

Information for General Practice - Ketogenic Diet therapy (KDT)

KDT is used to help manage drug-resistant epilepsy. It is a medically supervised high fat diet, which is low in carbohydrate and contains enough protein for normal growth.

When is it used?

KDT is usually used when current drug therapies are not providing sufficient relief of seizures. It is considered a non-pharmacological treatment by [NICE NG217](#) and should be considered if epilepsy is drug resistant or other treatment are unsuccessful.

How successful is it?

After trying two or three different anti-epileptic medications, trialling KDT is more likely to give better seizure control than starting a new medication. Fifty to sixty percent of people will see a good reduction in the number of seizures they have, with ten percent becoming seizure free.

How is it managed?

KDT should only be managed under the guidance of a tertiary epilepsy service. Once established on the diet, patients will have a review of the diet's efficacy at 3 months with the specialist MDT. If measurable outcomes are achieved and the therapy is well tolerated, the ketogenic diet will continue for up to two years. All children will be supported to wean off the diet safely, and in some situations, may return to the therapy if their seizure control deteriorates (<20% return to KDT after the initial 2-year therapy).

Who is responsible for which aspects of care?

| Primary care responsibilities | KDT team responsibilities | Family/patient responsibilities |
|--|---|--|
| <ul style="list-style-type: none"> Standard Primary care provision Issuing of monthly Ketogenic product prescriptions. Issuing of monthly Ketone and glucose monitoring consumables Liaison with KDT team in cases of concern Issuing of appropriate low carbohydrate medication as required; liaison with KDT team where required. | <ul style="list-style-type: none"> KDT education provision for families Clear ongoing communication with primary and secondary care providers Provision of Blood glucose and ketosis monitoring meter Provision of initial prescription of dietary products and ketone monitoring consumables Supervision of patient ketone/ glucose monitoring Oversight of diet effectiveness and seizure management: <ul style="list-style-type: none"> Weekly review for 6 weeks Nurse and dietitian review at 6 weeks Consultant led MDT review of diet efficacy at 3 months. Ongoing monitoring and support for diet duration (typically 2 years), including micronutrients, lipids, growth, and seizure activity. | <ul style="list-style-type: none"> Following the KDT diet as recommended Twice daily monitoring of Ketones Glucose monitoring as required. Hyperketosis treatment Hypoglycaemia treatment Liaison with KDT team for concerns |

KDT is a regional tertiary service. Occasionally, where it has not been possible or appropriate to obtain blood samples during a KDT appointment, the team may reach out to the local secondary care providers for blood results/ monitoring to prevent excessive patient travel. The KDT team will then interpret any blood results and request treatment amendment as required.

What products are required to support KDT?

There are multiple types of ketogenic diets;

Classical diet, Medium chain triglyceride (MCT) diet and Modified ketogenic diet

All these Diets are very unnatural, and every meal must be made following a detailed food regimen. Every food item in the meal needs to be measured accurately, often using electronic scales. Every meal and snack of every day needs to follow the prescription. If extra foods, particularly those containing carbohydrate are eaten, then this can cause a sudden drop in blood ketone levels. This may result in sudden increase in seizures.

The most appropriate diet will be chosen by the patient's dietitian working with the family, and prescribed products will be required to support achievement of adequate ketone levels irrespective of the diet chosen.

Multiple different product types are likely to be required to support the diet:

| Product Type | Details |
|------------------------------------|--|
| Complete feeds | Can be used as meal replacements, tube feeds or to supplement the diet. The most appropriate feed will be selected dependent on the patient's age, nutrient requirement and tolerance. A mix of different complete feeds may be required to meet requirements and be acceptable. |
| Supplementary items for tube feeds | Required in some instances to achieve the minimum quantity of carbohydrates for brain function in tube fed patients or to treat hypoglycaemia. |
| Ready meals and food mixes | Additional Items prescribed to improve diet tolerance and practical implementation. Multiple items may be prescribed to provide flexibility to the family. |
| MCT oils and products | Various types of oils are available, Families are given samples to ascertain which are the most suitable for their style of cooking |
| Vitamins and Minerals | For patients who are relying less on complete feed prescriptions vitamin and mineral supplementation may be required |
| Ketone and glucose monitoring | Required monthly issue of ketone testing strips (urine or blood) on request issue of blood glucose testing strips Lancets x 200 6 monthly |

