GUIDANCE FOR SCHOOLS
KETOGENIC DIET THERAPY (KDT)

Ketogenic Dietitians
Research Network

What is KDT and why do we use it?

A GUIDE FOR SCHOOL STAFF

Ketogenic Dietary Therapy (KDT) is a proven medical treatment for children with epilepsy which is low in carbohydrate, high in fat, with adequate protein.

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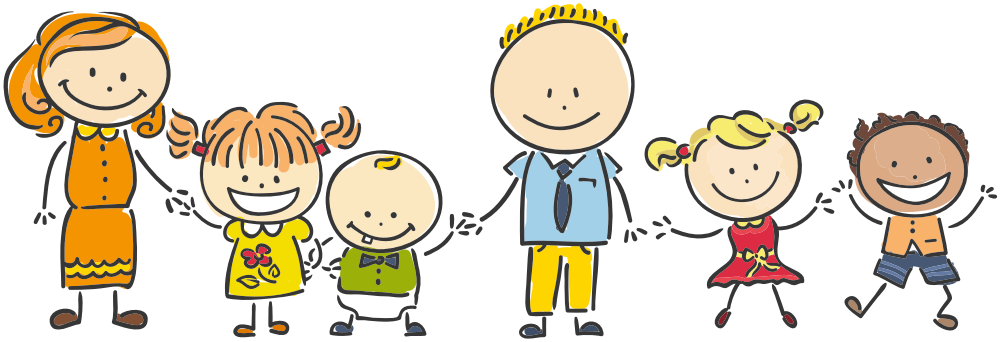
What is KDT and why do we use it? A guide for school staff

- KDT is a proven medical treatment for children with epilepsy, as well as some neurometabolic conditions – GLUT1 Deficiency Syndrome and Pyruvate Dehydrogenase Deficiency (PDH).
- The diet is low in carbohydrate, high in fat, with enough protein for growth.
- KDT can help children whose epilepsy is difficult to manage with medication alone.
- KDT is managed by a multi-disciplinary team, which may include a Paediatric Neurologist, Ketogenic Dietitian and Epilepsy Specialist Nurse (this can differ between centres).
- KDT is not a "fad diet."
- KDT is a medical treatment and should be treated like another medication.
- The diet should not be initiated by parents or carers without management of the specialist team.
- The diet can help reduce seizures and potentially improve quality of life. Alertness, behavioural problems and learning ability can improve on the diet.
- KDT can be used for children who are orally fed, tube fed or those on blended diet and some children may be nil by mouth.
- Some children will use prescription products. These may need to be given at school.



How does the diet work?

- On a 'normal' diet, we use glucose (sugar) to fuel our brain. On KDT, we switch the brain fuel from glucose (sugar) to fat, which produces ketones to fuel the brain.
- There are many different ways that KDT can potentially help seizures. Ketones may have an anti-seizure effect. Following KDT can also change the levels of chemical messengers in the brain.

Is the diet for life?

- No, if used to treat epilepsy. The diet is followed for around 3-6 months and if there is benefit for the child, they can continue for two years. Then they may wean off the diet, with the hope that any benefits are maintained, but this is not always the case. Some children stay on the diet for longer than two years, but this decision is made between parents and the healthcare team.
- Yes, if the child has a neurometabolic condition (for example Glut-1 deficiency or Pyruvate Dehydrogenase deficiency syndrome).

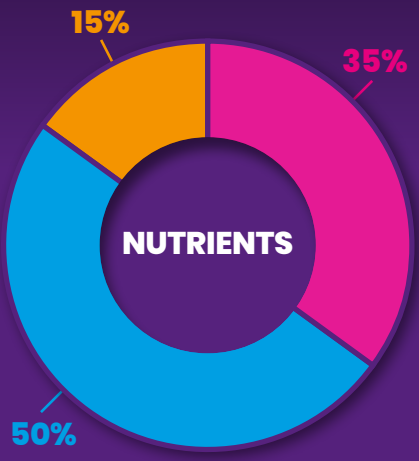
What does starting KDT look like?

- It is a big change for the whole family. It is important to offer positive support.
- Each child or young person has a specific diet plan that is unique to them.
- Weaning onto the diet can take a few days to a few weeks, or sometimes longer.
- The balance of each meal or feed can look different to a 'normal' diet, as there is more fat and smaller than normal amounts of carbohydrate and (sometimes) protein.
- Food may look or smell different to a 'normal' diet, so it may be worth discussing this in class.
- Food portions may look small. This is normal on the diet. Most of the calories come from the high fat content in meals.
- Please make parents or carers aware if a child appears hungry when following KDT. This is not expected on the diet.

Positive support is key to success!

