



# WHAT IS KETOGENIC **DIET THERAPY?**

We would like to thank the advisory support of we received from M.A. Leung, H. Champion and B. Van de Bor in the production of this booklet.

Version 2, MAY 2019



#### WHAT IS A KETOGENIC DIET?

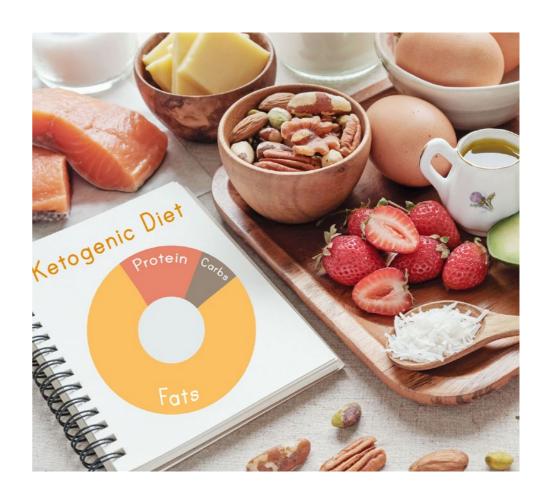
A ketogenic diet is a high fat, low carbohydrate and adequate protein diet.

The ketogenic diet is used in children with uncontrolled drug resistant epilepsy to help reduce seizures.

The ketogenic diet is designed to force the body to use fat as an energy source instead of glucose. When fat is broken down for energy it produces a compound known as ketones.

These ketones are thought to exert an anti-epileptic effect in the brain.

The diet has been used for nearly 100 years and has been shown to be effective in half of children who trial the diet.<sup>1</sup>



1. Cross, J. H. and Neal, E. G. (2008), The ketogenic diet – update on recent clinical trials. Epilepsia, 49: 6-10. doi:10.1111/j.1528–1167.2008.01822.x



# WHAT ARE THE POTENTIAL BENEFITS OF KETOGENIC DIET THERAPY (KDT)?

In addition to possible reduction in seizures other benefits may include:

- Potential reduction of drugs and their side effects
- Increased alertness
- Increased energy levels
- Increased feeling of well being



### WHAT ARE CARBOHYDRATES?

Carbohydrates are found in bread, pasta, potato, rice, fruit and vegetables.

Carbohydrates are broken down to glucose by the body to provide energy.

In the ketogenic diet fat will be used as the primary energy source.





# **WHAT IS FAT?**

Fat is found in avocado, oils, cream, butter and mayonnaise.

It is an essential part of your child's diet and will provide the majority of calories that your child needs.

Fat is broken down by the body to make ketones for energy.





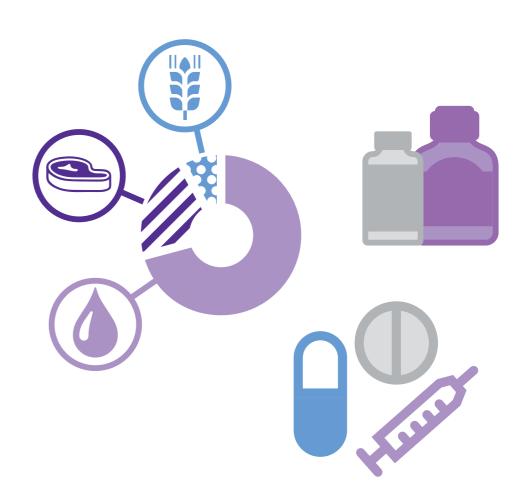
# WHAT IS PROTEIN?

Protein is found in meat, chicken, fish, eggs, nuts and legumes. It is important for children's growth and is used to build and repair tissues in the body.



## **HOW IS KDT MANAGED DAY TO DAY?**

- A carbohydrate and sugar restricted diet
- High fat
- Adequate protein to meet requirements
- A suitable vitamin and mineral supplement
- On going anti-epileptic medicines





### **HOW IS KDT MONITORED?**

- Twice daily finger pricks to monitor levels of ketones in the blood
- Ketones can also be measured in urine
- A nurse specialist will show you how to test ketones and the ideal range of ketones to aim for
- You will be asked to record your child's ketones and seizures in a daily seizure record chart



#### ARE THERE ANY SIDE EFFECTS OF KDT?

When children first start the diet, they may experience feelings of tiredness, irritability or generally feel unwell for a few days. This is temporary.