Prescription management:

Many Ketogenic Diet items are difficult to source and therefore for continuity of supply patients are registered by the KDT dietitians with the relevant home care companies:

For Ketovie products: Dial a Chemist

For Vitaflo products (including K.Flo, K.Vita, k.Yo, MCT Procal and K.Quik) : Vitaflo To you

For Nutricia Products (Including MCT oil, Liquigen and Keotcal products) : Nutricia Homeward OR Local home enteral feeding provider (Fresenius Kabi/ Abbott)

Other products such as Ketoclassic meals and Kanso bars are not available through direct to patient deliveries and therefore should be requested through local pharmacies.

It is important to ensure that **these prescriptions are sent to the correct pharmacy** as they will deliver items directly to the patient, along with all the consumables required for safe and effective tube feeding where required. Consider using nominated pharmacies where possible to avoid confusion of prescriptions.

The KDT team will indicate the relevant distance pharmacies on the patient letter.

| Supplier name | Pharmacy name | ODS code | Postcode |
|--------------------------|--------------------|----------|----------|
| Nutricia (Homeward) | D&M Gompels | FL377 | ZE1 0AA |
| Fresenius Kabi | Calea UK Limited | FVG64 | ZE1 0AA |
| Abbott (Hospital2Home) | H2H Pharmacy Ltd | FWN00 | ZE1 0AA |
| Ketovie (cambrooke) | DialaChemist | FAT95 | BB5 5JB |
| Vitaflo (Vitaflo To you) | Brunswick Pharmacy | FG783 | L3 4BQ |

Low Carbohydrate Medicine information:

A patient information leaflet is available with more information on [low carbohydrate medications](#) . Patients and families receive training on how to read labels and recognise appropriate ingredients. Medications may need to be changed to an appropriate form prior to starting the diet, this will be reviewed by the KDT team and information provided to the primary care team.

Where a new medication is required to be started in primary care, the family and prescriber together, should review the ingredients to ensure it is appropriate for the ketogenic diet. Where there is concern or a sugar containing medicine is required, please contact the KDT team for support.

Medicinal formulations:

- Tablets - Suitable
- Granules - Suitable
- Capsules - Suitable
- Powdered drugs - Sometimes suitable
- Sugar-free oral solutions / suspensions - Sometimes suitable
- Sugary syrups - Unsuitable (avoid)

Developed for use in Norfolk and Waveney by Cambridge University Hospital. Approved by TAG March 2024, Review March 2026

Constipation is a common side effect of the diet, and local review is appropriate to assess and manage this by primary care clinicians. Appropriate carbohydrate free laxative options include Cosmocol Paediatric 6.9g powder for oral solution or paediatric Movicol 13.8g sachet powder for oral solution(unflavoured). Optifibre is not recommended for the treatment of constipation but may be used as maintenance therapy if further inclusion of fibre is not possible through diet. if initiated by the KDT specialist team in line with [NICE guidance CG99](#).

Ketone and Glucose monitoring

Patients and carers are taught to monitor blood glucose and ketones and should check them daily a detailed leaflet is available ; [Ketogenic dietary therapy \(KDT\) monitoring | CUH](#)

Aim is for ketosis to achieve urinary ketones above 40mg/dl or blood levels of 2.6 mmol/L Hypoglycaemia should be treated with 5 g of carbohydrate at readings below 2.6g mmol/L.

Hypoglycaemic treatment is 5 g of Carbohydrate: For orally fed patients 50ml of fruit juice is recommended. For tube fed patients 1 scoop of Maxijul may be used.

The service has previously used the Abbott Optium Neo to monitor Blood glucose and Ketones for this cohort of patients, however in line with the [National Commissioning recommendations for blood glucose and ketone meters](#), they are aligning meter choice in line with both local and national recommendations (see **Products used to monitor ketosis / blood glucose control section below**).

KDT contact information

Dietitians [01223 216 655](#): queries about the diet, ketones, low blood sugars or high ketones, change of feed regime, or home delivery company.

