanilla extract and a squirt of sweetener in a freezer proof bowl.

Place in a freezer for 20 mins.

Remove, then stir mixture until smooth.

Repeat process twice more, then leave until frozen.

Divide into 5 equal servings.

### Cheese and mushroom scrambled eggs

Recipe serves: 1

	Fat (g)	Carbohydrate (g) excluding fibre
11 g KetoCal 4:1 Powder (unflavoured)	17.84	1.87
26 g egg white	–	–
15 g egg yolk	4.7	–
3 g olive oil	2.73	–
10 g water. distilled	–	–
2 g Parmesan cheese	0.59	0.02
4 g white mushrooms	0.01	0.01
<b>Total entire recipe</b>	<b>25.87</b>	<b>1.9</b>

Directions:

Add olive oil to a frying pan and heat gently.

Beat the remaining ingredients together.

Add the mixture to the pan and whisk gently until the mixture is cooked through and a scrambled consistency is achieved.

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