Other side effects when the diet is continued long term may include:

- Constipation
- Reflux
- Raised blood triglycerides and cholesterol levels
- Kidney stones
- Bone health and increased risk of fractures
- Very rarely pancreatitis



#### **HOW IS KDT MANAGED DURING ILLNESS?**

- During illness please follow the advice from your
  GP, local paediatrician and neurologist.
- Contact your dietitian or epilepsy nurse specialist for further advice.
- If new medications are prescribed please request for the reduced carbohydrate preparation. We understand this may not always be possible.
- You may also be asked to measure blood glucose levels.





### **KEY MESSAGES**

- It is important that ketones are monitored **regularly** and there are **no delays** in correcting high ketone or low blood glucose levels.
- Maintain regular contact with your Ketogenic team.
- Speak to your dietitian or nurse specialist about the recommended frequency for testing ketone and glucose levels.
- Children who are well established on the diet may be able to reduce the frequency of testing.
- Your ketogenic team will advice you accordingly.





#### **CHECKLIST FOR FAMILIES**

- Check that you have all the relevant products prescribed from your GP before starting the diet.
- Some children may start the diet in hospital so make sure that you have a supply of relevant products to go home with.
- Carefully follow the recipes provided by your dietitian using weighing scales where indicated.
- Remember to measure ketones as instructed by the ketogenic team.
- Record seizures and ketones in your child's daily seizure record chart.
- Regularly update your ketogenic team.





### WHAT ELSE IS MONITORED DURING KDT?

- Growth your child will have their height and weight measured at every clinic visit.
- Your child will have the following vitamins and minerals checked at routine clinic visits.
  - ~Vitamin D
  - ~Selenium & Zinc
  - ~Carnitine
- Lipid profile the level of fats such as cholesterol and triglycerides in your child's blood.
- Bone health blood levels of vitamin D as well as bone scans to check for bone density.



#### **TAKE HOME MESSAGES**

- A ketogenic diet is a high fat, low carbohydrate and adequate protein diet.
- Moving onto the ketogenic diet can be a big change for your child and your family.
- The diet can still taste good so speak to your dietitian about new recipe ideas when you need to.
- There are also regular cookery days and events through-out the year which you can attend.
- Half of children who trial the diet will benefit from a 50% seizure reduction.<sup>1</sup>



1. Cross, J. H. and Neal, E. G. (2008), The ketogenic diet – update on recent clinical trials. Epilepsia, 49: 6-10. doi:10.1111/j.1528–1167.2008.01822.x



# TAKE HOME MESSAGES (CONTINUED)

- Regular measurement of ketones are essential to monitor the management of the ketogenic diet.
- Record all seizures in your child's daily seizure record chart.
- Do maintain regular communication with your ketogenic team to support your child and to get the best experience from the ketogenic diet.
- During illness follow the advice given by your local doctor or speak to your epilepsy nurse specialist.
- Remember to request that all prescribed medicines are low in carbohydrate where possible.





#### **HELPFUL HINTS**

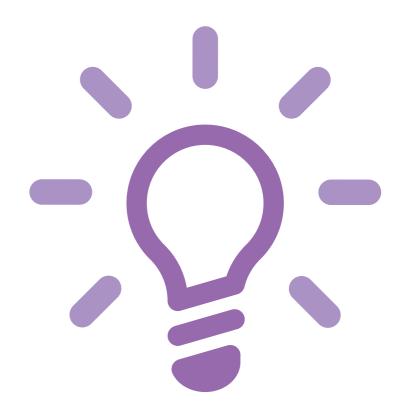
- Ensure that you have a good supply of your special dietary products and that they are in date.
- Your special dietary products are prescribed by your GP. These are obtained via a pharmacy or home delivery.
- Medications to control epilepsy should be given as directed by your neurologist – always keep supplies available and change to tablets and reduced carbohydrate preparations as soon as possible.
- Keep a spare set of batteries for weighing scales at home so that you never run out.





### **HELPFUL HINTS** (CONTINUED)

- Once your child is established on the diet, consider batch cooking and then freezing favourite meals to save time.
- A copy of your child's feeding plan can be sent to your child's nursery or school. Your dietitian and nurse specialist can speak to your child's school about ketone testing and managing high or low levels.
- Ask your child's school to let you know about special occasions in advance. You can then prepare ketogenic diet friendly celebratory snacks so that your child can join in on the celebrations.





# SIGNS THINGS AREN'T QUITE RIGHT

- Sometimes blood levels of ketones can be high and blood levels of glucose can be low.
- Some children can develop symptoms of high ketones or low blood glucose levels.
- Treat abnormal levels and symptoms immediately.
- Inform your ketogenic team.





#### MyKetoPlanner

A free online tool to support the ketogenic community with recipe development and sharing

www.MyKetoPlanner.co.uk

www.MyKetoPlanner.ie