Neurology nurses [01223 216 662](#): queries about increases in seizures, change in medications and other concerns.

In an emergency, contact the paediatric neurology on-call registrar.

During working hours, call the Child Development Centre [01223 586618](#).

Out of hours or at the weekend, call Addenbrooke's Hospital on [01223 245151](#) and ask for the on-call paediatric neurology registrar.

Nutritionally complete feeds (suitable for tube feeding or oral consumption, quantities will be individualised to the patient's needs)

| Indication for use | Description | Per 100kcal cost | Annual cost estimate (1000kcal/day regimen) | Additional considerations |
|---------------------|---|------------------|---|---|
| K.Yo | Nutritionally complete (3:1 ratio) 3kcal/g semi solid texture feed (3-10 years) | £1.92 | £6514.6 | To be prescribed in multiples of 36x100g presentation, not 4x100g for better value |
| Ketocal 4:1 LQ | Nutritionally complete 1.5kcal/ml liquid feed | £2.06 | £7519 | |
| Ketocal 4:1 powder | Nutritionally complete 1.kcal/ml Powder feed (110 years) | £1.99 | £7270 | |
| Ketocal 2.5:1 LQ | Nutritionally complete 1.5kcal/ml liquid feed (Suitable > 8years) | £2.06 | £7519 | |
| Ketocal 3:1 Powder | Nutritionally complete 0.66kcal/ml powdered feed (suitable from birth to 6 years) | £1.98 | £7214 | |
| Ketovie 4:1 | Nutritionally complete, 1.5kcal/ml liquid feed containing MCT (Suitable from 3 years) | £1.89 | £6881.5 | CHO very low, may require additional Maxijul Rx to achieve minimum CHO intake of 5g/d |
| Ketovie 4:1 Peptide | Nutritionally complete 1.5kcal/ml hydrolysed protein feed (Suitable from 3 years) | £1.69 | £6156.4 | CHO very low, may require additional Maxijul Rx to achieve minimum CHO intake of 5g/d |
| K.Flo | Nutritionally complete 1.5kcal/ml feed (4:1 ratio - Suitable from 3 years) | £1.83 | £6679.5 | CHO very low, may require additional Maxijul Rx to achieve minimum CHO intake of 5g/d |

Supplementary items

For patients who are tube fed additional products may be required to achieve the minimum quantity of carbohydrates:

| Product | | | | Presentation | <u>Cost per presentation</u> | Description | Monthly prescription quantity |
|-----------------------|------|-------|---|--------------|------------------------------|--|-------------------------------|
| Maxijul Super soluble | 200g | £3.69 | Carbohydrate fortifier, for supplementation of tube feeding. May be used to manage hypo glycaemia in tube fed patients. | | | 1x 200g / month | |
| Resource Optifibre | | | | 250g | 13.73 | Low carbohydrate Fibre supplement for maintenance therapy in constipation management when greater fibre intake is not possible in the diet | 1x250g/month |

MCT diet products:

Families and patients are offered trials of the 4 MCT products, a mixture of different products may be used to achieve an adequate intake of MCT as these are mixed into foods and certain forms are more appropriate than others depending on the family's cooking styles.

| Product | Presentation | <u>Cost per presentation</u> | Description | <u>Volume of product and cost to achieve 10g MCT</u> |
|------------|--------------|------------------------------|--|--|
| MCT Procal | 30 x 16g | £31.98 | Neutral tasting food fortifier and MCT supplement powder | 16g = £1.066 |
| K.Quik | 15 x 225ml | £64.35 | Ready to use liquid emulsion of MCT (20%) | 50ml= £1.07 |
| Liquigen | 250ml bottle | £13.21 | 50% MCT emulsion | 20mls= £1.06 |
| MCT oil | 500ml | £20.94 | MCT liquid | 10mls= £0.42 |

K.Vita is a novel product, which can be used a single product to support Ketogenic diet therapy. This is useful where patients have had positive responses to the ketogenic diet but have not been able to tolerate it long term, or where there are social concerns for compliance. environment.