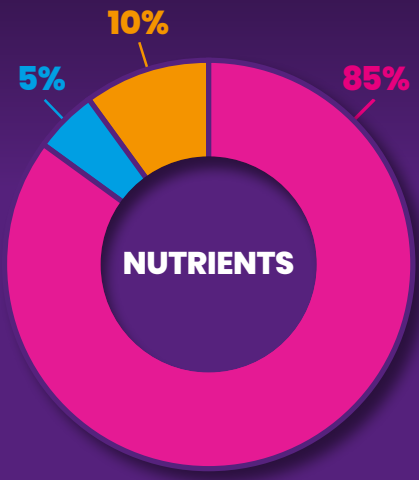
'Normal' diet versus Ketogenic diet

Example of a 'normal diet'



Normal amounts of fat, carbohydrate (CHO) and protein

Example of a 'ketogenic diet'



Low in carbohydrate (CHO), very high fat and adequate protein

KEY

Fat CHO Protein

Oral feeding

- High-carbohydrate foods, such as bread, breakfast cereals, potato, pasta and rice, are normally avoided with KDT. They can be replaced with specialised low-carbohydrate foods that can be bought online or in health food shops, or foods that are naturally low in carbohydrate. Ketogenic breads, cakes and muffins can also be made at home using specialist products.
- Milk and yoghurts need to be limited. Alternatives are available.
- Fruit and vegetables are allowed in measured quantities.
- Fatty foods such as oil, double cream, mascarpone, butter and mayonnaise make up a large part of the diet.
- Nuts are a great source of fat but are often not allowed in schools. Please consider this on a case-by-case basis, as nuts are used extensively as a flour replacement in keto baking.

Blended Ketogenic Diet

- Some tube-fed children use foods blended to a thin puree (single cream) consistency - (IDDSI level 4) in place of prescription feeds.
- These blended feeds are always given as a bolus using a syringe and not via a feeding pump.
- Follow school policy regarding storage and reheating of blended meals.
- Feeding tubes must always be flushed with water before and after giving a blended feed.

Tube feeding

- Some children are unable to eat safely and therefore need to be fed through a tube. A nasogastric tube is placed directly into the nose and a gastrostomy tube is placed directly into the stomach.
- Prescription ketogenic feeds can be bolus fed using a syringe or delivered via a feeding pump.
- If the child is tube fed and on KDT, specific ketogenic prescription feeds are used. Parents or carers will send the feed into school in a large container.
- Ketogenic feeds are very high in fat and need to be mixed and shaken prior to being given.
- If feed is sent to school in one large container and needs to be decanted into a smaller container to feed, the feed is then considered non-sterile and can only hang for four hours, after which it should be discarded.
- Ketogenic feeds need to be kept in the fridge and any remaining feed discarded after 24 hours.

Monitoring/testing on the diet

- Parents may measure ketones and blood sugars twice daily using a hand-held monitor. This is normally in the morning before school and before bed.
- More frequent monitoring may be required when dietary changes are made.
- 'Ideal' ketone levels vary considerably between individuals.
- Schools do not routinely measure ketones or blood sugars. However, it is useful to be aware of the symptoms of high ketones ('hyperketosis') and low blood sugar ('hypoglycaemia').

Table 1: Signs of hyperketosis/hypoglycaemia

Hyperketosis (High ketones)	Hypoglycaemia (low blood glucose)
Facial flushing	Cold, clammy
Nausea and vomiting	Confused
Very rapid, panting like breathing	Aggression/Agitation
More tired or lethargic than normal	Lethargic, no energy
"fruity" odour on breath	Sweating

Please ring parents if the child is showing any of the above symptoms. This is most likely to occur during illness or when they are starting the diet.

Side effects of KDT

- Like any new medical treatment, there can be side effects from the diet, which the multi-disciplinary team need to manage
- Side-effects that you may notice in school include changes to seizure activity, tiredness, alertness, loss of appetite, sickness, constipation, bruising, hyperketosis and hypoglycaemia
- If you notice any changes, please let parents or carers know

Feeling unwell on Keto at school

- Being on KDT will not make children immune to developing the usual coughs, colds and tummy upsets
- Illness may upset ketone or glucose levels and increase the risk of seizures

What if a child is well enough to be at school but requires medication?

All medications, whether prescribed or over the counter, such as paracetamol need to be sugar and carbohydrate free

Please consult the child's ketogenic diet plan and then contact parents if you are concerned about a child's health.

Day-to-day management of the diet in school

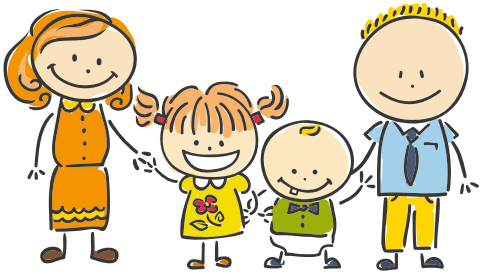
School meals, snacks, fluids

- Only food or feed provided or agreed by parents or carers can be eaten in school.
- Children must eat all the food provided.
- Let parents or carers know if full meals or feeds are not consumed.
- If the child eats something that is not part of their dietary plan, please make parents or carers aware.
- It is vital on the diet to ensure adequate fluid intake. Water can be given freely. There are some varieties of low-calorie fizzy pop or squash that children are allowed – please check with parent or carer.
- A meal replacement ketogenic 'shake' can be left in school in case a meal is spilled or not consumed for another reason.

Birthdays, cookery lessons, parties, physical education, school trips

- Speak with parents or carers in advance to allow time to prepare an alternative.
- Extra snacks on physical education days may be required.
- Children on the diet can still go on trips, it just takes a bit of organising with parents or carers in advance to prepare suitable foods.

If in doubt, discuss with parent or carers.



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To view the Matthew's Friends and Rhea video visit:
www.matthewsfriends.org

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Ketogenic diet therapy must ONLY be undertaken under the advice and supervision of a ketogenic dietitian in partnership with a neurologist. Every effort has been made to ensure the information was correct at the time of publishing. KDRN assume no responsibility and herein disclaim any liability to any party for any cause.'

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