| | | | | |
|--------|-------------|---------|--|-------------|
| K.Vita | 30 x 120mls | £474.60 | An alternative dietary management option for drug resistant epilepsy. Unique blend of medium chain fatty acids (decanoic acid -C10 and octanoic – C8). | 30mls=£3.96 |
|--------|-------------|---------|--|-------------|

Vitamins and mineral supplements

| | Indication for use | Description | Per daily dose cost |
|-------------|-----------------------|-------------------------------------|--|
| Fruitivits | children from 3 years | 30 x 6g=£86.53. | 6g= £2.89 |
| Phlexy-vits | >11 years and adults | 30 x 7g=£87.00. Tabs, 180=£99.92 | 7g = £2.9 1 tab =£ 2.75 Tube fed element |

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Ready meals and supplementary options

Additional Items prescribed to improve diet tolerance and ease.

Multiple items may be prescribed to provide flexibility to the family; however these items represent less than 2% of the dispensed ketogenic items.

Maximum 1 box / month – for carers and pressure relief

| Product | Presentation | cost | Description | Per portion |
|--|--------------|---------|--|--------------|
| Ketoclassic bar | 14 x 30g | £26.43. | Individually packaged high fat, low carbohydrate snack bar | 30g =£1.89 |
| Ketoclassic savoury | 14 x 2 x 30g | £52.45. | Individually packaged high fat, low carbohydrate roll | 60g=£3.75 |
| Ketoclassic meal: chicken flavour | 14 x135g | £92.98. | Pre packed, readymade high fat, low carbohydrate chicken meal | 135g=£6.64 |
| Ketoclassic meal: bolognese flavour | 14 x 130g | £80.66. | Pre packed, readymade high fat, low carbohydrate Bolognese meal | 130g = £5.76 |
| Ketoclassic porridge | 2 x 300g | £42.25. | Pre packed high fat, low carbohydrate porridge | 40g=£2.81 |
| Ketoclassic muesli | 2 x 300g | £42.25. | Pre packed, readymade high fat, low carbohydrate muesli | 40g=£2.81 |
| Ketoclassic Bisk | 14 x 30g | £24.92. | Individually packaged high fat, low carbohydrate snack | 30g= £1.78 |
| Kanso DeliMCT Cacao Bar | 4 x 25g | £5.85. | 4.8:1 ratio bar with 21% MCT Can be mct exchange ; can be mixed with oil for palatability | 25g = £1.46 |

Products used to monitor ketosis / blood glucose control

Table 1 – Existing patients are using these products

| Product | Presentation | Description | Cost per presentation | Month request |
|---|-------------------|---|-----------------------|--|
| KetoStix (Bayer) | 50 strips /pot | Reagent Strips for urinalysis | £3.11 | 2 x 50 strip pot for patients testing urine |
| Freestyle lancets (Abbott) | 200 lancets / box | 28-Gauge Sterile lancets (for use with compatible Abbott lancing devices) | £7.64 | Single use; 1x200/month for blood monitoring For urine tests: as required after 1 st issue from hospital |
| Freestyle Optium β-ketone testing strips (Abbott) | 10 strips / box | Blood β-ketone test strips | £21.94 | For urine tests: as required after 1 st issue from hospital |
| Freestyle Optium glucose test strips (Abbott) | 50 strips / box | Blood glucose test strips | £16.30 | As required after 1 st issue from hospital |

Table 2 - Updated products as per NHS England and local guidance on cost effective testing strips and devices

| Product | Presentation | Description | Cost per presentation | Month request |
|-------------------------------------|-------------------|-------------------------------|-----------------------|--|
| KetoRx | 50 strips /pot | Reagent Strips for urinalysis | £2.25 | 2 x 50 strip pot for patients testing urine |
| AgaMatrix Ultra-thin (200) | 200 lancets / box | 28-Gauge Sterile lancets | £5.43 | Single use; 1x200/month for blood monitoring For urine tests: as required after 1 st issue from hospital |
| GlucoFix Tech β-Ketone Sensors Test | 10 strips / box | 10 strip pack | £9.95 | For urine tests: as required after 1 st issue from hospital |
| GlucoFix Tech Sensors Test Strips | 50 strips / box | Pack/50 | £5.95 | as required after 1 st issue from hospital |

